

POVERTY AND HIV

FINDINGS FROM **THE CRUSAID HARDSHIP FUND 2006**

Crusaid

HIV & AIDS:
help & hope
for people
in poverty



INTRODUCTION

It has been three years since the first Poverty and HIV report: *Lessons from the Hardship Fund 2003*. Despite a consistent push from across the HIV sector to keep HIV on the public and political agenda, many of the issues raised in the previous report still stand.

Crusaid's decision to partner with the National AIDS Trust (NAT) on this second Poverty and HIV report: *Findings from the Crusaid Hardship Fund 2006* allows us to give important and researched recommendations the widest possible audience.

These recommendations have emerged from a careful analysis of the Crusaid Hardship Fund data between 2000 and 2005, and we are very grateful to Helen Gilbert for her assistance in this work.

Our aim remains to make a real and tangible difference to the lives of people living with HIV, which benefits the nation's sexual health in the long term.

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FOREWORD



For many people living with HIV in the UK, poverty is a harsh reality. Many of these people have faced barriers such as discrimination in the workplace, social stigma, hate crime, difficulties accessing benefits and inappropriate accommodation. They are living on little or no income.

People living with HIV are not only at real risk of poverty, but in many instances this deprivation can actually contribute towards worsening health.

Since being established in 1986, Crusaid's Hardship Fund has provided much needed financial assistance and support to people living with HIV. Crusaid provided over 30,000 grants to 15,000 people between 2000 and 2005. This represents one in four of the total number of people in the UK being seen in that period for HIV care. These grants have provided basic requirements such as food and clothing, as well as enabling access to respite care, mobility equipment and help with household goods.

It is of great concern that the average income for applicants to the Crusaid Hardship Fund has decreased from just over £93 per week in 1999 to around £60 per week in 2005. For many people, the Fund has been a vital lifeline when there was nowhere else to turn, or when all other statutory provisions have been exhausted. Crusaid continues to work to ensure those who are experiencing the worst levels of poverty are helped by the Fund.

The Crusaid Hardship Fund has intervened to help people who are experiencing benefit dependency, a sudden change in employment status, problems with homelessness or unsuitable housing, or other changes that can occur as a result of being diagnosed or living with HIV.

This report identifies examples of how the Crusaid Hardship Fund has helped. It uses stories from people who have used the Fund, and draws on key pieces of research to illustrate that poverty and HIV remain a challenge for our society, but one that can be overcome. The report ends with key recommendations that will help society to take on this challenge.

Crusaid and NAT continue to work to improve the lives of people living with HIV, but it is discouraging that this work is still so necessary. New laws are providing renewed promise and support to help remove the obstacles faced by people with long-term conditions – to enable full participation in our society. But more still needs to be done to translate this aspiration into a reality.

Dame Denise Platt
Chair of the National AIDS Trust

ABOUT CRUSAID

Crusaid's mission is to direct money, knowledge and support to poor and marginalised people and communities affected by HIV and AIDS, in the way that best meets their needs and helps them achieve a decent quality of life.

Through highly effective grants and projects, made possible by the generous support of our donors, Crusaid is determined to make a lasting difference to the quality of life of people affected by HIV and AIDS. Enabling people to obtain and retain their dignity, health and independence is at the heart of all we do.

Crusaid manages the Crusaid Hardship Fund, as well as a domestic and international project portfolio with a current focus in Africa.

Based on 20 years experience of HIV and AIDS, Crusaid directs funds where they can make the biggest impact. We make small grants which meet urgent, genuine needs for individuals. We are involved with innovative projects in poor and marginalised communities which serve as a catalyst for long-term and lasting change.

Crusaid's role is as relevant now as at our launch in 1986, even though much has changed since then. 20 years ago, HIV infections in the UK were confined almost exclusively to the gay community. Now, over half of all people diagnosed with HIV have been infected through heterosexual sex. The Crusaid Hardship Fund has been a lifeline to one in three of all people diagnosed with HIV in the UK.

In the last 20 years, Crusaid has helped direct £17.5 million towards charitable projects. Of this, a total of £7.8 million has been made available to people in acute need through small grants from the Crusaid Hardship Fund.

Crusaid relies on the support of our donors, benefactors and partners; providing a community-based response to the HIV and AIDS pandemic. With more people affected by HIV and AIDS than ever before, the calls for our help have never been greater.

ABOUT THE NATIONAL AIDS TRUST

The National AIDS Trust is the UK's leading independent policy and campaigning voice on HIV and AIDS. A registered charity, NAT develops policies and campaigns to halt the spread of HIV and improve the quality of life for people affected by HIV, both in the UK and internationally.

All NAT's work is focused on achieving four strategic goals:

- > effective HIV prevention
- > early diagnosis of HIV through ethical, accessible and appropriate testing
- > equitable access to treatment, care and support for people living with HIV
- > eradication of HIV-related stigma and discrimination

THE CRUSAID HARDSHIP FUND

The Health Protection Agency estimates that, at the end of 2005, there were 63,500 people living with HIV in the UK¹. The Crusaid Hardship Fund – financed in partnership with the Elton John AIDS Foundation and the M·A·C AIDS Fund – is a vital lifeline for people living with HIV who are experiencing extreme financial hardship.

The Crusaid Hardship Fund targets the people most in need – helping them achieve a decent quality of life. With the support of funders, donors and referring agents, Crusaid has awarded over £3.25 million in grants between 2000 and 2005 alone.

Since 1986, the Crusaid Hardship Fund has helped one third of all people diagnosed with HIV in the UK. In the late 1980s and early 1990s, the main function of the Fund was to provide respite care and hospice placements for terminally ill people. Now, thanks to great advances in drug treatments, the Fund is also being called upon to support people in other ways – providing financial assistance to those living with HIV and in poverty.

Not only does the Crusaid Hardship Fund help with one-off grants but, increasingly, it is helping individuals find a long-term route out of poverty. The Fund enables people to return to work – by retraining in skills, helping with CV writing and interview techniques, or giving grants to buy a suit for interviews – making it possible for people to climb out of the poverty trap. But, for the majority, the reality is still that basic assistance with food, toiletries or clothing remains the main priority.

Applications are made via a referring agent. They are rigorously means tested so that every award is supported by relevant documentation, to ensure that grants are made to those most in need. The Crusaid Hardship Fund does not provide help with luxury items. The vast majority of applications are to cover critical purchases such as food, bedding or a fridge to store medication at the correct temperature.

Once assessed, applicants to the Fund are placed in one of four categories based on the level of disposable income they have:

Assistance Level 1: An applicant at this level already receives an income that makes them ineligible for assistance from the Crusaid Hardship Fund. A grant will only be made available under exceptional circumstances and then only by appeal.

Assistance Level 2: An applicant receives what Crusaid considers to be 'reasonable' benefits. They can make one successful application in a twelve-month period for a maximum of £250 towards white goods, respite care or to furnish their first independent accommodation.

Assistance Level 3: If an applicant has no net income, but receives low benefits from the local authorities, NHS or Home Office for example, they are entitled to receive up to £300 within a twelve-month period. In any six-month period, only one successful application is allowed. Level 3 grants can cover all areas mentioned under Level 2, plus utility bills or basic living expenses.

Assistance Level 4: At this level, the person applying does not receive financial assistance of any kind – for example in cash, vouchers, subsistence costs or asylum support payments. They will have maximum access to the Fund: up to £400 in a twelve-month period, with one successful application permitted within any six-month period. Expenses covered include emergency accommodation and essential necessities such as food.

Following the largest ever stakeholder review, the Crusaid Hardship Fund has undergone a major transformation in the way it is administered and how it interacts with referring agents, such as social workers, clinical nurses, specialists and welfare advisors. The result is a more proactive, accessible and flexible Fund.

Levels of funding given to individuals may seem low when considered in isolation, but the difference a well-targeted grant can make to a person in dire poverty can truly be life changing.

“Although just a small amount, the difference **Crusaid’s Hardship Fund** grant has made to my client’s physical situation and self-esteem is priceless.”

Phyllis, Social Worker

THE CRUSAID HARDSHIP FUND: KEY FACTS AND FINDINGS

SUMMARY

- > Our experience leaves no doubt that poverty and HIV are inextricably linked in the UK.
- > Applicants to the Crusaid Hardship Fund now have more basic needs, such as food, and are experiencing greater deprivation than in previous years.
- > Increasing numbers of those applying to the Fund with severe poverty are asylum seekers.

KEY ACHIEVEMENTS

- > Since 1986, over 26,000 people living with HIV and in poverty have received £7.8 million in grants from the Crusaid Hardship Fund. This represents approximately one in three of all people diagnosed with HIV in the UK.
- > More than 15,000 people have benefited from over 30,000 grants via Crusaid's Hardship Fund between 2000 and 2005. This represents one in four of the total number of people in the UK being seen in that period for HIV care.
- > In 2005 alone, the Crusaid Hardship Fund gave out grants totalling over £400,000, with 2,890 grants given to 2,414 people. The average grant was £140.

EXTREME POVERTY

The profile of people applying to the Crusaid Hardship Fund is changing. The average weekly income for applicants has dropped from £93 in 1999, to £60 in 2005 (with figures not adjusted for inflation). Between 2000 and 2005, people living in extreme poverty, with no disposable income whatsoever, formed the highest number of applicants. There has been a significant increase in funds being provided to help pay for basic necessities, such as food and clothes, which are only made available to people qualifying for Assistance Levels 3 and 4 – those in the very greatest need. These are usually people who have little or no access to statutory services.

ETHNICITY AND RESIDENCY

In 2000, almost 45% of applicants to the Crusaid Hardship Fund were of African ethnicity and 33% were white British. In 2005, over 60% were of African ethnicity and 22% were white British.

39% of applicants between 2000 and 2005 were UK nationals, or had been granted refugee (or equivalent) status. 54% of applicants were at the time of application at some stage in the asylum or immigration process. Only 6% of applicants were of uncertain residency status.

Over 50% of applicants between 2000 and 2005 live in London. Other areas with high numbers of applicants include Manchester (6%), Birmingham (4%), Brighton (2%) and Luton (2%).

Over 72% of UK national applicants each year between 2000 and 2005 were white British men.

In 2005, 10% of UK nationals applying to the Crusaid Hardship Fund had no net income (which can occur when people have lost their job and are waiting for benefit entitlement to begin, for example).

Since 2000, the largest proportion of applicants who qualify for Assistance Level 4 (those in greatest need) are asylum seekers, with the percentage varying between 33% and 45%.

AGE

In 2005, the largest proportion (42%) of applicants to the Fund were between the ages of 30 and 39.

Between 2000 and 2005, Africans represented the largest proportion of the youngest age groups, accounting for 70% of the under 20s.

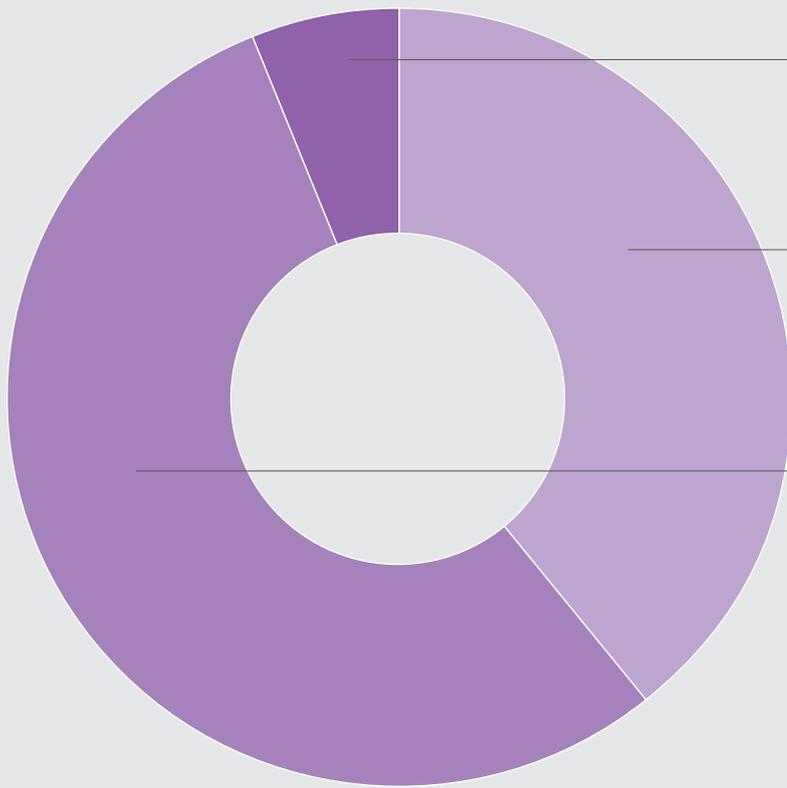
GENDER

The grants made between 2000 and 2005 were split between 51% male and 49% female applicants.

DEPENDANTS

In 2005, nearly 600 of the 2,890 grants awarded were provided to people who had one or more dependants.

RESIDENCY: 2000/05

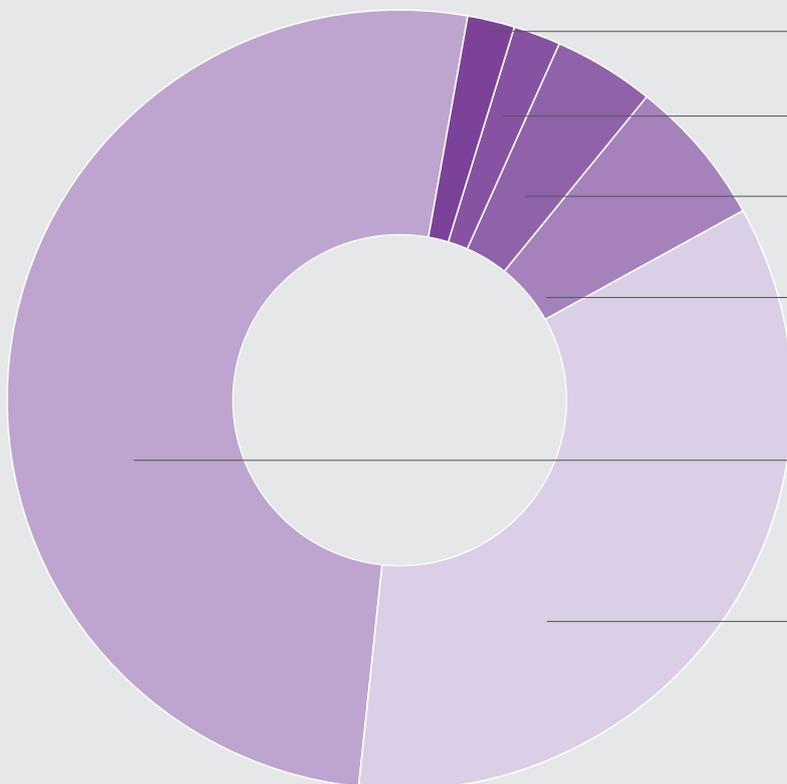


7% of applicants to the Crusaid Hardship Fund were of uncertain residency status.

39% of applicants to the Crusaid Hardship Fund between 2000 and 2005 were UK nationals, or had been granted refugee (or equivalent) status.

54% of applicants to the Crusaid Hardship Fund were at the time of application at some stage in the asylum or immigration process.

LOCATION: 2000/05



2% of applicants to the Crusaid Hardship Fund between 2000 and 2005 live in Luton.

2% of applicants to the Crusaid Hardship Fund between 2000 and 2005 live in Brighton.

4% of applicants to the Crusaid Hardship Fund between 2000 and 2005 live in Birmingham.

6% of applicants to the Crusaid Hardship Fund between 2000 and 2005 live in Manchester.

Over **50%** of applicants to the Crusaid Hardship Fund between 2000 and 2005 live in London.

Other (34%)

HIV AND DISCRIMINATION

EMPLOYMENT

Employment is an essential opportunity for people to escape social isolation, provide resources for themselves and their dependants, support their own mental health and improve self-esteem.

Since the widespread introduction of combination antiretroviral therapies in the UK in 1996, the majority of adults living with HIV are either in employment, or are able to work. However, many people still face discrimination when they attempt to gain or retain a job.

Recent changes introduced by the Disability Discrimination Act 2005 (DDA 2005) now give people living with HIV protection from discrimination from the moment they are diagnosed. Employers are required to make 'reasonable adjustments' to remove any barriers faced by people living with HIV in the workplace. This protection covers recruitment, terms and conditions of employment, chances for promotion, training and transfer, as well as addressing issues of unfair dismissal or less favourable treatment. The legislation also protects against victimisation or harassment from colleagues.

However, as our case study illustrates, workplace discrimination still exists, despite these changes to the law. Many employers may be unaware that anti-discrimination law now protects people diagnosed with HIV. Workers who feel discriminated against may not be willing or able to fight a lengthy legal battle to defend their rights.

More research into the employment experiences of people living with HIV in the UK is now needed.

BROADER PROTECTION FROM DISCRIMINATION

The DDA 2005 not only covers discrimination in employment but also in other areas such as the provision of goods and services, education, housing and trade union membership.

Protection of this kind is long overdue since discrimination remains a reality for far too many people living with HIV. A recent research report², indicated that nearly a third of people said they had experienced discrimination as a result of their HIV status.

This discrimination can prevent people living with HIV from taking advantage of services and support which they need to help them avoid or escape from poverty.

For example, over half of this discrimination came from healthcare workers, especially from primary care professionals who are often the same people who refer those living with HIV onto other services and support.

In December 2006, most public sector bodies are required by the DDA 2005 to publish a scheme to promote disability equality, which should include consideration of HIV. This represents a positive opportunity for public sector bodies to improve services for people living with HIV.

The DDA 2005 is an important step forward in improving rights for HIV positive people and should help address issues of discrimination and poverty; however more needs to be done.

People living with HIV often experience what is known as 'multiple discrimination', where they are discriminated against on a number of different grounds at the same time. For example, being gay and HIV positive or being African and HIV positive. The law currently does not provide adequate protection against this sort of multiple discrimination, so it is essential that the long-awaited Single Equality Act promised by the Government does so.



GRAHAM'S STORY

CRUSAID HARDSHIP FUND GRANT £250

When colleagues at work were maliciously informed that he had AIDS, Graham's working life changed completely.

Graham was employed by a well-established retail chain as a store assistant when he began having problems with headaches and nausea. Thinking it was flu, Graham took a few days off, but after collapsing on the high street he spent one week in hospital where he was diagnosed with HIV.

Once he was fit enough to return to work, Graham found that his condition had been made public without his consent. Graham found everyone's attitude quickly changed around him.

"My bosses never said anything in particular but kept making it clear that I should consider taking a long rest and maybe not return at all," remembered Graham. "But I wanted to work and was able to work."

A 'well-meaning' colleague bought him a cup, plate and fork so Graham did not infect anyone in the canteen. An anonymous petition was posted to request Graham be given his own toilet cubicle.

Naturally, Graham found this treatment very distressing. It was made worse when he received an anonymous letter telling him not to attend the staff Christmas party because, "no one wants AIDS for Christmas."

Graham did not realise he was entitled to protection against the open discrimination he was facing. Eventually, he felt so isolated that he had no option but to resign. Graham approached the Department for Work and Pensions (DWP) for support. However DWP rules state that, as he had made himself voluntarily unemployed, he would need to wait 14 weeks before being eligible for benefits.

At home, Graham's relationship with his wife also changed. Though supportive at first, once Graham's wife tested negative she moved out, taking their daughter, and abandoned Graham. "To be excluded by my own family was so painful. Everything around me seemed to be in ruins," said Graham.

Discrimination at work led directly to Graham losing his employment. With no income and no benefit support, he had no idea how he could survive. It was at this point that Graham first heard about the Crusaid Hardship Fund.

Following an application made by a welfare advisor, the Crusaid Hardship Fund provided some bridging support to pay the electricity bill, make a contribution to his gas bill and keep his mobile phone going. At a time when Graham's world appeared to be falling apart, it showed him that he was not alone. By enabling him to stay in his home, Crusaid's grant helped Graham feel there was hope for his future.

Graham remarked, "I still do not know if I am coming or going, but Crusaid's support has helped me through one of the most difficult points in my life."

HIV, HATE CRIME AND ABUSE

HATE CRIME AND ABUSE

Hate crime and abuse are a terrifying reality for some people living with HIV. The result can be mental health problems, homelessness and abandonment, all of which drive people into poverty. Tackling HIV-related poverty means tackling HIV-related hate crime and abuse.

Despite legislation, Home Office guidance and greater efforts by the Crown Prosecution Service (CPS) to eliminate hate crime, it still occurs as our case studies show. More work is needed to address this social problem.

The Home Office/Association of Chief Police Officers (ACPO) guidance on hate crime³ refers to homophobia, disablism, and racism. However, this guidance does not specifically mention people living with HIV, even though there is still widespread ignorance of the fact that hate crime against HIV positive people is an example of disability-related hate crime.

Between 30th October and 8th December 2006, the CPS engaged in a public consultation on prosecuting cases of disability-related hate crime. This is an important opportunity for the CPS to improve its response to HIV-related hate crime and alert other parts of the criminal justice system to the particular burden of abuse endured by some people living with HIV.

The CPS and police must also give explicit consideration as to how to respond to hate crime against people living with HIV which is motivated by multiple types of stigma or discrimination. Examples of this are homophobia and HIV-related stigma, or racism and HIV-related stigma.

Particular attention must also be paid to the question of HIV-related violence or abuse in domestic contexts. The CPS policy on domestic violence prosecutions makes reference to 'outing' of HIV status to a partner as an example of behaviour that might amount to a criminal offence of domestic violence.

Research amongst African women in London living with HIV⁴, suggests revealing HIV status to an established sexual partner can, on occasion, result in rejection, eviction from the home and refusal to allow contact with children – all of which can trigger acute need and deprivation. Domestic violence policy and disability-related hate crime policy need to dovetail to protect people living with HIV from abuse in these situations.

In 2007, NAT and Crusaid will begin monitoring applications to the Crusaid Hardship Fund, where applicants have experienced hate crime or abuse.

TACKLING STIGMA

Hate crime and abuse are particularly extreme examples of more generally held stigmatising attitudes in society. To end hate crime and abuse we must also address the remaining ignorance and stigma around HIV in the UK. Whilst there is some evidence that stigma has recently decreased⁵ – there has also been a significant decline in the last five years in understanding how HIV is transmitted. This does not bode well for the future, unless this trend is reversed, since stigma thrives on ignorance. Recent prosecutions for 'reckless transmission' of HIV have also resulted in misleading, sensationalist and stigmatising newspaper coverage.

NAT is working with the National Union of Journalists to produce guidance on how to report on HIV accurately. The Press Complaints Commission (PCC) also needs to be involved when stories appear in newspapers which clearly breach the PCC's Code of Practice.

If we are to end HIV prejudice, it is as important to improve understanding of HIV in schools, where HIV should be addressed across the curriculum, not just in sex and relationships education. Curriculum policy might seem a long way away from poverty issues. However, creating a society with positive, well-informed and supportive attitudes to HIV, instead of one where HIV-related stigma abounds, will be one of the most effective ways to end the social marginalisation which generates poverty.



JOHN'S STORY

CRUSAID HARDSHIP FUND GRANT £275

"Until it happened to me, I had no idea how devastating personal attacks on people with HIV can be in the UK today," said John, who was diagnosed with HIV in 2003. His experience in his community highlights how urgently hate crime arising from stigma needs to be addressed.

Although he was managing fairly well, John had been the victim of homophobic attacks for two years. John's car was damaged by a group of local youths who also taunted him in the street almost every day. The name calling in public was deeply distressing to John, especially after police involvement failed to put a stop to the incidents.

"It got so bad I was afraid to go out," John revealed. Then John's house was broken into and ransacked. His property was damaged and homophobic graffiti was scrawled over his walls. Despite contacting the police again, John still felt very vulnerable.

Finally, when John was verbally abused and assaulted in the street he knew he could no longer cope on his own. It is in circumstances like this, when there is no one else to turn to, that the Crusaid Hardship Fund can transform people's lives.

John knew he could no longer stay at his flat, and together with his social worker, they were able to identify a flat in a new area that he could move to. But John's few savings had been used up replacing his vandalised belongings and securing his new accommodation. He had no money left to move home. Fortunately, the Crusaid Hardship Fund was able to support him with removal costs and enough money to replace essential items, such as saucepans and a kettle.

"I couldn't have made a fresh start without Crusaid's help," said John. "I was trapped in a terrifying place and my grant helped me get back to a normal life."

DAVID'S STORY

CRUSAID HARDSHIP FUND GRANT £310

Being gay and living in a small town was difficult for David, aged 17, so he made the tough decision to leave his family and start a new life in London.

Soon after moving, David met a man in a nightclub who had lived in his home town and knew of David's family. They began a relationship and David moved in with him. "This was a whole new world for me. It felt so good not to have to hide."

David tried to find work but was unsuccessful. After a while, David's partner argued that if David could not find a job, he should "go on the game to bring some money in". David was frightened by the prospect but agreed to go along with it.

"I know now how stupid I was but, at the time, I felt trapped. I became very sick after three months and only then found out my partner was HIV positive and that I was also infected."

David told his partner he would not sleep with anyone else but he was beaten up and violently raped. Unless he continued, David's partner threatened to throw him on the street and tell his family.

Over the next two months David had sex with his partner's friends and endured regular beatings. "I did not know what else to do," David later told his social worker after he was admitted to hospital with a case of HIV-related bronchial pneumonia.

David's social worker spoke to the Crusaid Hardship Fund, and he was given rent for an emergency shelter so he could escape his partner. The Fund also paid for train tickets to travel with a volunteer counsellor to tell his family about his sexuality and HIV status.

"I thought my family would hate me, but my mum just kept crying and asked me to move back home until I got myself sorted."

With the help of the Crusaid Hardship Fund, David is now getting his health and life back on track.

HIV, ASYLUM AND IMMIGRATION

ASYLUM SEEKERS

HIV is a global issue. As people move around the world, including to the UK, some will be HIV positive and have particular vulnerabilities and needs linked to their immigration status.

Over the last five years, 54% of applicants to the Crusaid Hardship Fund were at some point within the asylum and immigration system, and 6% were of uncertain or non-legal residency status.

The number of asylum seekers coming to the UK is falling (asylum applications fell by 24% in 2005), but there are still a significant number of people claiming asylum in the UK. At the end of 2005, 50,000 asylum seekers were being supported by the National Asylum Support Service.

Asylum seekers are denied the right to work (there is only a right to request permission to do so after twelve months in the country) and this increases the likelihood of poverty. The support provided for asylum seekers is minimal and, as the Crusaid Hardship Fund data demonstrates, in many cases it is not enough to prevent real poverty and distress.

There are also a considerable number of migrants who are living in the UK irregularly, including those who have overstayed their work or visitor visas, failed asylum seekers, trafficked persons and people whose residency status is uncertain. For these people, without legal residency status and without the right to work or access to benefits, the situation is far worse.

Some failed asylum seekers and visa overstayers are prevented from receiving free HIV treatment on the NHS. There have been claims of people migrating to the UK in order to benefit from free NHS care – so-called ‘health tourism’ – but there is no evidence that this is a real phenomenon. Research conducted by the George House Trust and Terrence Higgins Trust⁶ showed that the most recent migrants with HIV were unlikely to be aware of their status until they had been in the UK for more than nine months.

The Government has acted to ‘regularise’ – in other words, make legal – the residency status of some of those living long term but unlawfully in the UK. The Asylum Seeking Families Concession 2003 was an important opportunity for a family group to have their status regularised, but did not extend to individuals who were by themselves.

DISPERSAL

Asylum seekers, if they are to receive living and accommodation support from the Home Office, have to agree to be ‘dispersed’ from London and the South East, or from initial accommodation centres, to other parts of the country. They have no choice in this process.

Research conducted by NAT⁷ revealed real problems arising from the dispersal process for asylum seekers living with HIV. These included inadequate notice before dispersal, being dispersed when too ill to travel, disruption to care and medication, and social isolation in the dispersal area.

In response to submissions from NAT and other organisations, dispersal policy was changed to provide four to six weeks as the normal notice period. Dispersal now also requires the approval of the treating HIV clinician, and accommodation providers in the dispersal area have a contractual obligation to ensure the asylum seeker registers with a GP.

However, there is evidence that these recent welcome changes in dispersal policy for people living with HIV have not been consistently implemented in practice. There is particular concern in relation to children living with HIV and pregnant women.

REFUGEES

Poverty is not confined to those still awaiting the outcome of their claim to remain in the UK. Refugees and those granted leave to remain also endure high rates of unemployment, and constitute a significant proportion of those receiving Crusaid Hardship Fund support (5% of Level 4 grants, 15% of Level 3 and 20% of Level 2, between 2000 and 2005).

Research cited by the Refugee Council found an employment rate amongst refugees of 29%, compared with 60% for people from ethnic minorities.⁸ Furthermore, those in employment are often employed in jobs which do not reflect their qualifications and are often low paid. Refugees continue to experience discrimination which directly relates to their refugee status.

For those living with HIV, there are obvious additional challenges in finding suitable employment. Integration needs to begin whilst someone’s claim to remain is being considered. To this end it is important that access to vocational training and further and higher education are available.



MAY'S STORY

CRUSAID HARDSHIP FUND GRANT £400

May lives a life of constant uncertainty. As an asylum seeker, she is unable to work and both May and her daughter have to survive on less than £4 a day. She has been in the UK for three years and is still waiting for a final decision by the Home Office as to whether she can stay in this country.

May was originally placed in London and survived with the help of friends she met in the capital who faced similar situations. Overnight, the support network that meant so much to her was destroyed following a visit from her Home Office caseworker. May was told that she would be relocated the next day. She was advised to pack just enough to fit into a car boot but no more.

"It was very frightening, I felt like a criminal. In fact I wondered if they were taking us to prison," recalled May. After a lengthy journey, May and her daughter were taken to a social services office in Yorkshire before being moved to a house share with another family.

"The first thing they said wasn't 'hello'," May recollected, "they said we had better not have AIDS!"

Frightened that her need for medication and fresh foods would arouse suspicion and lead to questions she could not answer, May was filled with anxiety for her and her daughter's future. May applied to the Crusaid Hardship Fund. She was awarded a small fridge and a microwave for their room to give them more security and privacy.

May recently applied to the Fund a second time. She received valuable assistance to help buy new bedding, towels and basic foodstuffs.

"Having a little security means so much to us. At this very uncertain time, my grant helped me feel more in control of my life."

PRUDENCE'S STORY

CRUSAID HARDSHIP FUND GRANT £200

31-year-old single mum, Prudence, fled persecution in Angola and gave birth to her son shortly after arriving in the UK. Following postnatal checks Prudence was diagnosed HIV positive, and kept the traumatic news to herself.

After living for six months on food vouchers in council-provided accommodation, the Home Office decided to reject her claim to remain in Britain. Prudence's vouchers stopped and she lost the room she'd been provided with.

A friend's sister agreed to take Prudence and her young son in until she received word about being sent back to Angola. Despite being grateful to have a roof over their heads again, Prudence was terrified her status would be disclosed. When the woman who took her in noticed Prudence wasn't breast-feeding, her worst fears were realised. Prudence was told to leave because she was HIV positive and ended up on the street in the middle of winter.

It wasn't long before Prudence became very ill. She was taken by ambulance to hospital after being found collapsed in a doorway with her young child. The baby was taken away to be cared for by social services.

"I tried so hard to make a new life. When my child was taken away I was finished. I had nothing left," she told us.

Prudence feared she would never see her son again. But after making a full recovery, she was reunited with him. Whilst awaiting the Home Office's date for them to leave the UK, she was provided with a place to stay by another friend.

At a time when Prudence desperately needed support, a grant from the Crusaid Hardship Fund provided basic essentials like food, nappies and toiletries to help her survive. While Prudence has lost her chance to make a new life in the UK, she is determined not to lose her hope and her dignity. Her Crusaid Hardship Fund grant has helped her towards achieving this.

HIV AND HOUSING

HOUSING NEEDS

Poor quality housing can have a seriously detrimental effect on people living with HIV. This is especially so for people who have health problems associated with their HIV status.

For example:

- > Damp accommodation with inadequate heating creates an unhealthy and potentially dangerous environment for people with respiratory infections and tuberculosis.
- > For people living with HIV who suffer from fatigue and breathlessness, stairs can become an insurmountable daily obstacle.

Shared housing can create problems when people do not want others to be aware of their HIV status. Daily treatment regimes, periods of ill-health and frequent clinical appointments can be difficult to explain. Shared accommodation may force individuals to make decisions that could harm their health rather than risk disclosure of their HIV status.

It is widely acknowledged that poor housing and housing support are related to, and have the potential to exacerbate, many basic needs. These include sustenance, sleeping, mobility, caring for children and developing and maintaining relationships.

A needs assessment conducted by Brent Local Authority⁹, highlighted the importance of privacy in accommodation (including own toilet and kitchen facilities) for people living with HIV. It also identified that confidentiality and empathy were paramount in the provision of housing support. The assessment highlighted, however, that those in greatest need were least likely to be receiving adequate support.

FAILURES IN HOUSING PROVISION

The importance of stable and high quality housing for people living with HIV has been recognised by the Government. The Supporting People programme was established by the then Office of the Deputy Prime Minister in 2003 to offer vulnerable people a stable home environment to enable greater independence. The programme identified people living with HIV as one of the eight key client groups to be targeted.

However, despite this programme, people living with HIV continue to live in sub-standard housing which can have a detrimental impact on their health.

Sigma Research has undertaken a number of research studies to explore the needs of people living with HIV. Their 2001/02 survey¹⁰ showed that:

- > 18% felt unhappy about their current housing or living conditions;
- > 21% had experienced housing problems in the previous 12 months (including 4% who had experienced homelessness);
- > 16% had ongoing housing problems and felt that further help or support would be useful.

Their 2003 *Project Nasah* report¹¹ – conducted in partnership with NAT, NAM and the African HIV Policy Network – showed that black Africans were seven times more likely to report problems with housing and living conditions than white British respondents previously reported.

Sigma Research estimate (from 2001 and 2002 data) that the proportion of people living with HIV that experience housing problems in any given 12 month period is 54% of black African UK residents and 18% of other ethnicities.

The fact that people from ethnic minorities experience poorer housing standards is recognised by the Department for Work and Pensions (DWP). In their annual report for 2006¹², they state that within London's social rented sector, the rate of overcrowding is 7.8% for white households but 17.8% for black and ethnic minorities.

Waverley Care, a support organisation providing services to people living with HIV in Scotland, conducted a study in 2005¹³ on the issues facing Africans living with HIV in Scotland. This study, identified poor housing as one of the three main areas of concern. It was particularly significant that all the HIV positive asylum seekers in Glasgow who were interviewed had housing problems including overcrowding, poor quality stock, damp and lack of heating.

Asylum seekers are especially vulnerable to exploitation since they are least able both legally and financially to take action to improve the poor quality of their housing.

It is clear that poor standards of housing exacerbate existing health inequalities, contribute to the cycle of poverty and ill-health, and need to be addressed as a matter of urgency.



PHILLIP'S STORY

CRUSAID HARDSHIP FUND GRANT £250

The link between poor housing and ill-health is well established. It is a matter of serious public concern when such housing endangers people whose immune systems have been weakened by HIV, making them even more vulnerable to infection.

Phillip is 44. He suffers with extreme ill-health as a result of his HIV status, including chronic oesophageal ulceration, which causes vomiting, diarrhoea, skin rashes, lesions and problems swallowing. In 2005, he suffered a further setback with a collapsed lung.

Phillip lived with his disabled father for some time in local authority accommodation. When his father died, he was desperate to move out of the damp, draughty, unsuitable flat before his already serious health condition worsened further.

Despite being on the council's relocation list for more than four years, Phillip is still waiting to be rehoused on health grounds.

Already in a weakened state, Phillip has suffered from opportunistic colds and chest infections, which have been compounded by his other health issues. A pressing concern for Phillip's doctor was also that Phillip was becoming very depressed with his situation and felt extremely isolated.

"I know many people want a better home. I understand I'm not the only one. But it isn't my comfort I'm worried about – it's my life."

In response, the community specialist nurse made a request for the Crusaid Hardship Fund to support Phillip so that he could attend one week's respite care in a positive and encouraging environment. This enabled him to talk with other people in similar situations and build up his energies after his most recent round of health problems.

Phillip said, "The isolation I felt has started to lift. The damp is still there and I continue to battle with the council, but the week away paid for by Crusaid's Hardship Fund has helped me recharge my batteries."

ALICE'S STORY

CRUSAID HARDSHIP FUND GRANT £300

Home for Alice is not a warm and welcoming place. Everything about it compounds the pain and frustration caused by her failing strength.

Alice is HIV positive and has been very unwell for a considerable time. She lives with chronic asthma, pains in her legs and feet, as well as extreme weight loss, which has led to weakness and lethargy. Alice is unable to manage her own shopping or housework and has difficulty getting up the stairs.

The property she occupied is in very poor repair and next door to a disused building. Mice have invaded every room. It is so damp, black mould grows on the walls. Alice is only able to reach her room by climbing over 40 steps. It is an exhausting process. She has suffered bad falls at least four times in the past twelve months. With no proper heating system, she's cold nearly all the time, and freezing in winter. It is no surprise her health is suffering and she is constantly ill with chest infections.

Alice receives basic benefits and finds it almost impossible to heat her flat or keep it clean. Alice has been on a rehousing list for more than five years and despite making 16 bids, she has been unsuccessful in finding a new flat.

"When you are chronically ill, society assumes you have nothing left to offer and thinks it's okay to leave you on the scrap heap, so they can concentrate on people they see as more useful," commented Alice.

To help alleviate her distress, her social worker requested a Crusaid Hardship Fund grant to help Alice cope with the costs of running an electric heater. The Fund has also helped Alice to replace mouldy bedding, towels and curtains. Crusaid also petitioned the council in support of the social worker's efforts to push forward rehousing to help solve the problem in the long term.

HIV, DEPENDANTS, SOCIAL CARE AND BENEFITS

DEPENDANTS

According to the Child Poverty Action Group¹⁴, children in the UK face a high risk of income poverty. In 2003/04, 28% of children (3.5 million) were poor and 52% of households classified as income poor contained at least one child.

In addition, children living in households headed by an adult from an ethnic minority are more likely to be living in low-income households than their white counterparts. This is a particular issue given the high prevalence rates of HIV in black African communities within the UK.

In the study of African women living with HIV in London – *My heart is loaded*¹⁵ – 55 of the sample of 62 women were mothers and 39 of these had children living with them in the UK. Others were forced to leave children behind in Africa, often with relatives.

Those mothers who were compelled to leave children in Africa felt enormous guilt. But significantly, many also felt pressure to send money home to families when they were themselves living in extreme poverty. Inevitably, this only worsened their own situations.

A recent study by the National Children's Bureau¹⁵ identified cases where children who had been separated from their HIV positive parents had come to the UK as visitors and had not returned home.

Because these children were not officially recognised as being here, the family received no additional financial support and this increased the level of poverty the family experienced.

Statistics from the Crusaid Hardship Fund show that 20% of applicants in 2005 had dependants.

INTEGRATING HEALTH CARE AND SOCIAL CARE

The situations mentioned above and elsewhere in this report indicate that current benefits and social care systems are not meeting the needs of people living with HIV.

Often, the complex nature of these systems can prove difficult to negotiate, and this report also highlights instances where the often slow pace of accessing benefits and support have led to acute poverty.

Recent Government policy, particularly the intentions stated in the Government White Paper *Our health, our care, our say*¹⁶, have indicated a welcome commitment to greater integration between health care and social care services.

Yet people living with HIV pose particular challenges for service provision, with slow responses to changing circumstances often placing people in situations of jeopardy, as the case study of Felix shows.

The only Government resource specifically allocated to delivering social care in England for people living with HIV is the AIDS Support Grant. However, implementation is currently inconsistent and this resource faces an uncertain future.



JOAN'S STORY

CRUSAID HARDSHIP FUND GRANT £300

Joan is rightly proud of her two sons aged five and seven. As a single mother, she has worked hard to provide for them. Though it has been a struggle, Joan has managed to get by, despite being diagnosed HIV positive three years ago.

Joan received Home Office permission to stay in the UK after fleeing her small village in Zimbabwe following a death threat because of her HIV status.

Joan holds down a physically demanding job and looks after her family well, but in March she was diagnosed with cervical cancer. The course of treatment prescribed included both radio- and chemotherapies.

"My first concern was what I will do about my children whilst I am unwell. Who will look after them? No one knows of my HIV status."

Joan was not alone in her concerns. Children whose parents have HIV are particularly vulnerable when their mum or dad need emergency hospital treatment or respite care.

To help make sure Joan's boys were not split up with different foster carers, Joan's social worker approached the Crusaid Hardship Fund and was awarded a childcare grant to provide care for her children during her treatment.

Following long-term discussions with the Support Care Project in South London, Crusaid has subsequently funded a pilot Support Care programme, which trains foster carers who can support families like Joan's in their own home.

FELIX'S STORY

CRUSAID HARDSHIP FUND GRANT £150

Felix is 40 and was diagnosed with HIV in late 2004. He was also diagnosed with Hepatitis C and started on a 48-week regime of injections and tablets to treat this condition.

Felix had to stop working at his job in the tourist industry as the nature of work made it difficult to accommodate his Hepatitis C treatment. Felix is not a UK national but has lived and worked in the UK for the past three years. "I have paid all my taxes and owe no one anything," he said and he assumed it would be okay for him to stop working until his treatment was completed.

Felix was contacted within three weeks of stopping work and was told his Statutory Sick Pay was being stopped because his employment insurance policy does not cover anything HIV-related. This news took him completely by surprise since his reason for being off work had nothing to do with his HIV diagnosis.

He had not planned for this eventuality and found he did not have the means to pay for his outgoings. At a time when he needed to prioritise his own health and treatment, his lack of income seriously threatened his chances of recovery. Felix applied for income support but was told he would have to wait for nine weeks.

During this time, the Crusaid Hardship Fund provided small grants for food, toiletries and a little support with his outstanding rent.

"Part of supporting a person living with HIV is about anticipating problems and tackling them head on before they impact on a person's HIV health," commented Felix's social worker.

"With support from the Crusaid Hardship Fund I was able to help Felix deal with his situation before his health became worse."

KEY POLICY RECOMMENDATIONS

The Crusaid Hardship Fund is an essential lifeline for thousands of people faced with poverty and destitution. But policy changes are also necessary if the root causes of poverty are to be addressed effectively and in the long term. The following policy recommendations below identify priorities for action, as well as some additional recommendations, all of which, if implemented, would make a significant difference to the prospects and lives of many people living with HIV.

ASYLUM AND IMMIGRATION

- a) Consistent implementation of the new dispersal process for people living with HIV, and in particular improved communication with Home Office caseworkers, must be achieved as a matter of urgency.
- b) Asylum seekers should be automatically granted permission to work after six months and be able to access the same entitlements to further and higher education as refugees and/or UK citizens on welfare benefits.
- c) The subsistence for asylum seekers should be increased to a level that is equivalent to income support.
- d) The Government must consider a regularisation programme for the many living long term in the UK without legal residency status. In particular, the Government should extend the terms of the Asylum Seeking Families Concession 2003 to all asylum seekers who could meet the criteria of that concession, irrespective of family circumstances. This could have a significant impact in providing rights and ending poverty.

DISCRIMINATION, HATE CRIME AND ABUSE

- e) Public sector bodies should develop disability and HIV awareness training for staff, to ensure that discriminatory or inaccurate perceptions about HIV are addressed, and act as champions to encourage the adoption of a similar policy by private sector organisations.
- f) Research should be undertaken to gain an overview of the employment situations of people living with HIV in the UK, including levels and types of employment, the experiences of people disclosing their HIV status to employers, and the ability of people to manage their condition whilst in paid employment.

- g) The Home Office, Crown Prosecution Service and Association of Chief Police Officers should provide clear guidance for addressing hate crime which arises from multiple types of stigma, and also provide specific advice on how to respond to HIV-related hate crime.
- h) The Crown Prosecution Service and police should agree and enforce policies on HIV-related domestic violence to protect people who disclose their status to a partner.
- i) Media organisations, including newspapers, television, and new media outlets, should adopt and implement best practice in reporting HIV, as outlined in *HIV: A Guide for Journalists* currently being developed by NAT, to ensure fairer and more accurate coverage of HIV issues.

HOUSING, DEPENDANTS AND SOCIAL CARE

- j) All local authorities should treat as a priority the housing needs of people living with HIV, particularly those who are in poor health or socially vulnerable, or those whose condition may deteriorate.
- k) The Government and local authorities should develop specific strategies which will provide improved integrated services for people with HIV across both health care and social care, using initiatives such as Individual Budgets, as set out in the White Paper *Our health, our care, our say*.
- l) The implementation and effectiveness of the AIDS Support Grant scheme in meeting HIV-related social need should be independently assessed before decisions are taken on its future. The Government must ensure that local services are properly funded and supported to meet the complex needs of people living with HIV.

ADDITIONAL POLICY RECOMMENDATIONS

- m) All appropriate public sector bodies should ensure that their disability equality scheme includes measures to address HIV-related hate crime, record incidents and implement appropriate remedies and redress.
- n) The Commission for Equality and Human Rights should consider and address the multiple discrimination experienced by people living with HIV, and champion the early introduction of a Single Equality Act to address this issue.
- o) Schools should adopt HIV awareness as part of their obligations under the Disability Equality Duty, targeting staff and pupils, to help promote positive attitudes towards people living with HIV. They should also implement a 'zero tolerance' policy towards negative HIV and/or homophobic language and bullying.
- p) All schools should teach pupils about HIV. In addition to Personal, Social and Health Education, HIV should be specifically incorporated into other areas of the curriculum.
- q) Local authorities should ensure that care needs assessments and eligibility criteria include reference to people living with HIV, and their dependants.
- r) In meeting the care needs of adults living with HIV, social care services should ensure that the care needs of children acting as carers are properly addressed.

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All the names of people in the case studies
have been changed to protect their privacy.

