



HIV & AIDS: help & hope for people in poverty

# HARDSHIP FUND

POVERTY  
AND HIV

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# FOREWORD

**"With an average weekly income of £42 per week, successful applicants to the Hardship Fund now have less than half the income they had a decade ago. Many have no income at all."**

**The relationship between poverty and HIV is cyclical. Poor health caused by HIV increases demands on personal resources at the same time that ability to work and generate income becomes limited, creating an entry-point into poverty. Equally, poverty can cause significant deterioration of the health of someone living with HIV, with insufficient access to adequate nutrition, housing and healthcare and reduced capacity to pursue a healthy lifestyle. Applicants to the Hardship Fund are challenged daily by the need to manage their HIV while experiencing severe personal hardship.**

However, HIV not only causes poverty because of its health impact but because of its social impacts. There is still significant stigma attached to the virus, and the discrimination directed at people with HIV is for some as great an impediment as any health problems they experience. HIV stigma can lead to discrimination at work, abuse from neighbours, and even denial of treatment in healthcare settings.

It's been only three years since Crusaid and NAT last explored the connections between HIV and poverty in the UK<sup>1</sup>, but the degree of financial hardship experienced by applicants to the fund has increased dramatically in that time. In 2010, while this report was being finalised, Crusaid merged with Terrence Higgins Trust (THT), the UK's oldest and largest HIV charity. THT is committed to the continuation of the Hardship Fund, for the many reasons illustrated in this report.

With an average weekly income of £42 per week, successful applicants to the Hardship Fund now have less than half the income they had a decade ago. Many have no income at all. The severity of poverty experienced shows how fundamental the Hardship Fund has been in meeting basic needs and supporting the quality of life and dignity of people living with HIV.

The dramatic increase in extreme poverty among people living with HIV over such a short period of time shows how urgently the underlying causes of this hardship need to be addressed. Thus, this report is not limited to issues of HIV treatment and care, but addresses the full range of policy and administrative practices which disproportionately affect people living with HIV in poverty. Our recommendations set out a clear agenda for change.

We urge decision-makers nationally and locally to read this report. It contains some shocking statistics which underline how profoundly and harmfully poverty and HIV are interconnected in our society. In the three years reviewed here, one in every six people living in the UK with an HIV diagnosis approached the Hardship Fund for assistance at least once.

But behind the statistics the report also contains detailed snapshots of real and complicated lives, with problems that interact and compound each other. For those assessing needs, planning services or determining policy, this report also looks beyond the data to the people we have an obligation to help.



**Deborah Jack, Chief Executive, NAT & Sir Nick Partridge, Chief Executive, Terrence Higgins Trust**

<sup>1</sup> NAT and Crusaid. 2006. Poverty and HIV: Findings from the Crusaid Hardship Fund 2006. These reports cover England, Wales and Northern Ireland. For findings from the Crusaid Hardship Fund in Scotland, see Crusaid, Waverley Care and HIV Scotland. 2007. Poverty & HIV: Findings from the Crusaid Hardship Fund in Scotland.

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## About the Hardship Fund

The Hardship Fund is a small grants programme managed until 2010 by Crusaid in partnership with the Elton John AIDS Foundation, the MAC AIDS Fund and the Monument Trust. From June 2010 Crusaid, including the Hardship Fund has merged with Terrence Higgins Trust. The Fund is often the only recourse open to people affected by HIV who are living in poverty.

## About NAT

NAT is the UK's leading charity dedicated to transforming society's response to HIV. We provide fresh thinking, expert advice and practical resources. We campaign for change.

All our work is focused on achieving four strategic goals:

- Effective HIV prevention in order to halt the spread of HIV
- 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

## About Terrence Higgins Trust (THT)

THT is the UK's largest and oldest HIV charity.

## Our vision

A world where people with HIV live healthy lives free from prejudice and discrimination, and good sexual health is a right and reality for all.

## Our mission

**Maximise** sexual health in the UK, and minimise the spread of HIV and STIs, by encouraging people to value their sexual health and by leading innovation to increase access to local sexual health services

**Empower** everyone living with HIV in the UK to maximise their health and wellbeing by working to ensure the best possible HIV treatment and support services

**Lead** public and political support for HIV & sexual health issues, and campaign to eradicate stigma & discrimination

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# EXECUTIVE SUMMARY

This report explores the relationship between poverty and HIV, and highlights policies which may alleviate or exacerbate this poverty. It makes 20 policy recommendations designed to tackle poverty amongst people living with HIV at its root causes.

Since 1989, the Hardship Fund has made small, targeted grants to people living with HIV in urgent financial need, to help applicants maintain their health and effectively manage their condition.

The report draws on both quantitative and qualitative sources to identify trends in applications to the Hardship Fund between 2006 and 2009. In this period, 1 in 6 of all people being treated for HIV applied to the Fund.

The average income after housing costs of applicants to the Hardship Fund between 2006 and 2009 was £42 per week. This is 55% less than the average weekly income reported by applicants a decade ago (£93).

The report identifies six major drivers of poverty among people living with HIV, which both cause and compound the experience of hardship:

## 1. The immigration system

The immigration and asylum systems limit the ability of many migrants to generate and receive income, leaving them in poverty. Over a quarter of Hardship Fund recipients were asylum seekers, who are not permitted to work and live on around £35 a week in asylum support payments.

Immigration and asylum rules and support should promote dignity and a life free from poverty – changes should include the right to work after six months, the end of voucher-based support, and an increase in the rate of asylum support to the level of income support.

## 2. Insufficient benefits

Two-thirds of successful applications to the Hardship Fund received some form of state benefit, and 17% of referrals said problems relating to benefits were a main cause of hardship – in many cases due to poor administration and delays in receiving benefits. Recent changes to the disability benefits system are likely to increase this uncertainty.

The Department of Work and Pensions needs to improve standards of efficiency and accuracy in benefits administration, as well as HIV training for staff, so that people living with HIV are not left in poverty because of poor decision-making or processes.

## 3. Poor physical or mental health

Poor physical and mental health arise from poverty, but can also push someone into poverty. Despite the availability of highly effective HIV treatment, many grant recipients were seriously ill at the time of applying to the Hardship Fund. Many such cases were linked to late diagnosis, and subsequent lack of timely access to treatment.

Better commissioning of HIV testing, mental health and social care services for people living with HIV is necessary to act as both a health promotion and an anti-poverty intervention.

## 4. Unemployment

Around 90% of grants went to applicants who were not in paid employment. The main reasons for inability to work were poor physical and mental health problems, immigration control conditions, and stigma and discrimination.

The Equality and Human Rights Commission needs to ensure that employers and employees are aware of provisions against HIV discrimination in the Equality Act, including the prohibition of pre-employment health questionnaires.

## 5. Inadequate housing

Living in poor quality housing- which is overcrowded, or subject to draughts, damp or mould- can have serious health consequences for people living with HIV. Grant recipients were just as likely to live in a hostel or bed and breakfast (4%) as own their own home (either with a mortgage or outright). Even more were reliant on UKBA accommodation (around 10%). Most of those living in rented accommodation were in council housing.

A woman wearing a black blazer is holding a large purple folder. She is standing against a white background. The folder is held in front of her, and her hands are visible at the bottom of the folder. The top of the page features a decorative header with vertical bars in shades of purple and blue.

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When providing housing, local authorities and the UK Border Agency need to take into account specific HIV-related housing needs, and the impact that sub-standard housing and the risk of homelessness have on the health of people living with HIV. They need to improve their housing stock to better meet these needs.

## 6. Responsibility for children

Around a quarter of successful applicants were parents or guardians, responsible for a total of 6,800 children affected by HIV. The costs associated with caring for children can cause severe financial stress in a low income household. If that household is also affected by HIV, there are additional pressures created by special health needs and HIV stigma and discrimination.

**Children affected by HIV and poverty should be given specific support through tailored social care provisions.**

# WHO IS THE HARDSHIP FUND HELPING?

- Average weekly income has dropped 30% since 2005, and is now only 20% of median income of the general population
- The average amount awarded increased to £167 (from £140 in 2005)
- Between 2006 and 2009, the Hardship Fund gave £1.24 million in grants
- 20% of grants were to repeat applicants

## Who is the Hardship Fund helping?

Professor Peter Townsend suggested that in the UK, poverty is experienced when someone's "resources are so seriously below those commanded by the average individual or family that they are, in effect, excluded from ordinary living patterns, customs and activities".<sup>2</sup> These resources include housing, education, health, employment, safety from crime, and access to services- as well as income.

A common measure of low income in the UK is 60% of the median weekly income of the general population.<sup>3</sup> At present, the low income threshold is £115 a week for a single person without dependents, after housing costs.<sup>4</sup>

Between April 2006 and March 2009 9124 people living with HIV applied to the Hardship Fund. This represents about 16% of all people accessing HIV treatment in the UK at this time.<sup>5</sup> In all, 7934 people were awarded grants. Some people were given more than one grant, to an agreed maximum level, due to continuing problems.

The average income after housing costs of applicants to the Hardship Fund between 2006 and 2009 was £42 per week. This is 55% less than the average weekly income reported by applicants a decade ago (£93).<sup>6</sup>

At only 20% of the median population income for a single person, the average recipient of a Hardship Fund grant is living in extreme poverty.<sup>7</sup>

## How do Hardship Fund grants help people living with HIV?

The Hardship Fund offers several types of grant:

- A grant for short-term **respite care** may be considered based on the identification of specific medical, psychological and/or social need.
- Clients may be provided with **white goods** – washing machines, microwave ovens, fridge-freezers and cookers - to help maintain health and well-being.
- A **start-up grant** can assist a client setting up in their first independent accommodation.
- A grant can help with a **one-off expense** which the client is unable to meet with their current income and which can be directly linked to their HIV status.
- For clients with very limited income, **utility bills** may be paid.
- The most basic needs of food, toiletries and travel may be paid through an **ordinary living expenses (OLE)** grant, for those on an extremely low income, or with no income at all.

<sup>2</sup> JRF, 2009. [www.poverty.org.uk](http://www.poverty.org.uk)

<sup>3</sup> as used by JRF, Oxfam GB, End Child Poverty etc.

<sup>4</sup> JRF, 2009: £199 per week for a couple with no dependent children; £195 per week for a single adult with two dependent children under 14; and £279 per week for a couple with two dependent children under 14.

<sup>5</sup> Based on the 56,665 accessing care at the end of 2007, which is a middle point in the time period analysed. HPA.

<sup>6</sup> Reported income- not adjusted for inflation

<sup>7</sup> JRF data shows that the median income is approximately £192 a week.

**The most common demographic profile among successful applications to the Hardship Fund between 2006 and 2009 was of a black African woman in her 30s. However, the findings from the Hardship Fund illustrate compellingly that the experience of living with HIV in poverty is not particular to any age, gender or ethnicity.**

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### Ethnicity

The majority of successful applications (60%)<sup>8</sup> were made on behalf of black African clients. The second most commonly reported ethnicity was white British (23%), followed by non-British European (6%).

### Residency Status

Successful applications were most likely to come from a British citizen (34%). Other frequently reported residency statuses were 'seeking asylum' (27%) and 'right to remain in the UK' (19%).

More asylum seekers sought grants for ordinary living expenses - food, clothing, toiletries and transport - than applicants of any other residency status (41% of OLE grants).

### Gender & Sexual Orientation

Slightly more women (53% of successful applications) than men (47%) applied to the Hardship Fund. However, over the same period of time, women only represented around a third of people living in the UK with an HIV diagnosis.<sup>9</sup>

Women who received money from the Hardship Fund were generally younger (under the age of 40) and more likely to report having dependent children (75% of applicants with children) than men. Men were more likely to live alone than in any other household arrangement (58% of men).

Historically, the Hardship Fund did not ask about the sexual orientation of applicants so this data is unknown. It is clear from the individual referral circumstances that a large proportion of the grants to men are to those who are gay or bisexual, but the exact proportion is not calculable.

### Geography

The data in this review relates to Hardship Fund grants awarded across England, Wales and Northern Ireland. Grants in Scotland were separately administered. Successful applicants were most likely to come from London (38%), followed by the North West (20%) and the South East of England (13%).

Over the three years, however, there has been a shift in the distribution of grants away from London (40% in 2006/07 to 34% in 2008/09) and the South East (14% in 2006/07 to 11% in 2008/09) to other areas of the country, such as the West Midlands (10% in 2006/07 to 15% in 2008/09). This may reflect broader economic and social trends,<sup>10</sup> as well as the impact of specific policies such as the asylum dispersal programme.

### Age

The majority (over 70%) of successful applications were for clients aged between 30 and 50 years old. The most represented age group in grants allocated by the fund was 30-39 years old (41.6%). Around 10% of applicants were over 50 years of age.

Applicants in their 30s were the largest group receiving Start Up grants to set up a new home (42% of Start Up grants). The majority accessing grants for respite care were in their 40s (58% of grants for respite care went to this group).

Detailed charts showing the full breakdown of this data are available from the web version of this publication on the NAT ([www.nat.org](http://www.nat.org)) and THT ([www.tht.org.uk](http://www.tht.org.uk)) websites.

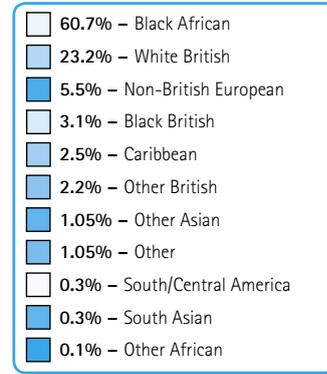
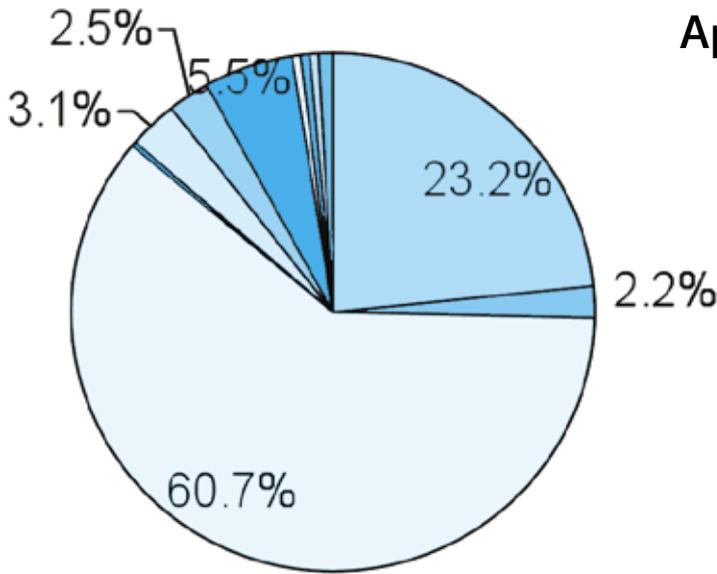
<sup>8</sup> Of those who reported their ethnicity. All frequencies noted in this report are percentages of those who responded to that question. Percentages are given to the nearest 1%.

<sup>9</sup> 34% of those accessing care in 2007. Figures from 2007 are used as this represents a mid-point in the time period covered by the research. HPA. *HIV in the United Kingdom: 2008 Report*.

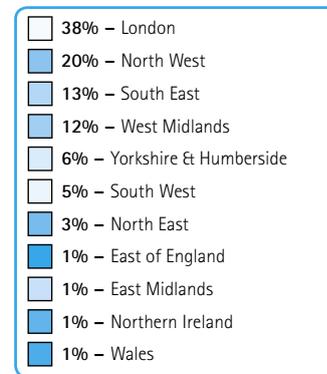
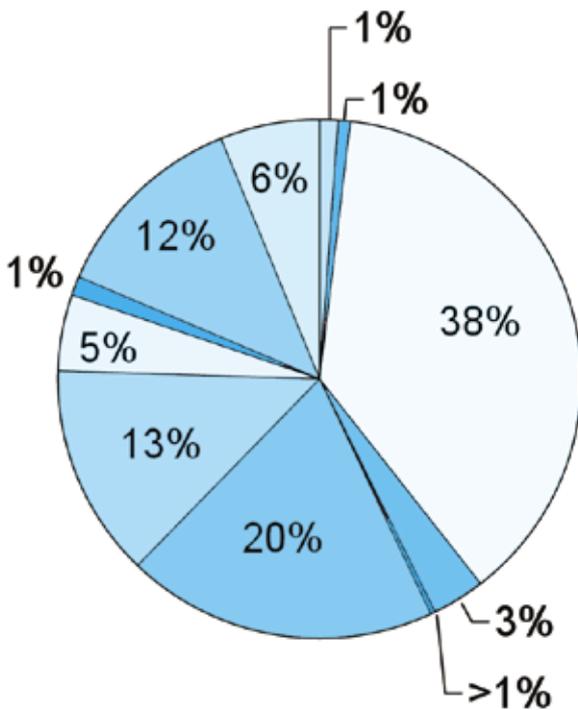
<sup>10</sup> In particular, employment rates in the West Midlands have been lower than the overall rate in England since at least mid 2007, and the gap continued to widen into 2009. Office for National Statistics. 2010. *Labour Force Survey, seasonally adjusted data*.

# WHO IS THE HARDSHIP FUND HELPING?

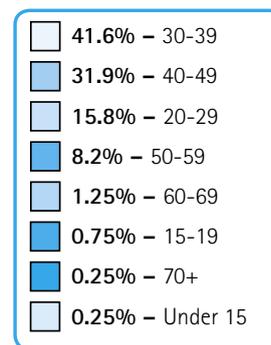
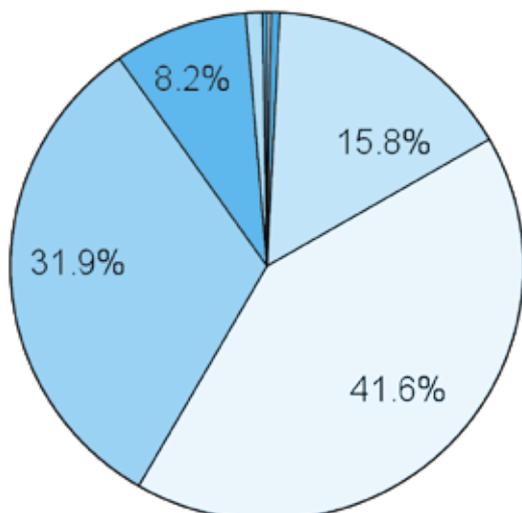
## Applications By Ethnicity



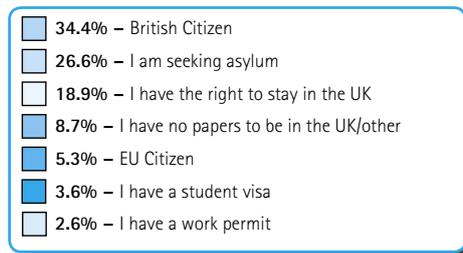
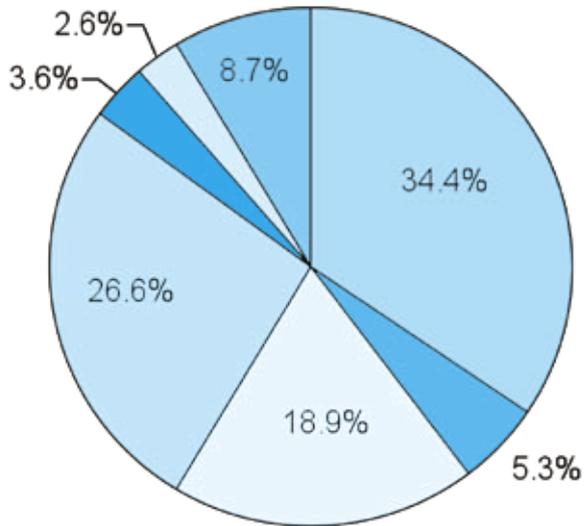
## Applications By Region



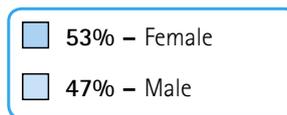
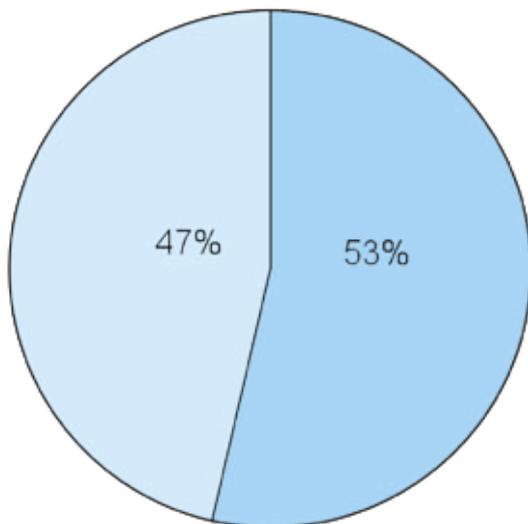
## Applications by Age



## Applications by Residency Status



## Applications by Gender



# DRIVERS OF POVERTY

## What are the drivers of poverty among people living with HIV?

All applications to the Hardship Fund are made by registered referrers (such as social workers) on behalf of their clients. As part of the application, referrers write a cover letter giving relevant details of their client's household, health and financial circumstances. These tell the individual stories behind the statistics. They offer an explanation of the causes of poverty - both structural and personal - as well as the impact of poverty for people living with HIV.

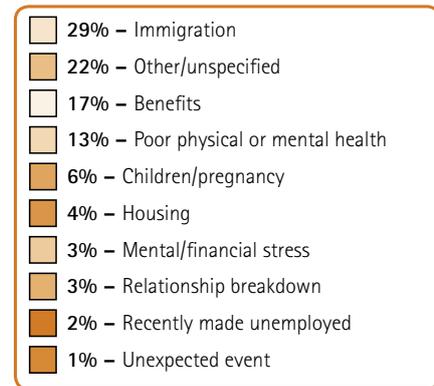
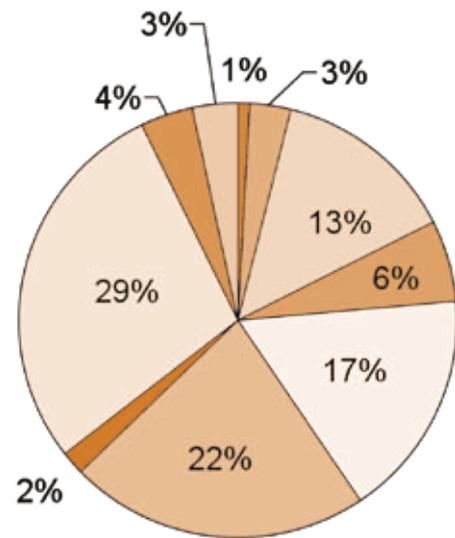
For the first time, this report draws upon an analysis of the narrative content of these referrals, as well as a statistical analysis of all successful applications between 2006 and 2009. A sample of 1,080 letters, representing 44% of those which were successful in obtaining grants in the last financial year (April 2008-March 2009) were analysed. The causes of hardship identified by the referrer were noted. From this exercise, it is possible to give an overview of the key drivers of poverty among people living with HIV today.

From the letters analysed, the most-cited identifiable causes of hardship among people living with HIV were:

1. The immigration system (29%)
2. Insufficient benefits (17%)
3. Poor physical or mental health (13%)
4. Responsibility for children (6%)
5. Inadequate housing (4%)

Where specific drivers of poverty have been identified, these have shaped the themes of discussion in this report. However, the second largest category recorded in the analysis was 'other'. As this is not a single identifiable driver of poverty, it has not been included above. However, it is worth noting the sorts of issues raised by referrers which could not be more precisely categorised. These tended to be for essential material needs and daily expenses which were unaffordable. The most common items mentioned were clothes (22%); food costs (20%); basic furniture for a current home (12%) or new accommodation (12%); everyday travel (9%); bedding (6%); and study costs (5%).

## Primary and Secondary Causes of Hardship- Referral letters



# THE IMMIGRATION SYSTEM

The legal status ascribed to a migrant affects their ability to access work, housing, benefits and healthcare, leaving them vulnerable to poverty.

Patterns of migration are a defining feature of the HIV epidemic in the UK today – the Health Protection Agency (HPA) estimates that 76% of new HIV infections among heterosexuals diagnosed in the UK in 2008 were acquired overseas.<sup>11</sup> With many people living with HIV being migrants, it is not surprising that the UK immigration system has a profound impact on the experience of living with HIV.

The legal status ascribed to a migrant affects their ability to access work, housing, benefits and healthcare. Reduced capacity for generating and receiving income makes asylum seekers and migrants particularly vulnerable to poverty. For migrants living with HIV, lack of resources and the instability caused by involvement in the immigration system can undermine efforts to manage their condition.<sup>12</sup> For the many migrants who are only diagnosed with HIV after arriving in the UK, the pressures of immigration controls are another source of stress at an already difficult time.

Referrals to the Hardship Fund illustrate this. The experience of the immigration system was the most prevalent cause of hardship experienced by successful applicants, identified in 29% of referrals.

## No recourse to public funds

Mentioned in 14% of all referrals analysed, "no recourse to public funds" was the greatest cause of immigration-related hardship experienced by successful applicants- and therefore the most-identified single cause of hardship overall. "Public funds" include benefits like income support, disability living allowance and housing benefit (but not asylum support).

Around 4,500 successful applications to the Hardship Fund were made on behalf of applicants with no recourse to public funds. This includes asylum seekers and those whose asylum claim has failed; migrants who are staying in the UK on visitor visas, student visas and working visas; and some who had overstayed these visas or who had no papers to be in the UK.

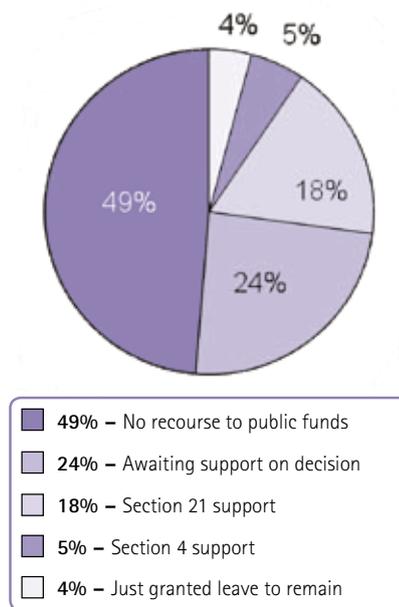
Others may have the right to remain in the UK, but are not automatically entitled to access public funds. These restrictions particularly affect EEA nationals of the recent EU "accession countries"<sup>13</sup> the third most reported ethnicity in successful Hardship Fund applications between 2006 and 2009 was non-British European.

Letters to the Hardship Fund tell many stories of migrants living legally in the UK on student and working visas, who have depleted their savings or incurred rent arrears when they became too ill to work. In other cases,

poor physical and mental health related to HIV meant that a migrant overstayed their visa. Their resulting non-standard residency status in turn affected their ability to meet their basic care needs. In these cases, immigration control conditions exacerbate vulnerability in a time of health crisis.

**Recommendation: Migrants living with HIV are at risk of unintentionally breaching visa conditions if they become suddenly ill. UKBA should show flexibility in working with migrants whose poor health or hospitalisation has contributed to a breach of immigration controls.**

Immigration Issues



<sup>11</sup> HPA. 2009. *New HIV diagnosis in the UK by prevention group and estimated world region of infection.*

<sup>12</sup> Crusaid. 2009. *Poverty Without Borders- a report on poverty, HIV and migration from the Crusaid Hardship Fund.*

<sup>13</sup> A2 and A8 Nationals

# THE IMMIGRATION SYSTEM

## Asylum support

A quarter of successful applications to the Hardship Fund were from individuals seeking asylum, who are not permitted to work. They may only apply for the right to work after they have been in the country for 12 months without an initial decision. Common sources of income among those applying to the Hardship Fund were therefore asylum support in the form of cash or vouchers from the UK Border Agency (45% of successful applications from asylum seekers) or local authorities (10%, under Section 21- discussed further below). However, more than 30% of asylum seeker applicants received no income from public funds, wages or tax credits: this could mean reliance upon friends, family or charity, or no income source at all.

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**Recommendation: Asylum seekers should have the right to work after 6 months. For asylum seekers living with HIV, the ability to take up employment would offer an exit out of poverty.**

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As of October 2009, current rates of cash support for a single asylum seeker without children have been reduced from 68% of the £64.30 received by a single person living on income support to 55% of this rate: £35.13 a week. The justification for this reduced rate is that asylum seekers can request accommodation, and do not have to pay rent or utility charges while living in this housing. However, many individuals in receipt of income support, job seeker's allowance and employment and support allowance are eligible for housing benefit to cover part or full rent, if they are judged to be living on a low income. Council tax benefit may also be paid on their behalf. There is clearly no justification for asylum seekers receiving a mere £5 a day, when it is considered that £9 is the absolute minimum needed for the rest of the population.

Not surprisingly, 7% of all referral letters cited insufficient asylum benefits as the primary cause of hardship. A common theme in these letters was the struggle to buy enough nutritious food to maintain health. The cost of warm clothes and appropriate footwear for autumn and winter was also frequently mentioned. After buying food and other essentials, there is often no cash left over for travel costs; one applicant did not have enough money to travel to hospital appointments. This is particularly an issue for asylum seekers living in rural areas.

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**Recommendation: Subsistence payments for asylum seekers should be increased to a level that is equivalent to income support. At only 55% of the level of income support, asylum payments are insufficient to meet the basic needs of asylum seekers living with HIV, with serious health implications**

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## Section 21 Support

Some asylum seekers may be eligible for support by local authorities under Section 21 of the National Assistance Act 1948.<sup>14</sup> However, following a 2008 decision in the House of Lords,<sup>15</sup> eligibility is more restrictive and some asylum seekers who were once entitled to Section 21 support on the basis of their HIV status now have to apply for UKBA support instead.

It is crucial that those who do lose their entitlement are given at least 21 days' notice, and supported in their transition to UKBA support.

It should be noted that even asylum seekers who have retained access to Section 21 support are still not guaranteed protection from poverty. In 5% of referral letters analysed, the very low level of support offered through Section 21 was itself a cause of hardship.

# THE IMMIGRATION SYSTEM

## After the asylum decision

As part of the New Asylum Model's focus on fast-tracking asylum claims, 2007/08 saw the accelerated resolution of many outstanding asylum claims. Under the UKBA Case Resolution Programme (also known as the "legacy" programme), 220,000 cases had been concluded by September 2009. Of these claims, 74,000 asylum seekers (34%) were granted leave to remain in the UK.<sup>16</sup>

However, the resolution of an often long-awaited asylum claim can trigger a period of vulnerability for asylum seekers. 28 days after a claim has been resolved, state support offered during the asylum process is withdrawn. This is often followed by a lengthy delay before the right to work or claim benefits is confirmed formally. This was reflected in referrals which reported "just been granted leave to remain" as a primary cause of hardship. These were most commonly seeking help to purchase basic home furnishings such as mattresses and kitchen utensils. As the legacy programme will continue until the summer of 2011, many more individuals and families will be in a similar situation, unless there is real improvement to decision-making processes and timelines in the welfare system.

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**Recommendation: UKBA and DWP should work together to ensure that asylum seekers who have just been granted leave to remain and are eligible for benefits are guided and assisted through the application process, so that the delay in receiving benefits is minimised. Such delays leave asylum seekers living with HIV without income to meet their basic needs.**

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Asylum seekers whose claim has not been successful and who have not been granted humanitarian protection or discretionary leave are expected to return to their country of origin. Some refused asylum seekers are detained, and forcibly removed. Others may volunteer to return. In some cases, though, this is not immediately possible, owing to being unfit to travel or having no safe route available. In this case, an asylum seeker may be offered support under Section 4 of the Immigration and Asylum Act 1999.

Section 4 support takes the form of vouchers or a special pre-paid cash card, which may be used at a limited number of outlets for a designated range of products at each outlet (chiefly food and toiletries). Without access to cash, unsuccessful asylum seekers have no means to buy anything not available from the UKBA list. A 2008 study of the impact of this system by the Refugee Council found that the vouchers were, in the majority of cases, insufficient to buy the amount of food needed, as well as other essentials like nappies. As well as adding to financial hardship, the use of vouchers contributed to poor physical and mental health, and made unsuccessful asylum seekers more visible in the community- and therefore more vulnerable to discrimination and abuse. The Refugee Council concluded that the current system is "inhumane, ineffective, and results in unnecessary suffering".<sup>17</sup>

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**Recommendation: The Section 4 voucher and card system adversely affects the physical and mental health of asylum seekers living with HIV. Section 4 support should be provided as cash benefits. The voucher and card system should be discontinued. Section 4 support should be equivalent to income support.**

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### Clyde's Story

#### Hardship Fund Grant £200

Clyde is a 42 year old man who has been in the UK for 6 years. He originally arrived with a job offer, but the company went into receivership after just two months and Clyde had still not been paid. He was stuck in an area he did not know, without any money for rent or food. Clyde slept rough for a couple of weeks and then became ill. Once in hospital he was diagnosed with HIV-related pneumonia.

Having claimed asylum, Clyde was relocated to the West Midlands, where he has been provided accommodation under the dispersal policy. He receives Section 4 support in the form of vouchers for food, toiletries and clothing to the value of £35 per week.

Clyde cannot use his vouchers to buy bus tickets, and has no cash, so has to walk everywhere. His hospital is five miles from where he is provided accommodation, and twice in the six months before making his application he had missed medical appointments when feeling too unwell to make the walk.

After being dispersed, Clyde found it difficult to make friends and develop any support networks. He became isolated, which had serious consequences for his mental as well as physical health.

"I cannot get the bus and even if I walk to meet people, a cafe would not take a voucher for a cup of tea".

<sup>14</sup> Home Office. 2007. Funding for asylum and failed asylum seekers. <http://www.homeoffice.gov.uk/about-us/freedom-of-information/released-information/foi-archive-immigration/5704-funding-asylum-seekers?view=Html>

<sup>15</sup> M v Slough Borough Council

<sup>16</sup> Melanie Gower. 2010. Asylum: 'Legacy' Cases. House of Commons Library Standard Note. SNHA-04439. 4 January 2010. <http://www.parliament.uk/commons/lib/research/briefings/snha-04439.pdf>

<sup>17</sup> Lisa Doyle. 2008 *More Token Gestures*. Refugee Council

# INSUFFICIENT BENEFITS

Incapacity benefit, which was a source of income in 7% of people receiving grants from the Hardship Fund, has now been replaced by employment and support allowance (ESA). The DWP estimated that 50% of applicants would not pass the assessment.

Two-thirds of successful applications to the Hardship Fund received some form of state benefit, and 17% of referral letters said that problems relating to benefits were a main cause of hardship. The most common benefits among successful applicants were income support and housing benefits (15% of successful applications fell into each category), followed by child benefit (8%) and incapacity benefit linked to HIV status (7%).

Ethnicity and gender divisions were noticeable around certain benefits. For example, incapacity benefit because of HIV-related health issues was most common among successful white British applicants (two-thirds of those on the benefit) and men (80% of those on the benefit). Child benefit was more common among successful black African applicants (65%) and women (80% of those on the benefit).

## Benefit delays

For someone living with HIV, who is dependent upon state payments for income security, delays in benefit entitlements can trigger major financial and personal crisis. This was the case in the 4% of successful applications to the Hardship Fund which said that awaiting expected benefits, awaiting a benefits appeal, or awaiting a benefits decision was the primary or secondary cause of hardship.

The time lag between initial application for benefits and decisions can range from weeks to even months, with no ongoing communication during this period. During this time, the applicant may be left with no income. In some instances, appeals are related to an applicant being assigned an incorrect benefit in the first place. If all applicants were properly advised on their entitlements, the cost of the appeals process as well as the personal cost to the individual could be avoided.<sup>18</sup>

Crisis Loans are available to some who are left without income while awaiting a decision, but do not always create an effective safety net in practice, with delays in receiving these payments as well. Delays are also rife for individuals switching between benefits; this is a particularly vulnerable time for refugees moving off asylum-related payments. Asylum payments are so minimal (only 55% of the amount received on income support) that no one who had been living on them for any length of time would have any savings or financial buffer zone between the end of these payments, and the start of a new entitlement.

**Recommendation:** People living with HIV should not be left in poverty because poor decision-making affects their benefit entitlements. As recommended by the House of Commons Work and Pensions Committee, the Secretary of State should report on DWP decision-making standards annually. These reports should be used as a basis for improving decision-making within DWP.

Over the past two years, reforms to the benefits system have changed the application process for certain disability-related benefits, to which some people living with HIV may be entitled. In October 2008, incapacity benefit, which was a source of income in 7% of successful applications to the Hardship Fund, was replaced by employment and support allowance (ESA) for new applicants. Eligibility for ESA is subject to passing a work capability assessment (WCA) which draws on documentation and, in most cases, a face-to-face medical assessment, to confirm eligibility on disability grounds. The teams making the face-to-face assessment are medically trained, but need not be a doctor or a specialist in HIV or any other condition. When ESA was introduced, the DWP estimated that 50% of applicants would not pass the WCA.<sup>19</sup> Statistics to date, however, show the proportion of rejected claims to be much higher.

Individuals who do not pass the WCA will, in many cases, be assessed as suitable for job seekers allowance (JSA). As such, many more people living with HIV will be subject to conditionality-based benefits. This puts pressure on people living with HIV to seek work even when they have poor physical or mental health. The shift to JSA also means that many who would have once received up to £89.80 in incapacity benefit, in acknowledgement of the extra costs associated with managing their HIV-related health needs, will receive far less (£64.30 for a single person over 25).

**Recommendation:** Work Capability Assessments (WCAs) should take into account the impact of fluctuating conditions, such as HIV, on ability to enter and remain in employment. Staff who carry out face-to-face medicals, and DWP staff who make decisions on applications, should be trained to a standard competence level in HIV and its impact.

<sup>18</sup> NAT. *Decision making & appeals in the benefits system: response from NAT*. September 2009.

<sup>19</sup> Ibid.

# INSUFFICIENT BENEFITS

## Living on benefits

Even more common than problems relating to awaiting benefits, benefit decisions and appeals was the challenge of subsisting on benefits and finding them insufficient to meet essential needs. This was cited in 13% of referrals.

Benefit rates are set to provide the bare minimum required to meet essential daily needs. This leaves nothing for unexpected events, such as bereavement, burglary, or urgent house repairs. The personal financial crisis triggered by these events leads individuals to the Hardship Fund.

Even more frequently, though, applicants who are living on benefits need help with the costs of health and personal care needs associated with HIV such as healthy food, new clothing (because of weight fluctuations), or bedding (due to night sweats), or modifications to the home such as insulation or installation of a shower. The review of referral letters also revealed a large proportion of people on benefits and living with HIV who needed help simply to cover their utility bills.



Having only enough money for bare essentials, makes it near-impossible for people on benefits living with HIV to effect positive change in their life. For example, one applicant to the Hardship Fund was living in a hostel and attempting to make changes to a previously chaotic lifestyle. However, her benefits wouldn't cover her bus fare to get to her support group or even see a friend. Side effects from her medication caused her to gain weight rapidly and she could neither fit in her old clothes nor afford to buy larger ones, even from charity shops.<sup>20</sup> Without access to a small one-off grant it is hard to imagine how she would have worked her way out of social isolation.

## Michael's story

### Hardship Fund Grant £240

**Michael is a 39 year old man with HIV who has had poor health for a number of years – and is particularly vulnerable to opportunistic infections. Once Michael has paid for housing and council tax contributions using his incapacity benefits, he is left with £86.40 to live on a week.**

Receiving Incapacity Benefit makes Michael ineligible to apply for a grant or loan from the Social Fund to help with any financial emergencies he may have, such as when his health deteriorated significantly due to problems with his flat that he simply couldn't afford to fix.

His council flat was very cold, with minimal heating. His clothing was worn out and did not fit him properly, due to treatment-related weight loss. He was spending nearly all of his available money on keeping portable heaters running to manage the cold. Michael had also recently changed some of his medication and was experiencing severe night sweats and diarrhoea. This meant that he was having to wash his bedding frequently, leaving the flat almost constantly damp, as well as cold.

Michael turned to the Hardship Fund. The grant he received helped to buy a more efficient oil-filled radiator, a couple of new sets of bedding, some warm clothes, and a month's electric credit on his key meter.

<sup>20</sup> Some people taking HIV treatment may experience a change in weight (loss, gain or distribution).

55% of new HIV cases in 2008 were diagnosed late, meaning they were diagnosed at a point after treatment should have been started.

People living with HIV in poverty face significant challenges to meeting their health needs. This is illustrated by the very basic resources purchased with Hardship Fund grants, such as fresh and nutritious food, warm clothing and home adaptations against draught and damp – essential for avoiding the additional health risks posed by a compromised immune system.

There is a strong link between poverty and poor health. A 2007 Joseph Rowntree Foundation study of various ethnic groups in a deprived area of London found relationships between ill health and financial hardship, unemployment and lack of social participation.<sup>21</sup> This and other studies have shown that the relationship between poor health and poverty is multi-directional and iterative.<sup>22</sup> This was borne out in approved applications to the Hardship Fund between 2006 and 2009: poor physical and mental health arise from poverty; but can also push someone into poverty.

## HIV Testing and Treatment

Poor physical and/or mental health was the third most common reason for needing financial help cited (13% of referral letters). This may come as a surprise, given that the advances of modern anti-retroviral (ARV) drugs have largely redefined HIV as a manageable long-term condition for those receiving effective treatment. However, the stories of serious HIV-related illness, opportunistic infections and CD4 counts below 50 cells/mm<sup>3</sup><sup>23</sup> that reach the Hardship Fund do not reflect a failure in the effectiveness of treatments available in the UK to halt the progression of HIV. Rather, they are the result of situations that are eminently preventable: late diagnosis, and subsequent lack of timely access to treatment.

55% of new HIV cases in 2008 were diagnosed late, i.e. at a point after treatment should have been started.<sup>24</sup> This was particularly prevalent among black Africans, 66% of whom were diagnosed late. Recent research has found that, once diagnosed, the vast majority of people living with HIV receive treatment in line with their clinical needs, regardless of their ethnicity, gender or sexual orientation.<sup>25</sup> This means that increasing uptake of testing, including avenues outside of Genito-Urinary Medicine (GUM) and antenatal clinics, is the key to reducing the unnecessary deterioration of health associated with untreated HIV. In this way, better HIV testing becomes an effective anti-poverty intervention.

**Recommendation:** In line with the UK National Guidelines for HIV Testing, new initiatives should be implemented to increase access to HIV testing in a wider variety of settings, especially for communities with high HIV prevalence rates.

Even for those who are diagnosed and start treatment in a timely manner, living in poverty still poses challenges to effective management of HIV. For ARV treatment to be effective, strict adherence to doses and timing is crucial.

There is a risk of developing drug resistance if schedules are not kept. Strict adherence to treatment is a challenge for anyone living with HIV. For those whose daily life is defined by poverty and disadvantage, though, there are particular barriers to consistency.

These barriers include the challenges of instability caused by their experience of the asylum or immigration systems; unsuitable, unstable or shared housing; and concealing their HIV status for fear of rejection or discrimination. Poverty also limits the ability of someone living with HIV to manage their condition more generally, with nutritious food, sufficient rest and a healthy living environment free of damp and draughts.

The price they pay for this reduced capacity to effectively manage their HIV health, including poor drug adherence, is deterioration of wellbeing. This can result in a vicious circle where people living with HIV can spiral ever deeper into poverty, leading to poor health, leading to worse poverty, leading to worse health.

<sup>21</sup> Salway, S., L. Platt, P. Chowbey, K. Harris and E. Bayliss. 2007. *Long-term ill health, poverty and ethnicity*. JRF.

<sup>22</sup> Hirsch, D. and N. Spencer. 2008. *Unhealthy lives: Intergenerational links between child poverty and poor health in the UK*. End Child Poverty.

<sup>23</sup> Treatment should commence when the CD4 count falls below 350cells/mm<sup>3</sup> - *British HIV Association guidelines for the treatment of HIV-1-infected adults with antiretroviral therapy 2008*.

<sup>24</sup> Less than 350cells/mm<sup>3</sup>. HPA. 2009. *HIV in the United Kingdom: 2009 Report*.

<sup>25</sup> Elford, J. F. Ibrahim, C. Bukutu, J. Anderson. 2008. "Uptake of antiretroviral treatment among people living with HIV in London: ethnicity, gender and sexual orientation." *Sexually Transmitted Infection*, 84: 176-178.

## Mental health

It is generally accepted that people living with HIV have a higher risk of mental health problems.<sup>26</sup> The recent study of people living with HIV, *What do you Need?* by Sigma Research found that more than 70% of respondents had experienced anxiety or depression in the past year. 56% of respondents also noted that they had ongoing problems with anxiety or depression, which they felt could be improved with greater help.<sup>27</sup>

Findings from the Hardship Fund did not reveal how many applicants overall experienced mental health problems, but in 4% of referrals analysed, poor mental health was itself cited as a cause of hardship experienced by the applicant. This may be because their mental health problems pose a barrier to employment, or a barrier to social participation generally.

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**Recommendation: Mental health problems can be an entry point into poverty. There should be consistent commissioning of accessible and appropriate mental health services for people living with HIV.**

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For some applicants, the stress of diagnosis can trigger mental health problems, or exacerbate existing problems. For others, the experience of poverty is itself a cause of extreme psychological and emotional stress. Nearly 200 applicants to the Hardship Fund were awarded a grant for respite care, providing a much needed break from situations of poor health and poverty. In one typical example, a client living with multiple health conditions in addition to side-effects from his HIV medication was able to spend a weekend at a long-term survivors' group. This also gave his partner a break from caring responsibilities. Grants such as these offer one-off periods of relief for people living with HIV, but for day to day support, proper social care provision is essential.

## Social care

Social care can play a crucial role for the health outcomes of someone living with HIV. It plays a role at the point that they receive their diagnosis, in helping them to understand their diagnosis and share this information with others in their lives, and in managing their medication and other special healthcare needs. A central part of this support may be to reduce the impact of other lifestyle factors that make adherence to treatment regimes difficult. These may include unsuitable accommodation, unstable relationships, emotional and psychological problems and personal care and coping needs – all of which arise regularly in the referral letters to the Hardship Fund.

*What do you need?* also revealed key social care support needs for people living with HIV. Around a quarter of respondents had experienced problems with chores and self-care and thought they would benefit from more help. Of those who had had difficulty in this area, 82% attributed the problem to physical health problems and 62% to mental health problems (respondents could choose more than one cause).<sup>28</sup>

The only source of dedicated funding for providing the social care and support needs of people living with HIV in the UK is the AIDS Support Grant (ASG), which is administered by local authorities. The ASG has been ring-fenced since 1989, although the ring-fence has now been removed. In 2009, NAT undertook an assessment of the ASG, and found it provided the very services mentioned by respondents to Sigma's research, including counselling (provided by 91% of authorities), peer support (82%), staff training (71%), carer support (67%) and personal care services (63%).

However, NAT's review also found shortcomings in respect to the consistency, transparency, and evidence-base shown in spending the ASG. More than half of local authorities surveyed had not carried out any sort of needs assessment before making decisions about the use of the Grant. However, good practice was also found among local authorities in terms of these and other aspects of using the ASG, which should be emulated.

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**Recommendation: The AIDS Support Grant should continue to be provided after 2011.**

**Recommendation: Local authorities should conduct comprehensive social care needs assessments for people living with HIV to ensure the AIDS Support Grant reaches people living with HIV and has the greatest possible impact. This is especially important now that the grant is no longer ring-fenced.**

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<sup>26</sup> NAM Fact Sheet, *Mental Health*. January 2009.

<sup>27</sup> *What Do You Need 2007-2008?* Sigma.

<sup>28</sup> *What Do You Need 2007-2008?* Sigma.

# POOR HEALTH

## Helen's story

### Hardship Fund Grant £288

Helen is 55 years old. Three years ago, her partner became very ill and was diagnosed HIV positive. As he was too ill to work they managed on her wage and the statutory sick pay he received. Helen worked as much overtime as she could. After a while Helen also became unwell, and after being admitted to hospital was also diagnosed HIV positive. Helen went back to work and continued getting overtime, but became run-down and found each day to be harder than the last.

A year ago, Helen was diagnosed with HIV-related cancer. She immediately started chemo- and radio- therapies. Helen had to stop work and take statutory sick pay as well. She received full pay for six months, but she was no longer able to get the extra overtime payments the couple had come to rely upon.

The couple's utility bills mounted. They were using the phone more with calling clinicians and family, and the electricity and gas bills also escalated with heating costs. Any spare cash went to cover transport to and from hospital for treatment, and to buy the fresh and nutritious foods advised by the HIV consultant.

The couple approached the Hardship Fund for support. A one off grant of £288 was made to clear outstanding electricity, gas and telephone bills. With the immediate pressure off, Helen was able to work with her referring agency around financial planning and debt management for the future.

## Phillip's Story

### Hardship Fund Grant £250

Phillip has lived in the same flat for 18 years, and 15 of these years he shared with his partner Stuart. Both of them were diagnosed HIV positive a decade ago, and managed well, but at the end of last year Stuart passed away from HIV-related pneumonia.

Phillip became very depressed after his bereavement. He has only a few friends and although they were very supportive he found it difficult to rely on them. After a few weeks he decided to start clearing out some of Stuart's things and took a few bags of clothing to a local charity shop. A couple of days later, Phillip heard a loud banging on his front door and when he opened it, he found the bags of clothes on his doorstep. There was a note with the bags that said that they could not be accepted because Stuart had "died of AIDS."

This devastated Phillip as he did not know how anyone would know about Stuart's HIV status, or his status, or why it should matter. He approached a counsellor who had been working with him and she investigated. She found that a volunteer at the charity had recognised him and had heard about how Stuart had passed away- so took it upon himself to reject the clothing. The counsellor contacted the manager of the charity shop who was extremely apologetic, but the damage was done.

After this experience Phillip refused to leave his flat, and became isolated and highly anxious. He started to take medication for his nerves and his counsellor suggested he should consider moving to make a fresh start. Phillip did not wish to leave his flat, though, as all of his memories of Stuart were there.

Phillip's counsellor eventually convinced him to try a visit to a specialist respite centre where he could meet people who would understand his situation. An application was made to the Hardship Fund, which paid for a week at the centre.

When Phillip had finished the week he made an appointment to see his counsellor and asked if he could get help with relocating to start afresh. This process is now underway and he is feeling far more optimistic about the future.



# UNEMPLOYMENT

**40% of those who had experienced discrimination after disclosing their HIV status believed they had lost their job as a result.**

There is a body of research demonstrating the positive effect of employment upon quality of a life for people living with HIV in respect to physical and emotional wellbeing, financial stability, independence and sense of purpose.<sup>29</sup> However, unemployment rates tend to be higher among people living with HIV than the general population.<sup>30</sup>

The financial precariousness caused by unemployment is seen in the Hardship Fund data. Only 8% of successful applications were from individuals in receipt of a wage, and 4% reported that they received Working Families Tax Credit (there will be overlap between the groups). This suggests that around 90% of grants went to applicants who are not currently engaged in the labour market.

## HIV and work

As previous chapters show, some people living with HIV are unable to take up employment because of specific physical and mental health problems. However, for many more, the barriers to employment are more likely to have a legal or social dimension related to their HIV status as to be directly connected to their current state of health. One such factor is the impact of immigration controls, as previously discussed.

For others, stigma and discrimination create an unnecessary barrier to full participation in work. A 2008 survey commissioned by NAT of people working with HIV found that physical health and treatment demands do not always hinder a career, but there is still significant reluctance to talk about HIV status in the workplace.<sup>31</sup> Of the 40% who did not disclose their status at work, commonly cited reasons for concealment included confidentiality concerns, and fear of poor treatment.

Unfortunately, these discrimination fears are not always unfounded: around 20% of survey respondents who had disclosed their HIV status had experienced discrimination at their current or previous workplace. Of those who had been discriminated against in their current job, nearly half had experienced exclusion, a quarter had been bullied and 42% had had their confidentiality breached. Such unlawful discrimination has been described by applicants to the Hardship Fund, for whom losing a job was an entry point to poverty (such as William, overleaf).

Another discrimination related concern for many who responded to NAT's survey was the use of pre-employment health questionnaires. Nearly a fifth of respondents had been asked specifically about their HIV status on a questionnaire, and less than half had disclosed their status on the form. Almost three-quarters of all respondents said that the idea of being asked about their HIV status on a pre-employment health questionnaire made them uncomfortable. Based on this evidence, NAT and THT successfully campaigned for the use of pre-employment health questionnaires to be outlawed in the new Equality Act.

**Recommendation: The Equality and Human Rights Commission needs to ensure that employers and people living with HIV are aware that the use of pre-employment health-related questionnaires is prohibited under the Equality Act 2010.**

Ongoing prejudice and discrimination is needlessly preventing many people with HIV from contributing socially and economically through employment, and leaving them open to financial vulnerability.

<sup>29</sup> See literature review in Douglas, N. 2009. I just get on with it: *A study of the employment experiences of gay and bisexual men and black African men and women living with HIV in the UK*. NAT. See literature review in Douglas, N. 2009. I just get on with it: A study of the employment experiences of gay and bisexual men and black African men and women living with HIV in the UK. NAT.

<sup>30</sup> Ibrahim, F., J. Anderson, C. Bukutu and J. Elford. 2008. "Social and economic hardship among people living with HIV in London". *HIV Medicine*.

<sup>31</sup> NAT. *Working with HIV*. September 2009.

# UNEMPLOYMENT

## Protections against discrimination

For some, losing a job can be the entry point into poverty. This makes formal legal protections against discriminatory employment practices crucial. However, discrimination in the workplace continues, despite the introduction of the Disability Discrimination Act (DDA) 2005, since replaced by the Equality Act 2010. The Equality Act protects against HIV-related discrimination in all stages of the employment relationship, from recruitment to dismissal.

The Equality Act entitles someone who discloses their HIV status to an employer to request a 'reasonable adjustment' to their role or workplace. The right to request such adjustments makes it easier to manage the day-to-day effects that HIV may have on work life (e.g. flexibility to attend clinic appointments). Crucially, though, these provisions also offer people living with HIV breathing space when they need it most - at 'trigger points', such as diagnosis and commencing treatment. Many applicants to the Hardship Fund have felt they had to give up work following their HIV diagnosis. However, by requesting that reasonable adjustments be made to their role, it should be possible for many who have just received an HIV diagnosis to retain employment while going through this difficult time.

Almost a third of respondents in NAT's study had exercised the right to ask for reasonable adjustments, and in most cases it was simple and inexpensive: time off to go to clinic, a change in hours, or a change to start or finish times were the top three requests.<sup>32</sup> However, just over one in ten requests were refused.

Where complaints are not dealt with satisfactorily through workplace procedures, the Equality Act allows for cases to be pursued in an employment tribunal. However, as well as the costs associated generally with such actions, for HIV-related discrimination cases there may be particular reluctance to initiate a hearing owing to concerns about privacy and public disclosure of identity and HIV status. As such, the effectiveness of the Equality Act continues to rely on awareness, compliance and proactive implementation within workplaces.

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**Recommendation: The Equality and Human Rights Commission needs to undertake further work to ensure that employers and people living with HIV are aware of the responsibilities and rights outlined in the Equality Act 2010.**

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## William's story

### Hardship Fund Grant £250

**William is a 44 year old man who has been living with HIV for 8 years. He was married with two children and had a good job with a well-known high street retailer. He had not disclosed his status to his employer, and as he was well and held a good attendance record saw no reason to change this.**

One of William's children became very ill, causing considerable stress for the family. William took some leave from work during this time, and his employer insisted he see an occupational therapist. The occupational therapist requested some information from William's GP. In providing the information, the GP also disclosed William's HIV status to his employer, without William's permission.

Around a month later William lost his job in a company restructure. He strongly believes that the real reason he lost his job was because of his HIV status. He sought legal advice, and his legal counsel agreed that William's suspicions were likely to be true. However, William was advised his case would be nearly impossible to prove, and he decided not to take the action.

After losing his job William became very stressed and unwell. His marriage broke down, and he had to leave the family home. He ended up living in a bedsit in a house with five other people, where he again had to hide his HIV status. Owing to his unsuitable accommodation, he was offered only limited access to see his children.

After much fighting, William managed to gain a one bedroom flat, but still did not have the resources to furnish it, or protect against the cold weather which was causing him health problems.

William approached the Hardship Fund, who provided a start-up grant to purchase bedding, kitchen equipment, a microwave oven and some curtains. Since furnishing his new accommodation, William has been able to enjoy greatly improved access to his children, who can stay over in his new flat.

<sup>32</sup>NAT. *Working with HIV*. September 2009

# INADEQUATE HOUSING

People living with HIV also have a range of specific accommodation needs, which means that their housing becomes a focal point for healthcare challenges, non-adherence to treatment, and relationship tension, as well financial pressure.

Housing problems were the fifth most commonly identified cause of hardship in the referral letters analysed. Only 4% of successful applications were from individuals who owned their own houses (either with a mortgage or outright), compared with a 70% rate of home ownership among the general population.<sup>33</sup> Successful applicants were just as likely (4% of cases) to be living in a hostel, or bed and breakfast.

Access to, and quality of, housing is an important marker of the experience of poverty generally. However, people living with HIV also have a range of specific accommodation needs, which means that their housing contributes to healthcare challenges, non-adherence to treatment, and relationship tension, as well as financial pressure.

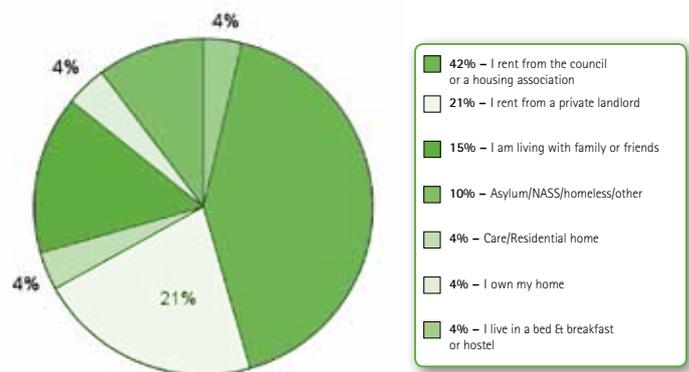
## Suitable accommodation

More than 60% of applications to the Hardship Fund were from people living in rented accommodation. Of these, the majority were tenants of a council or housing association. Each of these individuals has been allocated housing following an assessment, which takes into account health needs when deciding what priority the applicant should be given. However, research by NAT has found that many of the organisations making these assessments are working from outdated information about living with HIV.<sup>34</sup>

Relying on simple criteria such as CD4 count, an AIDS diagnosis, or particular symptoms of ill-health in judging vulnerability on health grounds does not address the reality of HIV as a long-term fluctuating condition, and as a disability. NAT has produced a practical guide on HIV and Housing in collaboration with Shelter, to ensure that those making assessments have a full understanding of the impact of HIV on housing needs.

**Recommendation:** All local authorities should follow the NAT Guidance on HIV and Housing, with particular attention to the need to carry out comprehensive assessments of the needs of people living with HIV who apply for social housing. This should include the fluctuating health of people living with HIV, mental health issues, and the need to comply with strict treatment adherence.

## Housing



Meeting health-related housing needs is crucial for people living with HIV, whether housing is provided by a council or privately. Hardship Fund grants to improve accommodation are common, with frequent requests for mattresses, bedding, insulation and white goods. Poor quality housing can exacerbate pre-existing health problems, physical or psychological, regardless of HIV status. However, the consequences of accommodation defined by overcrowding, draughts, damp, and mould are especially severe for people living with HIV.

HIV suppresses the immune system, making it more difficult to fight off respiratory conditions, which are triggered by heating and ventilation problems. The two most common AIDS-defining illnesses are respiratory-pneumocystis pneumonia (PCP) and tuberculosis (TB). Overcrowded living conditions also increase the risk of developing TB, which is seven times more common among people living with HIV.<sup>35</sup> Overcrowded and shared accommodation also presents special privacy concerns for people living with HIV. Having to store medication in a common area, and share a bathroom (a common side-effect of treatment is diarrhoea) become everyday challenges for someone who may not wish to disclose their HIV status.

**Recommendation:** Repairs and adaptations requested by tenants living with HIV should be addressed promptly, whether housing is provided by local authorities or by private providers contracted by UKBA.

<sup>33</sup> Figures for 2007, the mid-point of the period covered by this review. Communities and Local Government. 2007. *New Horizons Research Programme: Social Mobility and Home Ownership - a risk assessment*. <http://www.communities.gov.uk/documents/corporate/pdf/381408.pdf>

<sup>34</sup> NAT. *Housing and HIV*. January 2009.

<sup>35</sup> Ibid.

# INADEQUATE HOUSING

Asylum seekers, whose housing is provided as part of asylum support, are particularly likely to be living in overcrowded and unsuitable housing. Research by Shelter of privately-rented housing allocated to asylum seekers by UKBA found that 86% of dwellings were unsuitable for the number of people living in them, and 17% of all dwellings were not fit for human habitation.<sup>36</sup> A 2007 Joint Committee on Human Rights investigation found that some housing provided to asylum seekers contravened their human rights, specifically their right to private and family lives (Article 8 ECHR), as well as the right to adequate housing (Article 11 ICESCR). Approximately 10% of applications to the Hardship Fund resulting in grants concerned asylum seekers who were provided housing by UKBA.

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**Recommendation: UKBA urgently needs to improve its housing stock to ensure that the human rights of asylum seekers are respected. The inadequate housing currently provided presents significant challenges for managing HIV and maintaining good health.**

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## Risk of homelessness

For many people, moving house represents aspiration, or fulfilment of a sought-after opportunity. However, for applicants to the Hardship Fund, moving or setting up a new home is often a necessity, whether following a notice of rent arrears, loss of publicly-funded housing at the end of an asylum claim, or the breakdown of a relationship.

After renting, the most common housing arrangement among successful applicants to the fund was living with family or friends (15%). Many of these cases would meet the legal definition of homelessness.<sup>37</sup> Three-quarters of those living in this situation were black African. It is not surprising to find individuals experiencing hardship relying upon the hospitality of friends and family; however, there is a great deal of vulnerability and often precariousness in these housing arrangements.

There may be existing friction within family relationships, which exacerbates tension created by what is often unsustainable accommodation. For example, one client who had simply nowhere else to go ended up living with his ex-partner, causing them both a great deal of stress. Host relatives and friends may already be living with some degree of financial stress themselves, and cannot afford the extra hospitality needed. Specific nutrition needs, strict drug regimes and other healthcare needs make it more difficult for people living with HIV to 'muck in' with the rest of the household. In some cases the guest may not feel able to disclose his or her HIV status, so faces the daily challenge of trying to discreetly meet treatment and care needs.

Referrals to the Hardship Fund regularly tell stories of friends, relatives and partners who have eventually asked their friend or loved one to leave. Sometimes a grant will take the pressure off someone living in this situation, and their hosts, by allowing them to contribute financially, as well as buy essential items they will use such as bedding and clothes. However, in letters to the Hardship Fund, losing one's home was as often a cause of poverty as a result of it.

Mentioned in 3% of referral letters, relationship breakdown ranks closely behind housing problems as a major cause of hardship. A common experience among applicants was relationship breakdown directly related to their diagnosis, or the stress associated with it. One grant recipient, who was in the UK on a student visa, was refused further support from the family he was living with after he was diagnosed with HIV.

Others leave their home following domestic violence, which has its own consequences: for example, a mother who moved with her children so quickly following violence in her home, that many of their possessions were left behind. In this case, a Hardship Fund grant allowed her to buy clothes and shoes for her children as well as a few things for her home. Another young applicant used a Hardship Fund grant to pay off outstanding legal expenses for a domestic violence case she made against a family member. As a student entirely supporting herself after having left her home, these outstanding fees could have created unmanageable personal debt.

The breaking up of a home in such situations can become an entry point into poverty and, in some cases, homelessness. Regardless of the reason, though, leaving the home of a friend, relative or partner creates a situation of personal risk and vulnerability.

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**Recommendation: All local authorities should follow NAT Guidance on HIV and Housing when assessing applications, with particular attention to the enormous impact that becoming homeless will have on the health of someone living with HIV.**

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<sup>36</sup> Garvie, D. 2001. *Far from home: the housing of asylum seekers in private rented accommodation*. [www.shelter.org.uk](http://www.shelter.org.uk)

<sup>37</sup> 1996 Housing Act. In England and Wales, a person is legally homeless if: there is no accommodation that they are entitled to occupy; or they have accommodation but it is not reasonable for them to continue to occupy this accommodation.

# INADEQUATE HOUSING

## James' story

### Hardship Fund Grant £200

James is a 35 year old man who came to the UK to seek asylum in the UK. A couple of years ago in April, he was granted leave to remain in the UK. As he was no longer eligible to stay in the housing he was provided by asylum support, he moved in with a friend. James applied for incapacity-based income support for ill-health related to his HIV and treatment side-effects, but was told that he was not eligible. He was told to apply for JSA, and did so in June. By September, he was still signing on but had yet to receive any money.

James's friend decided he was not in a position to keep supporting him, and James became homeless. He approached his local authority for some housing support but was told he was not classed as a medical priority.

After about six months, there was an official investigation into why James had not received any JSA payments. The findings were that due to backlogs, by the time James' claim was to be processed he was homeless, and as such no longer qualified for the benefit.

James continues, with the support of his referring agency, to pursue his benefit entitlement. There is also an ongoing challenge to the local authority's judgement on James' eligibility for housing. For the present, he is living between friends' houses, sleeping on their floors, and occasionally in shop doorways.

James approached the Hardship Fund, who provided a grant to meet basic needs such as bus fares, shoes, some toiletries, basic food stuffs and a little cash in his pocket.

## Mary's story

### Hardship Fund Grant £285

Mary is a 33 year old woman who discovered she was HIV positive after being raped. She moved town and gave up her job. She became very depressed and over a couple of years lost all contact with friends and family. She ended up living in a bed-sit. Her neighbour discovered her status, and started verbally abusing her whenever she left the house. At night the same neighbour would bang on the walls and make offensive comments.

Mary began sleeping during the day and at night would travel around the train and night bus system - she felt safer on public transport than she did at home. The transport company noticed Mary and contacted the police, who arranged for a social worker to speak to Mary.

The social worker made an application to the Hardship Fund. The grant meant that Mary could have a week's accommodation at an emergency shelter while she found a new place to live, as well as paying for relocation costs.



**More than 6,800 children<sup>38</sup> were assisted by the Hardship Fund between 2006 and 2009, the vast majority (97%) via grants allocated to their parents and guardians.**

## Children affected by HIV

The number of children in the UK born with HIV continues to drop thanks to improvements in treatment and routine ante-natal screening. One study found that, between 2000 and 2005, only 1.2% of children born to a mother who is living with HIV were infected, compared to 25.6% in 1993. However, children may be affected by HIV, even when they are not infected themselves; that is, when they are living in a family or household where someone else has HIV.<sup>39</sup>

Most recent data from the Institute of Child Health estimates that there are around 1,500 children living in the UK who have been diagnosed HIV positive, while the Children with AIDS Charity (CWAC) estimates that between 24,000 and 35,000 children living in the UK are affected by HIV.<sup>40</sup> These children equally feel the brunt of the social dimensions of living with HIV, chiefly stigma and discrimination. This impacts the child's experience of education, healthcare, and the formation of friendships and social networks, both in cases where a family member's HIV status is known, and also where the child feels compelled to keep this information secret. For some children affected by HIV, the major site of intolerance and harassment is school; and misinformation and discrimination may still flow from teachers down.

**Recommendation: Schools should be a place of support for children affected by HIV. Schools should provide 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. Teacher training should also include basic information about HIV.**

Children living in households that receive Hardship Fund grants may experience social exclusion in many different ways, which compound and interact with the experience of HIV related stigma. The financial dimensions of HIV related care places pressure on family budgets in a way that further limits opportunities for children. For example, one family applying to the fund noted that their teenage son might have to give up college as his travel costs were too much on top of the costs incurred through caring for another relative living with HIV.

All the children in families that received grants are living in low income households, which are associated with measurably poorer physical and mental health and life expectancy, and lower attainment in education and employment. For many, growing up in poverty is the beginning of a longer-term spiral of social exclusion.<sup>41</sup>

Applications to the Hardship Fund reveal that children affected by HIV and poverty are more likely to be from an ethnic minority (75% of successful applicants with children were black African) which may also add to experiences of prejudice. In addition, some children benefiting from the Hardship Fund are made vulnerable to exclusion as an impact of their journey through the immigration system.

## Parenting in poverty

Around a quarter of successful applications to the Hardship Fund were on behalf of individuals facing the challenge of parenting in poverty. The costs associated with caring for children and supporting their participation in schooling and other essential development activities can cause severe financial stress in a low income household. If that household is also affected by HIV, these pressures may add to those associated with managing health needs, and daily interactions marked by stigma and discrimination. It is not surprising, therefore, that 6% of referrals analysed said that a child or pregnancy related issue was a cause of their hardship.

Three quarters of successful applicants with children were women, and the majority of parents and guardians with HIV were black African. The 2006 study, HIV Positive African Women Surviving in London, highlighted the significance of "motherhood as a source of identity and legitimacy" among African women, and the anxieties that living with HIV may create around this role.<sup>42</sup> For the 48% of female applicants receiving grants from the Hardship Fund who were responsible for at least one child, the usual challenges of parenting in poverty are amplified by the experience of managing their HIV health.

<sup>38</sup>Up to 19 years of age

<sup>39</sup> BHIVA. 2008. British HIV Association and Children's HIV Association guidelines for the management of HIV infection in pregnant women. [www.bhiva.org](http://www.bhiva.org)

<sup>40</sup>CWAC. 2009. *An Analysis of HIV Affected Children in the UK*.

<sup>41</sup>[www.endchildpoverty.org.uk](http://www.endchildpoverty.org.uk)

<sup>42</sup>Doyal, L. and J. Anderson 'HIV-positive African women surviving in London: report of a qualitative study', *Gender & Development*, 14: 1, 95 – 104.

# RESPONSIBILITY FOR CHILDREN

Children experience the same issues that affect their parents and guardians who apply for Hardship Fund grants, including the impacts of the asylum system on family and home life. Families often live in situations of long-term uncertainty while awaiting the result of an asylum claim. A condition of requesting accommodation support from UKBA is that the asylum seeker making a housing application is 'dispersed', i.e. moved within the UK to a designated location where accommodation will be provided. The asylum seeker does not have a choice as to where they will be dispersed. This means the breaking up of community networks and separation from family and friends. For children, a change in school brings personal and emotional costs, such as missing exams and key parts of the curriculum, and losing friends. For parents, changing schools can also bring financial costs, such as new uniforms and travel.

As has already been discussed, the housing provided to families on low incomes - asylum seekers and UK residents alike - is frequently unsuitable for people living with HIV. Such accommodation is especially problematic for families with children, who may be vulnerable to the health impacts of heating and ventilation problems. Children have limited opportunities for play or homework in overcrowded properties, especially if safety concerns prevent them being outside alone. These deficiencies in their living environment compound the other barriers to social inclusion already experienced by children affected by both HIV and poverty.

The personal and social impacts of the experience of living in a household defined by poverty, with a primary carer who is living with a disability, means that many of these children will need extra support. Meeting these needs is essential to helping children out of a pattern of social exclusion and poverty.

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**Recommendation: Needs assessments of social care services should take into account the needs of dependent children affected by HIV.**

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In 1999, the government set a target of halving child poverty by 2010, and eradicating child poverty by 2020. As of 2008, these goals have been pursued through the Every Child Matters agenda, and the measures set out in the Child Poverty Bill. Families living in poverty have been promised a 'contract', whereby the government will provide the necessary support to help the family exit out of poverty, offer opportunities for all children, and provide financial support for those who cannot find work; while parents and carers show a commitment to taking advantage of opportunities that arise.<sup>43</sup>

However, it has already been shown that many of the applicants to the Hardship Fund do not have access to the full range of opportunities, especially the right to work (denied to asylum seekers). Others are allowed to work, but have no safety net of access to public funds when they fall ill, or things go wrong. The Every Child Matters agenda acknowledges the impact of disability on parents' opportunities to take up work. The impact of immigration controls should likewise be considered as a contributing factor to the poverty experienced by some families.

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**Recommendation: Government initiatives to end child poverty, such as the Every Child Matters agenda, should specifically address the needs of children of parents who are subject to immigration controls. Immigration restrictions on work and benefits disproportionately affect families who are affected by both HIV and poverty.**

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<sup>43</sup>HM Treasury. 2008. *Ending Child Poverty- Everyone's Business*. [http://www.hm-treasury.gov.uk/d/bud08\\_childpoverty\\_1310.pdf](http://www.hm-treasury.gov.uk/d/bud08_childpoverty_1310.pdf)

## Karen's story

### Hardship Fund Grant: £250

**Karen is 43 years old and has been living with HIV for 6 years. She has two children aged 8 and 11. Karen told her friend Anne about her HIV status, who was very supportive initially. Everything changed, though, when Anne's son was transferred to attend the same school as Karen's children.**

Anne wrote a letter to the head teacher disclosing Karen's status and insisting her children were removed from the school as a "matter of safety for the other children". The head teacher discussed the matter with the teaching staff, one of whom decided to "consult" with other parents about the issue without permission.

After Karen's HIV status became known throughout the school, her children were bullied and she was spat on outside the school. When she asked for a meeting with the teaching staff to deal with the problem she was told that it was not possible and that it was suggested her children might be happier at a different school.

Karen decided she did not want to fight the matter and moved her family so her children could start at a new school. She used all of her savings and available credit on this sudden move, with nothing left to furnish her house with basics such as flooring, curtains or kitchen appliances and utensils (which had been provided in her previous flat).

Over the next couple of months Karen became very unwell and ended up in hospital. During her stay in hospital an application was made to the Hardship Fund to provide some basic flooring for the bedroom and living areas as well as curtains and a fridge that worked. These were ready for when Karen was discharged.

*"I am very grateful to the Hardship Fund for the support which will make life a little easier and hopefully stop me going back to hospital."*

# RECOMMENDATIONS

The findings from the Hardship Fund 2006–2009 have shown not only that HIV can cause poverty, but that the sort of poverty experienced by many in our society has a particularly severe impact upon people living with HIV. The recommendations of this report, therefore, not only address drivers of poverty specific to HIV, but all policies and administrative practices which contribute to the extreme personal hardship experienced by applicants to the Hardship Fund.

## The Immigration System

- a Migrants living with HIV are at risk of unintentionally breaching visa conditions if they become suddenly ill. UKBA should show flexibility in working with migrants whose poor health or hospitalisation has contributed to a breach of immigration controls.
- b Asylum seekers should have the right to work after 6 months. For asylum seekers living with HIV, the ability to take up employment would offer an exit out of poverty.
- c Subsistence payments for asylum seekers should be increased to a level that is equivalent to income support. At only 55% of the level of income support, rates of asylum support are insufficient to meet the basic needs of asylum seekers living with HIV, with serious health implications.
- d UKBA and DWP should work together to ensure that asylum seekers who have just been granted leave to remain and are eligible for benefits are guided and assisted through the application process, so that the delay in receiving benefits is minimised. Such delays leave asylum seekers living with HIV without income to meet their basic needs.
- e The Section 4 voucher and card system adversely affects the physical and mental health of asylum seekers living with HIV. Section 4 support should be provided as cash benefits. The voucher and card system should be discontinued. Section 4 support should be equivalent to income support.

## Benefits

- f People living with HIV should not be left in poverty because poor decision-making affects their benefit entitlements. As recommended by the House of Commons Work and Pensions Committee, the Secretary of State should report on DWP decision-making standards annually. These reports should be used as a basis for improving decision-making within DWP.
- g Work capability assessments (WCAs) should take into account the impact of fluctuating conditions, such as HIV, on ability to enter and remain in employment. Staff who carry out face-to-face medicals, and DWP staff who make decisions on applications, should be trained to a standard competence level in HIV and their impact.

## Health and Social Care

- h In line with the UK National Guidelines for HIV Testing, new initiatives should be implemented to increase access to HIV testing in a wider variety of settings, especially for communities with high HIV prevalence rates.
- i There should be consistent commissioning of accessible and appropriate mental health services for people living with HIV.
- j The AIDS Support Grant should continue to be provided after 2011.
- k Local authorities should conduct comprehensive social care needs assessments for people living with HIV to ensure the AIDS Support Grant reaches people living with HIV and has greatest possible impact. This is especially important now that the grant is no longer ring-fenced.

## Unemployment

- l The Equality and Human Rights Commission needs to ensure that employers and people living with HIV are aware that the use of pre-employment health-related questionnaires is prohibited under the Equality Act 2010.
- m The Equality and Human Rights Commission needs to ensure that employers and people living with HIV are aware of the responsibilities and rights outlined in the Equality Act 2010.

# RECOMMENDATIONS

## Inadequate Housing

- n All local authorities should follow the NAT Guidance on HIV and Housing, with particular attention to the need to carry out comprehensive assessments of the needs of people with HIV who apply for social housing. This should include the fluctuating health of people living with HIV, mental health issues, and the need to comply with strict treatment adherence.
- o Repairs and adaptations requested by tenants living with HIV should be addressed promptly, whether housing is provided by local authorities or by private providers contracted by UKBA.
- p UKBA urgently needs to improve its housing stock to ensure that the human rights of asylum seekers are respected. The inadequate housing currently provided presents significant challenges for managing HIV and maintaining good health.
- q All local authorities should follow NAT Guidance on HIV and Housing when assessing applications, with particular attention to the enormous impact that becoming homeless will have on the health of someone living with HIV.

## Responsibility for Children

- r Schools should be a place of support for children affected by HIV. 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. Teacher training should also include basic information on HIV.
- s Needs assessments of social care services should take into account the needs of dependent children affected by HIV.
- t Government initiatives to end child poverty, such as the Every Child Matters agenda, should specifically address the needs of children of parents who are subject to immigration controls. Immigration restrictions on work and benefits disproportionately affect families who are affected by both HIV and poverty.

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