

# POVERTY AND HIV

2007

FINDINGS FROM **THE CRUSAID HARDSHIP FUND** IN SCOTLAND

**Crusaid**

HIV & AIDS:  
help & hope  
for people  
in poverty

*Waverley  
Care* 



# INTRODUCTION

This is the first report that has been produced on poverty and HIV in Scotland and is the result of a successful working partnership between Crusaid, Waverley Care and HIV Scotland. It clearly demonstrates that 25 years on in the history of the epidemic, HIV and poverty remain inter-linked. The report mirrors some of the findings from the 2006 report *Poverty and HIV*,<sup>1</sup> which was limited to England and Wales, but this report also identifies some key differences. For example, the age profile is older than the comparative cohort in England and Wales and highlights the potential longer-term effects of HIV and poverty and the need for policy to address HIV pensioner poverty.

The findings are based on an analysis of data from April 2002 to March 2007, thus covering a five-year period, which coincides with some major shifts in HIV diagnoses in Scotland. The Crusaid Hardship Fund in Scotland was administered by PHACE Scotland (now THT Scotland) during this time. There has been a growth in new diagnoses in four out of five of those years, with a noticeable growth in infections in Greater Glasgow & Clyde. During this period there has been a growth in new diagnoses among Scotland's migrant communities, especially those from sub-Saharan Africa.

A series of case studies was made available from requests made to Waverley Care, and the Head of Grants and Projects at Crusaid undertook a series of interviews with referring agencies to identify key issues. The results inform the report and the case studies are used to illustrate the realities of living with HIV in modern Scotland, how poverty affects people and how the Crusaid Hardship Fund has helped.

The report goes on to make key recommendations which it is hoped will receive appropriate consideration by statutory funders and policy makers alike.

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All names in case studies have been changed to protect individuals.

Photographs have been posed by models.

# FOREWORD



Many people today think of HIV as a long-term condition that can be alleviated through aggressive drug management. If they think a little bit more about it then they will be aware of the stigma and discrimination which still surround the illness. What most people may not be aware of is the cost to the patient of treating HIV. It is also the case that those who come from poorer backgrounds may be less likely to complete education and so not receive sexual education at school.

Crusaid's Hardship Fund was established in 1986 at the height of the UK HIV epidemic and since then has helped many thousands of people living with HIV. A dedicated Fund for Scotland was established in 1994. In Scotland the Fund has assisted over 2460 people. As this report illustrates, the Crusaid Hardship Fund helps people by providing grants for every day living, including food and clothing, and for important needs such as respite care and mobility equipment. For many people the Fund has been a lifeline, enabling them to live with dignity. This is especially true for those who are denied access to public monies because of their immigration status.

This report, produced in collaboration with Waverley Care, which administers the Fund in Scotland and HIV Scotland, contains examples of how the Fund has supported individuals. It also highlights key areas affecting people living with HIV, such as housing, immigration and discrimination. It shows that HIV and poverty are inter-linked and still all too prevalent. What most people are perhaps unaware of is how HIV can impact on every area of a person's life and leave them in a seriously reduced financial position.

## Susan Deacon

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# CRUSAID, WAVERLEY CARE AND HIV SCOTLAND

## **CRUSAID**

Since 1986, Crusaid has worked towards a vision where people living with HIV can live with dignity and have a decent quality of life.

Our UK projects fighting HIV related poverty have provided support across the UK sector to raise the quality of clinical care, promote education and awareness of the virus and support community projects in the advancement of good practice and advocacy.

Crusaid also manages an international portfolio providing clinical treatment, orphan care and community support to thousands of the most impoverished people who have nowhere else to turn. Crusaid's international funding is currently focussed in Africa.

The Crusaid Hardship Fund has disbursed over £8 million in small grants since 1988.

## **WAVERLEY CARE**

The projects of Waverley Care include:

- Milestone House, which was the UK's first purpose-built hospice for people with HIV and is now a respite and day care centre
- Waverley Care Solas, which operates a number of community-based advice, information and support services
- a Buddy Service
- most recently, an African Health Project, which operates in NHS Lothian, NHS Greater Glasgow & Clyde and NHS Lanarkshire areas.
- Waverley Care took over the administration of the Crusaid Hardship Fund for Scotland in April 2007

## **HIV SCOTLAND**

HIV Scotland is the independent body for HIV agencies in Scotland. Recognised by the Scottish Executive and other leading agencies, it is a first point of contact and information for all. It has been providing services to people living with HIV in Scotland since 1991.

As the first and only representative organisation of its kind, HIV Scotland is committed to developing strategic partnerships and to building collaboration between communities affected by HIV and service providers at all levels. A comprehensive range of policy, health promotion and development services are based on the expertise, knowledge and skills of its dedicated staff team, backed by the collective strength of Scotland's voluntary and community HIV sector.

# THE CRUSAID HARDSHIP FUND IN SCOTLAND

The purpose of the Crusaid Hardship Fund is to assist where a specific, HIV-related need presents itself. It does not exist to fill gaps in statutory funding or help to provide for luxuries. Funds are available only to persons with a HIV positive diagnosis, who need not be symptomatic. Monies can also be applied for on behalf of children (less than 19 years if in full-time education). However, an application must be made first to, and the outcome known from, the Children with AIDS Charity (CWAC).

In 2002 the Crusaid Hardship Fund was radically restructured and changed from being a direct client application to having a system of registered referrers (usually social workers), which ensures the applicant has access to professional support in (the few) instances when the Fund is unable to offer financial help.

Applications to the Crusaid Hardship Fund must be made on behalf of clients currently living in Scotland. There is no citizenship or permanent residency requirement, so UK nationals as well as foreign nationals, persons seeking asylum, persons with student or work visas, and residents in prison or detention centres are not excluded from applying.

Through a means-test assessment, applicants are categorised into one of four groups called assistance levels, which allows the Crusaid Hardship Fund to prioritise applicants by their disposable income. Level 4 applicants have the highest priority and can therefore access our highest value of funds without restriction by request of use, with level 1 applicants being our lowest priority; applicants at this level rarely receive financial assistance except in exceptional circumstances and then only by appeal. Built into the Fund's assistance level mechanism is the recognition of how poverty affects families. There has recently been an increase in the number of

applications from couples with children and lone parents.

What monies can be requested also depends on an applicant's assistance level. Request of use identifies what the applicant is requesting a grant for. Grants may cover ordinary living expenses for items such as food, travel, toiletries, bedding, clothing and children's items; respite support; start-up grants for assistance when moving into new accommodation; utility payments; or white goods such as fridges, cookers and washing machines.

In order to assess an individual who is seeking financial assistance from the Crusaid Hardship Fund fully, while ensuring transparency in such an assessment, the Fund requires independent supporting evidence in the form of documents detailing an applicant's income and outgoings such as rent or mortgage and council tax payments. Furthermore, the Fund collects other demographics from all applicants, which is used in statistical analysis to identify trends and help when adjusting Fund criteria, ensuring monies are directed to those most in need.

In 2006 the Crusaid Hardship Fund initiated an Emergency Fund pilot scheme that involved the dispersal of monies at a local level by professional workers from the 'referring agents' of the agent-based services – social workers, social work assistants, health advisors, welfare benefit advisors, and specialist nursing staff. The success of the pilot trials held in February and August/September 2006 led to the setting up of a permanent Crusaid Emergency Fund scheme delivering small payments to those in immediate need who present themselves to the participating agencies. It is worth noting that the success of the Emergency Fund scheme, as well as of the Crusaid Hardship Fund itself, can be attributed to the professionalism of the individuals who make up the referring agents.

# KEY FINDINGS

## **SUMMARY**

48% of people living with HIV in Scotland (2,460) have accessed the Crusaid Hardship Fund since it was set up, which suggests the Fund provides income for core needs to people living with HIV managing their day to day living requirements.

Applications have risen steadily over the past five years with the largest rise (14%) occurring in 2005/06.

The Crusaid Hardship Fund is typically used to pay for food and for travel to medical or social care appointments.

34% of applicants (834) are people with a link to sub-Saharan Africa. Of these, 233 people have no access to financial support from statutory sources because of their immigration status.

There are growing numbers of people living out with the four main urban areas (Greater Glasgow & Clyde, Edinburgh, Aberdeen and Dundee). Many clients stated that they will travel long distances to access treatment and care services rather than use local services for fear of stigma and discrimination. The growth of people living in non-metropolitan areas has implications for how services support them.

Housing features strongly as an area where people experience discrimination, especially on the grounds of ethnicity.

Around 35% of clients share their living space with non-family members; some 20% live in bed and breakfast accommodation.

There has been a growth in the number of clients aged over 40 in the last three years, indicating an aging demographic. Compared with the 2006 report, a larger percentage of the sample interviewed showed a diagnosis of more than 12 years, and people experienced considerable long-term hardship.

## **KEY ACHIEVEMENTS:**

The Crusaid Hardship Fund in Scotland has supported 1:2 people diagnosed with HIV.

The Fund has distributed over £1 million in Scotland since 1991.

The Fund has assisted 2,460 people living with HIV since 2002.

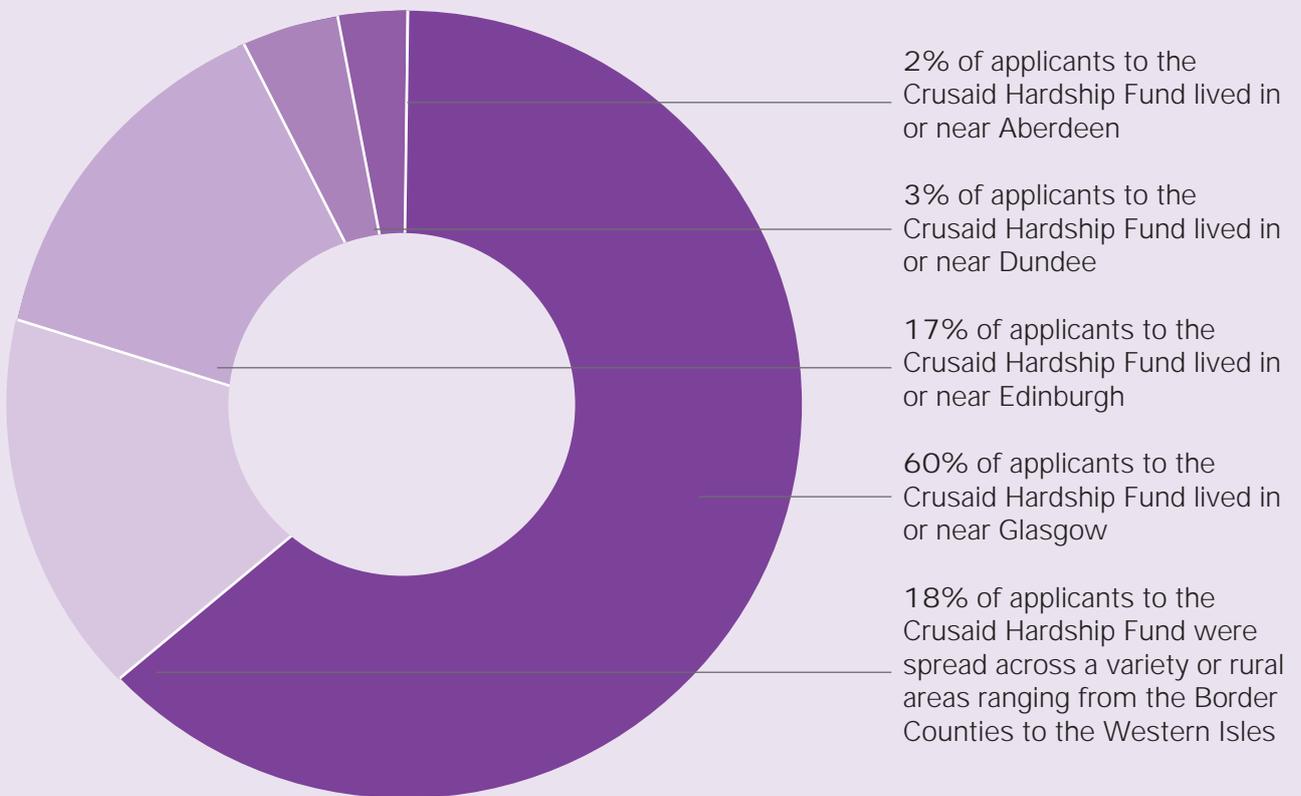
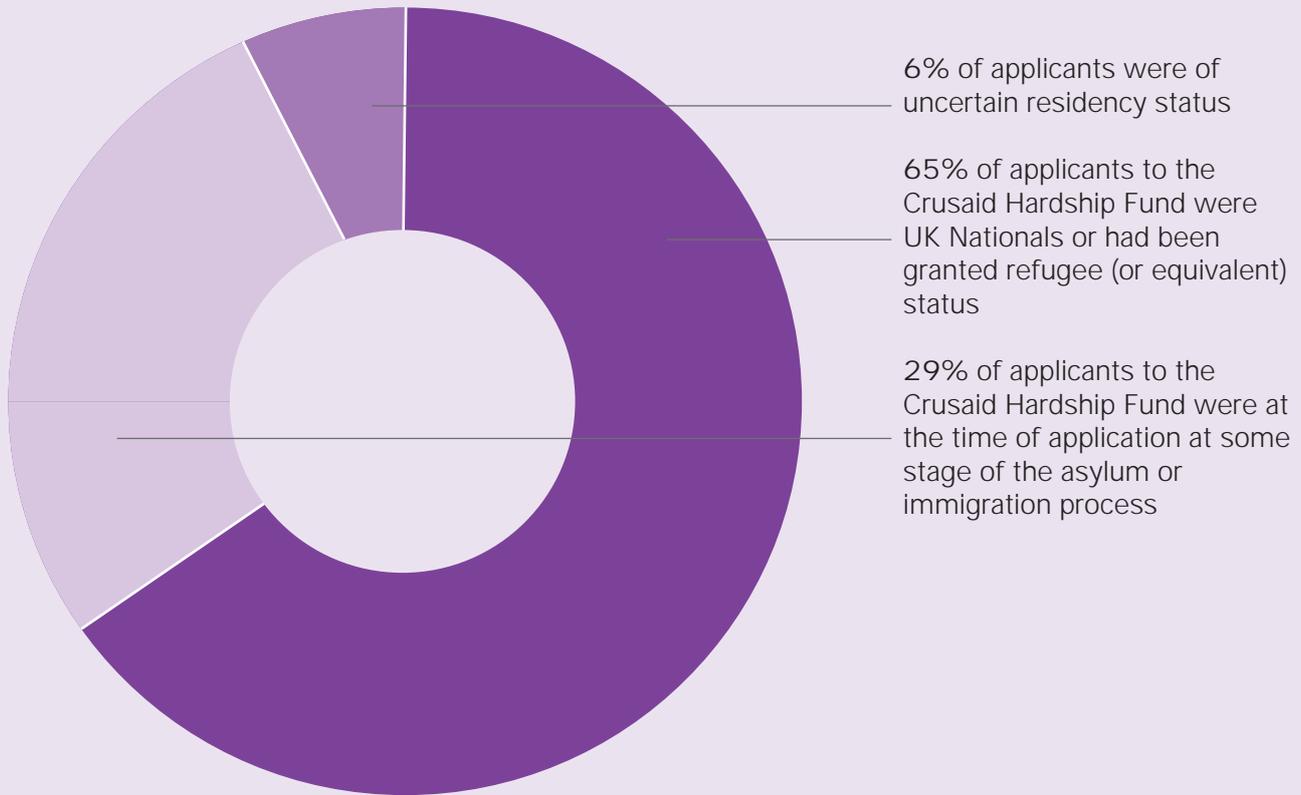
## **KEY FACTS OVER THE FIVE-YEAR PERIOD COVERED IN THIS REPORT**

The youngest client was aged 4 and the oldest 65.

49% of applicants were male and 51% female.

53% described themselves as British whilst 47% self defined as African, non British European or Southern Asian communities.

Of the 1,939 clients data referenced in the report:



# HIV, ASYLUM AND IMMIGRATION

More than 40 million people around the world are infected with the HIV virus. Scotland has long-standing links with certain parts of the world, especially countries in sub-Saharan Africa, which have been adversely affected by the spread of HIV.

Data from the Crusaid Hardship Fund in Scotland shows that 34% of applicants to the Fund come from Africa, the largest single group requiring assistance at the highest level. Within this group, 515 people were asylum seekers. As asylum seekers are denied the right to work (they can request permission to do so after 12 months in the country) it is not surprising that they have higher levels of need than others.

Previous Waverley Care research<sup>2</sup> has shown that asylum seekers frequently report that financial support provided through the National Asylum Support Services (NASS) is not enough to live on and where NASS support has been withdrawn they depend on friends, churches and charities to support them; as a result some face extreme poverty.

The same research has shown that people's experience of the immigration system is extremely negative, including not obtaining access to lawyers and problems communicating with the Home Office. Some asylum seekers were fearful that they could be subjected to the very behaviours that had originally caused them to flee their home countries. These levels of distress allied to the financial poverty they experience often leads to mental health difficulties.

Whatever their immigration status, nearly all migrants report that they encounter difficulties with the immigration system. People feel they cannot plan for a future, cannot work legally, run into financial difficulties and are often separated from families and loved ones for many years. Claims that people come to Scotland for free HIV treatment are ill founded. Research conducted by Waverley Care,<sup>2</sup> similar to research conducted in England and Wales by George House Trust and Terrence Higgins Trust,<sup>3</sup> shows that most migrants test late for HIV, often receiving an AIDS diagnosis at the same time, and several months after their arrival in the UK.



## ANNE'S STORY

"Anne", aged 23, arrived in Midlothian from Tanzania on a one-year work visa. She found work in a hospital, but became ill shortly afterwards. After visiting her local genito-urinary medicine (GUM) clinic, Anne was diagnosed with HIV, and was unable to work for a while.

Anne was not able to be supported by the City of Edinburgh Council as she was not a resident of the city and her local authority, unused to working with migrant workers, did not offer her any financial support.

In need of money to survive, Anne was forced to return to work sooner than planned.

The Crusaid Hardship Fund has been able to support Anne with basic necessities (food, clothing) and travel costs while she tries to find accommodation in Edinburgh to be nearer services and to have more support from social workers.

## MAKOSI'S STORY

"Makosi", aged 42, lives with her three children, two of whom are under the age of 6. Originally from Zimbabwe, Makosi fled to the UK when her brother was murdered for his political beliefs.

Makosi had lived in south London for three months, staying in a hostel with her children (then two only) when one evening she was raped. Following this attack, Makosi was found to be pregnant, and was diagnosed with HIV.

Makosi has very strong religious beliefs, and decided she should have the child. She was told two months after the child was born that she was going to be sent to Scotland as part of a disbursement programme. As Makosi had kept to herself since the attack she did not have any strong ties, and therefore did not mind moving. She was looking forward to making a fresh start.

Once in Scotland Makosi lived in a B&B and shared the bathroom with a hostile couple. She was told she should "go back to her own country" and was "not welcome".

Makosi started to attend a group via the local medical centre for single parents and through a social worker applied to the Crusaid Hardship Fund for respite costs to spend some quality time with a family counsellor to help her deal with the future.

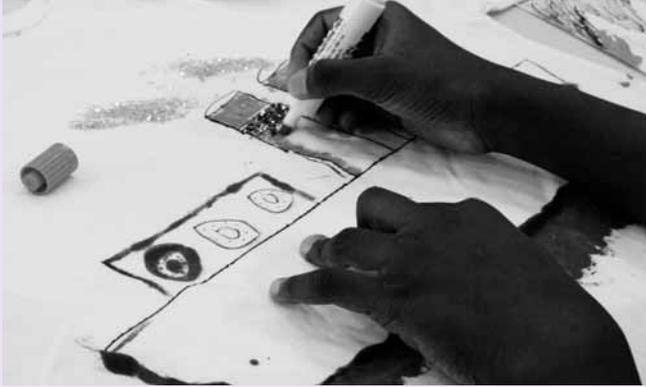
Makosi was given limited leave to remain in the UK recently and now is attempting to find work.

# HIV, CHILDREN AND FAMILIES

HIV services in Scotland have always focussed strongly on children and families because of the route of transmission via drug misuse. This focus has continued with the arrival of migrant families affected by HIV. Financial poverty caused by a person having HIV can affect the whole of their family. Research conducted by Children in Scotland and the University of Edinburgh describes the issues facing children and young people, including their involvement in social activities. They were sometimes prevented from attending sports events on financial grounds: "Several boys had joined junior football training teams in the hope of making it into senior clubs. Their enthusiasm had waned, however, when they discovered that they were expected to train twice a week, as they frequently experienced difficulties getting there."<sup>3</sup>

For some children the impact is far more stressful. Waverley Care's research<sup>2</sup> shows that many migrants to Scotland have children (23 from a sample of 25) although they do not always have their children with them in Scotland. Where children remain with relatives in Africa it is not uncommon for their parents in Scotland to try and send money home to help pay for their care. Child Poverty Action Group research<sup>5</sup> shows that children living in households headed by an adult from an ethnic minority are more likely to be living in a low-income household than their white counterparts. Sending money home to Africa and the presence of HIV in the family inevitably exacerbates this.

African community applicants to the Crusaid Hardship Fund in Scotland are most commonly women with at least one dependant.



## PETER'S STORY

"Peter" is now 7 years old and came to the UK when he was 4, with his mother, "Theresa", who wanted try and start a new life. They came to the UK after the smallholding they owned in Zimbabwe was broken into and his father and younger sister were killed. The person responsible was arrested but his family made life unbearable for Theresa so she decided to move to the UK: "I wanted to come to the UK because I had seen pictures and heard how friendly people were. I intended to get a job, maybe one day buy a small house and give my son a future."

After arriving in England, Theresa became very ill, which she assumed was because she was suffering from stress. However, she was diagnosed with HIV and told she had a CD4 count of just 23. Peter was placed in foster care while Theresa recuperated. She joined a women's group and started to rebuild her life with her son, but one day at 7am there was a knock at the B&B door where she lived and a couple of men and a women with a van told her she had to move. She did not understand and became highly distressed, but all they would say was that she had been sent a letter. She was placed in a home in Birmingham and soon became ill again requiring Peter to go into a foster home. Shortly afterwards she was contacted by the home office and told she would have to move again.

"By this point I thought, how much more of this must I take, but I had to be strong for my boy."

Theresa and Peter were re-located to Glasgow and as happened previously it was not long before the stress significantly affected Theresa's HIV health and she was hospitalised again. Peter was placed in a new foster home and after a week the foster family became very concerned about how depressed a child of only seven was. After interventions from child support services they discovered Peter was frightened because he believed his mother was going to die and leave him alone. He refused to make new friends because he did not want to be moved again and have to leave his friends behind, as had happened in the past.

The Crusaid Hardship Fund in Scotland has recently provided Peter and his mother with a small respite break at a specialist centre designed to help parents support their children through the disclosure process as well as to have some quality time together. Previously the Crusaid Hardship Fund had provided two other grants, one for basic food and another for travel costs for Peter to get to hospital to visit his mother.

# HIV AND HOUSING



Scottish public housing stock does not have a good reputation. Much of it is old and damp and located in peripheral housing schemes where amenities and transport links are poor. This can seriously affect the health of people living with HIV and is compounded by the traditional Scottish tenement style of build, which often involves climbing several flights of stairs. For people living with HIV who suffer from fatigue and breathlessness this can be a real problem.

Housing issues feature highly on the list of concerns experienced by people living with HIV. Around 35% of clients share their living space with non-family members and some 20% live in bed and breakfast accommodation. Sharing accommodation and trying to retain confidentiality over one's health and HIV status can be difficult. People may feel forced to make decisions about disclosure when they are far from ready to do so and may face hostility and rejection when they do disclose.

Some people do not even get to this position as

private landlords often discriminate between clients on the grounds of ethnicity. One Crusaid Hardship Fund client said that she was told by a private landlord that she could not have a flat because she was African and therefore "must have AIDS."

Housing is of major concern to asylum seekers. In Waverley Care's 2005 research<sup>2</sup> all the HIV positive asylum seekers interviewed in Glasgow had problems with their accommodation, including overcrowding, poor quality stock, dampness and lack of adequate heating; where these were reported to the local authority or housing association little if anything was done to remedy them.

The Crusaid Hardship Fund has had a growth in the number of clients who, after having been given leave to remain following disbursement to Scotland, are now living in Scotland and applying for start up grants or rental deposits in order to settle and start to build a home. It is important that services are in place to help support them in doing this.



## SARAH'S STORY

"Sarah", aged 41, lives with an HIV and Hepatitis C co-infection. Her HIV diagnosis has been diagnosed for 21 years (the route of her infection was through IVDU).

Sarah came to be known to the Crusaid Hardship Fund in Scotland after experiencing catastrophic flooding in her home following adverse weather conditions. The result of this flooding has meant that Sarah has lost all her possessions – clothing, soft furnishings and white goods.

Sarah had no home insurance to make a claim. As is necessary before applying to the Crusaid Hardship Fund in Scotland, alternative funding options were looked into and applied for (welfare supports, second-hand equipment and furnishing depots set up for those on benefits).

Sarah applied through her social worker to the Crusaid Hardship Fund for funding new clothing; bedding, floor coverings, white goods and respite stay to alleviate stress.

## PETER'S STORY

"Peter" is 42 and lives in Edinburgh; he had been with his partner Graeme for seven years. They considered themselves a well-sorted couple, were good friends and had reasonably well-paid jobs.

They had a fairly open relationship, which allowed occasional "playing the field" with each other's consent. One Christmas Peter was unwell through most of the festivities and after New Year, when it was obvious his poor health was caused by something more than just flu, he went to the doctor. After many tests he discovered he was HIV positive.

Graeme was very supportive at first, as were Peter's family and friends. Peter gave up his work at Graeme's insistence so as to concentrate on getting well. However, after a couple of months, Graeme started to get very moody and blamed Peter for a deteriorating lifestyle.

Then Graeme beat Peter up on numerous occasions, which on one occasion led to Peter being hospitalised. Peter told friends, family and the doctor that he had been mugged in the street. Peter felt that he owed Graeme a debt for staying with him. Over the next six months the relationship became highly strained and the men split up. Peter let Graeme keep most of the things they had bought together and promised to move out of Edinburgh to let them both start a new life.

A couple of weeks later Graeme became very ill and was admitted to hospital. Peter went to see him and after a discussion with a couple of his friends and a nurse discovered that Graeme was HIV positive and had known his diagnosis for over three years.

Although Peter could not prove anything, he had always been confused as Graeme was the only person he had ever had high risk and unprotected sex with. Peter now lives in a new city and is re-building his life.

The Crusaid Hardship Fund has provided two supports to Peter over the period: assistance with travel costs and a removal van to move home. Graeme has also received support from the Fund to help pay a very high gas bill through the winter.

# HIV AND DISCRIMINATION

All clients report HIV related discrimination and public perceptions of HIV as the biggest handicap to “living well” with HIV. It extends to all areas of people’s lives; many experience double discrimination as a result of their race or sexuality.

One area where the impact of discrimination is particularly felt is that of employment. For the majority of the population employment provides opportunities to socialise and economic resources to enhance their quality of life. The advent of Highly Active Antiretroviral Therapy (HAART) means that many people living with HIV are now in better health and able to consider returning to work or staying in work when receiving a positive diagnosis. However, analysis of data from the Crusaid Hardship Fund for Scotland shows an increase in the past two years of applications from clients who have had to give up work after treatment breakdowns. One of the most common issues cited was the inability to declare one’s status in the workplace and a subsequent inability to manage a strict drug regime while at work. Whether or not discrimination actually occurred at work, the client perception was that there was a real danger that they would be discriminated against.

Changes introduced by the Disability Discrimination Act 2005 (DDA 2005) mean that people living with HIV should be protected from discrimination from the moment of diagnosis. Employers are required to “make reasonable adjustments” to remove any barriers facing people living with HIV but, as we have seen, many people living with HIV either do not know this or do not feel able to avail themselves of the act’s powers. The legislation covers recruitment, terms and conditions of employment, chances for promotion and training, as well as addressing issues of unfair dismissal or less favourable treatment. The legislation also offers protection against victimisation or harassment from colleagues.

Discrimination can take place daily as the following case studies show. Although the taxi driver in Laura’s case is clearly in breach of the DDA 2005 as the provider of a service, there is no legislation to cover the abuse suffered by Mark. Such occurrences are commonly reported by people living with HIV.



## MARK'S STORY

"Mark" is 36 and has lived in a small town all his life. He has an elderly father for whom he used to be the main carer. He discovered he was HIV positive after a minor road accident, which left him with slightly impaired mobility.

Mark was very distressed and became a virtual recluse. His friends tried to engage him in social activities but he was not interested. After a long period of not going to work he lost his job, too. His father's GP did not feel Mark was capable of looking after his father and arranged for a welfare worker to visit and make an assessment of need.

As part of this, Mark was referred to the local hospital duty team for a psychiatric assessment. They visited him at home and he was placed on anti-depressants. Over a period of time he started to become more like his old self, and began trying to rebuild his friendships.

After a few beers in the pub, Mark told a friend about his HIV diagnosis and how much it worried him. The friend started shouting at him, telling him he had no right to come into a public bar and "give AIDS" to everyone else. The whole bar started shouting abuse and a barmaid had to help Mark out of the back entrance and he went home.

He broke down and told his father what had happened and his father told him it was his own fault for being "a queer". A lot happened over the next few weeks, and eventually Mark's father asked to be moved into residential care unit and Mark relocated to a nearby city.

Mark approached the Crusaid Hardship Fund on three occasions during this period: to help move his belongings, to buy some basic furnishings, and more recently, having become more composed, to pay his travel expenses so he could visit his father with a volunteer counsellor to try and re-build their relationship.

## LAURA'S STORY

"Laura" is 32 years old and lives in an inaccessible rural area. She has had an HIV diagnosis for the past two years after being diagnosed through her anti-natal clinic.

Laura's medical support and hospital treatment is a considerable way away. She has a small benefit as well as a small income from a part-time cleaning job.

Laura began using a taxi every week to attend hospital. After becoming comfortable with her regular driver, Laura let slip about her HIV status. After this the taxi company was unable to find her a driver who was free when she needed to go to the hospital and she missed two appointments.

The next week Laura travelled to the hospital by taking two buses, which exhausted her and on her return journey she went past the taxi office where she saw that many cars were not being used. She called the company and they again said they were flat out with no spare drivers; she accused them of refusing to take her because she was HIV positive and they responded that they could carry who they wished and told her not to call again.

Over the next few weeks Laura had the feeling that people were talking about her in shops and at the library. This came to a head when she heard a woman in a shop describe her loudly as the woman with AIDS.

Tired of the travelling and the discussions behind her back Laura found a small flat in Glasgow and approached the Crusaid Hardship Fund for support to move her possessions and to make the flat secure with new locks.

# HIV, ADDICTIONS AND CO-INFECTION



The HIV epidemic in Scotland was first noticed among intravenous drug users and this group still makes up a significant proportion of those with advanced HIV disease living in Scotland. Many are co-infected with Hepatitis C, another blood-borne virus, which can be fatal if it is not treated. Until 31 March 2007 there were 22,456 diagnoses of Hepatitis C in Scotland; 13,333 of these people were infected by via intravenous drug use. Treatment for Hepatitis C infection is not always successful and a dual diagnosis of HIV and Hepatitis C is not a good indicator for longer term health. Many people from this group have been infected for

more than 15 years and experience regular periods of chronic ill-health; some have children.

People who have misused or currently misuse drugs are often at risk of homelessness and this can be exacerbated by a chaotic lifestyle. In turn this can make it difficult to sustain regular care and treatment. Missing appointments is a common feature but equally many drug users feel that generalist services are less than sympathetic to them. All of these factors inevitably contribute to poorer outcomes in the longer term.



## RICHARD'S STORY

"Richard" is a 52-year-old man living with an HIV and Hepatitis C co-infection. He has known about his diagnosis for seven years and is heterosexual.

Richard moved to Edinburgh following harassment after a hostile response to his HIV status and started accessing basic benefits.

Richard was unable to get a reference from his previous employer as people at his former place of work were the main source of the abuse he had received. This, mixed with a general fear of putting himself back into a situation where he might suffer further harassment, has left Richard paranoid, and no longer able to work.

Richard fell into a period of depression and as a result experienced a number of side-effects with his treatments. He experienced significant weight loss and severe night sweats.

Richard approached a social worker who applied to the Crusaid Hardship Fund for an extra set of bedding and a mattress.

## ALICE'S STORY

"Alice" was born and raised in the Highlands and was part of a very strict family. She was beaten regularly by her father, who had considerable mental health problems. Alice's mother was a very strong Christian who believed that family was paramount and never asked for outside support.

Alice had one brother whom she idolised but at the age of 16 he was killed in an accident on a loch.

When Alice was 17 she ran away from home and went to Glasgow, where she met a crowd of people her own age and made friends. She felt they were the first real friends she had ever had and was determined not to lose them. They drank heavily and although she would join in, she managed to avoid drinking the quantities others put away.

Alice attended a party at an old house (a squat) and there she was persuaded to try some cocaine. She was not sure what she thought about the experience but didn't feel it was that bad; this experience led Alice to try other types of drugs and pretty soon she was injecting heroin.

Alice looks back and says that although it sounds stupid now, she didn't think twice about sharing a needle. They always wiped them down with a cloth and usually sterilised the needle with a lighter.

After four months of living in this way, one of Alice's friends overdosed and Alice became hysterical. She went out into the high street and a passerby called the police. Alice was taken to hospital and as part of the assessment process she discovered she was HIV positive.

The social worker arranged for her to go to a bed-sit and have supervision, and to contact her family, but her mother refused to see her and told the worker her daughter had made a choice and chosen the devil. The worker applied to the Crusaid Hardship Fund for basic food and clothing costs for Alice while she sorted herself out. Later she applied for a security bond to get a one-room private rental flat where she is trying now to restart her life.

# KEY POLICY RECOMMENDATIONS

The impact of poverty and deprivation on health and well-being is well documented and increasingly recognised in health and social policy. Use of the Crusaid Hardship Fund Scotland indicates, however, the need for effective long-term policy and action to address the underlying causes. National AIDS Trust (NAT) recommendations in the December 2006 report *HIV and Poverty*<sup>1</sup> remain highly relevant. Responsibility in some areas remains with the UK Government; other areas, such as health, justice, education, finance, sustainable development, children and early years, are now the responsibility of the devolved Parliament and Scottish Government. Voices heard in this report show that whatever the progress in tackling social injustice at broad population levels, the following recommendations, if implemented, would benefit people living with HIV, and reflect government priorities.

## **ASYLUM AND IMMIGRATION**

- a) Preparations for dispersal to Glasgow must ensure that individuals and families are supported through important changes and have adequate information on their health and social care through improved communication at all levels.
- b) Scottish Government proposals about the care, protection and education of asylum seekers and their children must be implemented, particularly those related to dawn raids, detention in Dungavel and legacy cases.
- c) Progress in enabling children of asylum seekers to access university and further education is to be welcomed. Career opportunities thereafter need to be consistent with this arrangement, and permission to work should be extended to asylum seekers who have lived in Scotland for more than six months.
- d) The subsistence level for asylum seekers should be increased to one that is equivalent to income support.

## **DISCRIMINATION, HATE CRIME AND ABUSE**

- e) Legislation proposed for the Scottish and Westminster Parliaments to deal with hate crime in relation to disability, sexuality and transgender status is welcomed and merit government support. The Crown Office and relevant courts should treat cases of multiple discrimination as serious aggravations.
- f) Public sector experience of the implementation of disability and HIV awareness training should be supported and resourced, and alliances formed with key private employers to apply best practice to the private sector.
- g) Collaboration with other disability and welfare organisations should seek to campaign for improved implementation of disability rights legislation in relation to employment, to ensure that people living with HIV enjoy the benefits of the legislation and are able to manage their condition well and maintain paid employment.
- h) Domestic violence and abuse related especially to HIV status needs to be addressed through raising awareness of rights and responsibilities targeted to the benefit of specific communities, with training and collaboration with police and community safety officers.
- h) Media organisations should adopt and implement best practice in reporting HIV, as outlined in *'HIV: A Guide For Journalists'*<sup>6</sup> to ensure fairer and more accurate coverage of HIV issues.

# KEY POLICY RECOMMENDATIONS

cont...

## ***HOUSING, DEPENDANTS AND SOCIAL CARE***

- j) Raising the income of those on low pay and reliant on benefits, is the key starting point for tackling poverty and addressing many of the difficulties that people frequently report. This will require effective coordination across the UK and Scottish levels of government.
- k) Employment and return to work are core to government policy in reducing poverty, but research indicates that people experience barriers to accessing paid work and difficulties in maintaining employment once in work, especially if they have a disability including HIV. Policy measures are required to promote flexible working and to help with the costs of return to work.
- l) All health and social services must liaise with local authorities in ensuring they provide affordable, secure and healthy housing for those living with HIV, who may also be in poor health or socially vulnerable, or whose condition may deteriorate.
- m) Those providing out-of-hours services, access to information and support, respite care, children's services and treatment should recognise the impact of poverty, deprivation and discrimination and provide appropriate referrals to welfare rights services.
- n) Innovative approaches to reduce family and individual poverty should be developed. Small grants schemes for people living with HIV and other long-term conditions would enable enterprise and small-scale income generation schemes.
- o) Age related poverty must be addressed by the Government when forward planning, both in relation to children and young people and also for older people living longer with HIV, especially in light of projections of increasing experience of pensioner poverty.

# FURTHER INFORMATION

## **USEFUL WEBSITES**

<http://www.nat.org.uk/Poverty-and-Social-Disadvantage>

[http://www.edinburgh.gov.uk/internet/Attachments/Internet/Social\\_care/About\\_Social\\_Care\\_and\\_Health/Monitoring\\_performance/Best\\_value/best\\_value\\_HIV.pdf](http://www.edinburgh.gov.uk/internet/Attachments/Internet/Social_care/About_Social_Care_and_Health/Monitoring_performance/Best_value/best_value_HIV.pdf)

<http://www.scotland.gov.uk/News/Releases/2007/08/03082811>

<http://www.scottishrefugeecouncil.org.uk/>

<http://www.povertyalliance.org/>

<http://www.paih.org/>

<http://www.jrf.org.uk/knowledge/findings/socialpolicy/2060.asp>

<http://www.npi.org.uk/reports/mpse%202006.pdf>

## **REFERENCES**

<sup>1</sup> Crusaid and National Aids Trust (2006), *Poverty and HIV: Findings from the Crusaid Hardship Fund 2006*.

<sup>2</sup> Sinyemu E. and Baillie M. (June 2005), *HIV Becomes Your Name: A Report on the Issues Facing Africans Living in Scotland who are HIV positive*, Waverley Care

<sup>3</sup> Terrence Higgins Trust and George House Trust (2003), *Recent Migrants using HIV Services in England*

<sup>4</sup> Children in Scotland and University of Edinburgh (2002), *Listening to Children and Young People Whose Parent or Carer is HIV Positive*

<sup>5</sup> Flaherty J., Veit-Wilson J. and Dornan P. (2004), *Poverty: The Facts*, Child Poverty Action Group

<sup>6</sup> National AIDS Trust (April 2007), *HIV: A Guide for Journalists*

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Waverley Care

THT Scotland

## **Images:**

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p13 Radu Fizesan, p16 Andrea De Stefani