WELFARE REFORM IN SCOTLAND:

The impact on people living with HIV and viral hepatitis

JULY 2014
HIV and hepatitis can clearly no longer be seen as health issues alone. The impact they can have on individuals and society as a whole affects many spheres, from social relationships and mental wellbeing, to employment and income.

While treatment for both conditions has improved vastly across the past few decades, they can still have a significant impact on individuals’ ability to work. People living with HIV, hepatitis or both may need the support of the welfare system to survive at some point in their lives. This report clearly shows reforms made to the system across the past few years have jeopardised this critical support for a group who remain disproportionately affected by poverty. Indeed rather than be beneficial, it seems the changes have created a system which can have a negative effect on people in great need.

This report gives a welcome insight into the impact of welfare reforms in the unique Scottish context, from the perspective both of those affected by the changes and the services that aim to support them. The recommendations it presents for change call for action by not only the UK Department for Work and Pensions, but also the Scottish Government, the NHS in Scotland and local authorities.

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FOREWORD

By Michael McMahon MSP, Convenor of the Welfare Reform Committee of the Scottish Parliament
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# ABBREVIATIONS

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<thead>
<tr>
<th>Abbreviation</th>
<th>Description</th>
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<tr>
<td>CAB</td>
<td>Citizens Advice Bureau</td>
</tr>
<tr>
<td>DHP</td>
<td>Discretionary Housing Payments</td>
</tr>
<tr>
<td>DLA</td>
<td>Disability Living Allowance</td>
</tr>
<tr>
<td>DWP</td>
<td>Department of Work and Pensions</td>
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<tr>
<td>ESA</td>
<td>Employment and Support Allowance</td>
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<tr>
<td>HBV</td>
<td>Hepatitis B virus</td>
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<tr>
<td>HCV</td>
<td>Hepatitis C virus</td>
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<tr>
<td>HIV</td>
<td>Human Immunodeficiency Virus</td>
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<tr>
<td>IB</td>
<td>Incapacity Benefit</td>
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<tr>
<td>JSA</td>
<td>Jobseeker’s Allowance</td>
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<tr>
<td>PIP</td>
<td>Personal Independence Payment</td>
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<tr>
<td>SWF</td>
<td>Scottish Welfare Fund</td>
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<tr>
<td>UC</td>
<td>Universal Credit</td>
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</table>
EXECUTIVE SUMMARY

Welfare reform is negatively affecting people living with HIV, hepatitis or both in Scotland. This report explores the precise nature of this impact in the unique Scottish context, both on individuals and on the services that exist to support them. The detail of this impact is then used to make a series of recommendations for the UK Department of Work and Pensions, the Scottish Government, NHS boards and local authorities.

The Welfare Reform Act 2012 ushered in an unprecedented level of change to benefits across the UK. Since it became law, concern has grown that those hardest hit by the changes are those in greatest need: people living with disabilities or in intense poverty.

Two years after Hepatitis Scotland and HIV Scotland’s initial report - ‘People living with hepatitis C and HIV: their views of welfare reform’ - looked at the potential impact of welfare reform in Scotland, this new report presents results from surveys of people affected by the changes and the services that support them, including direct quotes and examples of individual experiences.

The results show beyond doubt that welfare reforms being implemented at a UK level are not appropriate in a Scottish context, and not at all suitable for people with blood borne viruses. The reforms are causing significant uncertainty and anxiety, worsening the mental and physical health of people in grave need, and adding to the burden carried by specialist services that are already stretched and oversubscribed.

Ultimately the reforms are at odds with efforts and national strategies which seek to improve the lives of Scottish people - including the Sexual Health and Blood Borne Virus Framework’s aim to ensure that ‘people affected by blood borne viruses lead longer, healthier lives.’

The need for a new approach to social security has never been more pressing.
INTRODUCTION

The Welfare Reform Act 2012 introduced the biggest reforms the UK welfare system has seen in over 60 years. The UK Government claimed these changes would help transform the lives of millions of households, provide support to the most vulnerable and lift people out of poverty\(^1\). In practice, the cuts and changes to crucial benefits the Act brought about are having the opposite effect. It is increasingly clear that those hit hardest by the reforms are disabled people and those already living in poverty.

In 2012 Hepatitis Scotland and HIV Scotland undertook research to identify the impact the coming reforms could have on people living with HIV and hepatitis\(^2\). The research found that impacts were likely to be overwhelmingly negative, and highlighted the fact that increased financial hardship can significantly undermine people’s health and wellbeing.

Two years on, this report provides an updated account of the impact welfare reforms have actually had on people with blood borne viruses in Scotland and the services that support them. It outlines the range of benefits some people with blood borne viruses receive, the changes that have affected them and the impact the reforms are having. It also provides recommendations for actions to help ensure that people with blood borne viruses are not disadvantaged within the welfare system, and are supported to live healthy and fulfilling lives.

Methodology

The data for this report was gathered by HIV Scotland and Hepatitis Scotland between September and December 2013.

The views and experiences of people in Scotland living with HIV, hepatitis B, hepatitis C, two or all of these viruses were captured with a survey completed by 42 people, of which 83% were HIV positive, 12% had hepatitis B, and 22% hepatitis C. Several respondents identified as having two or more of these conditions. The survey was made available in hard copy and electronic form.

The views and experiences of services supporting people living with HIV or hepatitis in Scotland were also gathered using a survey. Service providers were asked to complete one survey per organisation to reflect the overall experiences of staff and service users, and 15 organisations responded. Of these, 47% represented a third sector service, 40% an NHS service, and 13% a local authority service.

The services that participated included: local authority care management teams; drug referral teams; viral hepatitis managed care networks; NHS hepatology services; NHS sexual health services; community mental health teams; carer support services; hospitals; and community-based third sector organisations.

\(^1\) Department for Work and Pensions Press release, Iain Duncan Smith: Welfare reforms realised, 8 March 2012

\(^2\) Hepatitis Scotland and HIV Scotland, People Living with Hepatitis C and HIV: Their Views on Welfare Reform, June 2012
About viral hepatitis in Scotland

Viral hepatitis is a disease that causes inflammation of the liver and can lead to serious illness and death if left untreated. It is estimated that around 39,000 people across Scotland are chronically affected by hepatitis C - many of them unaware they are carrying the virus - while hepatitis B infections are a growing cause of concern.

About hepatitis B in Scotland

The hepatitis B virus (HBV) is a major cause of liver disease. In some cases, a person can be infected with hepatitis B for many years without having any symptoms. If this happens, it can eventually progress to cause serious liver damage in some people. Many people infected with hepatitis B may be completely unaware they have it because of the often silent nature of the infection. Indeed, of the 9,000 people in Scotland estimated to have a chronic hepatitis B infection, only around 4,000 have been diagnosed.

People with hepatitis B, especially those who have had the virus for many years, may have severe symptoms as a result of the damage the virus does to the liver. These symptoms can make it difficult for an individual to obtain or keep employment. People in this situation can often be disadvantaged by welfare reforms.

About hepatitis C in Scotland

The hepatitis C virus (HCV) is also a major cause of liver disease, and as with HBV, a person can be infected for many years without having any symptoms. If left untreated, hepatitis C can eventually progress to cause serious liver damage.

In Scotland, it is estimated that approximately 39,000 individuals are chronically infected with hepatitis C, with many being completely unaware of it. The Scottish Government have responded to this, recognising hepatitis C as one of the most serious and significant public health concerns of our generation. Consequently the Hepatitis C Action Plan for Scotland was launched in September 2006, followed by the Sexual Health and Blood Borne Virus Framework in 2011.

People with long term conditions, especially hepatitis C, are disproportionately located in areas in Scotland where there is low economic activity and growth and high levels of unemployment. More than half of the HCV diagnosed population reside in the most deprived fifth of the country.

Physical health and indeed mental health are negatively affected by poverty and - in addition to the strain of living with viral hepatitis and facing multiple stigmas around drug use, poverty, claiming benefits etc - treatment for hepatitis C can have serious mental health side effects including anxiety and depression. Even if assessed as fit for work, many are unlikely to easily access employment. Their prospects of overcoming illness, whether physical or mental, can be adversely affected by financial hardship.

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3 Allan McLeod, Effect of and factors associated with deprivation among persons diagnosed with hepatitis C in Scotland, 2009
About HIV in Scotland

HIV is a major public health challenge for Scotland. Since 2001, the number of people currently living with HIV in Scotland who have been diagnosed has doubled, reaching an estimated 4,634 people as at December 2013\(^4\). It is also estimated that approximately 25% of people living with HIV in Scotland are yet undiagnosed. The NHS board areas with the highest prevalence of people diagnosed with HIV include NHS Lothian, NHS Greater Glasgow and Clyde, NHS Tayside and NHS Grampian\(^5,6\).

Advances in treatment mean that HIV is now considered a chronic condition which can be controlled with medications and healthy lifestyle choices. Although many people in Scotland living with HIV can now experience a much better quality of life, there are many others who have poor treatment responses and remain chronically unwell and disempowered.

People who are diagnosed with HIV late or very late (when the virus has had significant impact on their immune system) can need significant support and may require welfare support for day-to-day living. People who were diagnosed in the early days of the epidemic can also have complex support needs which often go unmet; in the late 1980s and early 1990s many people diagnosed with HIV were told that they were not likely to live more than a few years. This often affected their financial planning and outlook, with many even counselled to cash in their pensions.

HIV is unlike many other chronic illnesses because the seriousness of a person’s symptoms and the effects of medication can vary from day to day, which can make gaining and sustaining employment more difficult.

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\(^4\) Health Protection Scotland, HIV infection and AIDS in Scotland: Quarterly update to 31 December 2013 (ANSWER), 2014
\(^5\) SPAIN, www.spainn.scot.nhs.uk
\(^6\) Scottish Government, HIV Action Plan, 2009
WELFARE REFORM IN THE SCOTTISH CONTEXT

Although social security is a reserved matter for the UK Government, welfare reform impacts on devolved services and links with issues devolved to the authority of the Scottish Parliament such as health, social care and housing. There are also aspects of the welfare system over which the Scottish Government does have control and that are delivered by local authorities.

Many of the policies that will contribute to reducing welfare dependency in Scotland are in fact the Scottish Government’s responsibility, such as involving Scottish local authorities and public, private and third sector stakeholders. However, the disconnect between the UK Department for Work and Pensions and local health and social services must be addressed in order to resolve many of the challenges highlighted throughout this report.

At a UK level, this will require welfare reform to take account of the different legislative framework in Scotland so that it is integrated with Scottish housing, childcare, education, social care, training and other key devolved areas of responsibility. In Scotland, those areas of welfare which are devolved must be developed in a way which ensures that no-one is left in poverty and that people are supported to participate fully in society.

Poverty and issues relating to welfare have also become central to the debate around Scotland’s constitutional future, as society reflects on the impact of welfare reforms on Scotland and the role of the welfare state in binding the UK together. In the long term - and whatever the constitutional settlement following the referendum on independence - much more remains to be done to create a welfare system which treats people with dignity and respect and supports everyone to flourish.

Scottish Government priority strands:

The Scottish Government has set out its intention to mitigate the worst impacts of welfare reform, as far as it can, within the powers it has available. It has identified three priority strands which have guided its activities in this regard to date: local support (working with local authorities and the third sector); housing; and health.

> Health

A Welfare Reform and Health Impact Delivery Group was convened in 2012 to consider the impact of the welfare reforms and what action could be taken to mitigate negative effects. The group comprised of representatives of the Scottish Government, NHS Scotland, local government and the third sector.

The group has since developed an Outcome Focussed Plan to help mitigate the impact of the welfare reforms on health and health services in Scotland. This plan was not intended to be prescriptive but instead provides a set of principles and guidance for NHS boards to use to inform their local activities in collaboration with their community planning partners.

The activities it proposes include improving access to welfare advice and the establishment of formal referral links between NHS, local authority and third sector agencies.

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7 Scottish Government, Welfare Reform - Scottish Government Mitigation Paper, June 2013
8 See note 6
9 Scottish Government, Mitigating the impact of Welfare Reform on Health and NHS Health Services Outcome Focussed Plan, December 2013
In relation to the under-occupancy rule (most commonly known as the ‘bedroom tax’), the Scottish Government has attempted to compensate people who have had Housing Benefit reduced, by providing extra funding to the Discretionary Housing Payment fund. Discretionary Housing Payments (DHPs) are a reserved responsibility and come under the remit of the UK Department of Work and Pensions, but are administered by local authorities. They are intended to enable local authorities to provide additional support where someone requires extra financial assistance towards housing costs. The Scottish Government contributed an extra £20 million to the DHP fund in 2013/14 to help those struggling most. However, as demonstrated by the experiences detailed in this report, this has been insufficient to fully mitigate the impact of the under-occupancy rule in Scotland.

At a local level, there are examples of good practice in relation to responding to the effects of welfare reform. For example, a Poverty Leadership Panel has been established in Glasgow made up of public, private and third sector organisations, as well as representatives from communities living in poverty. It has developed an Action Plan for Change which declares challenging the impact of welfare reform a priority issue, with key actions and a commitment that panel members will all contribute to the action plan’s goals.

Greater investment in local advice and support services has been another mitigation strategy. This has included Scottish Government funding for a range of third sector organisations to assist them to advise people on benefit entitlements and promote engagement with anti-poverty initiatives. While this is certainly welcome, given the demand for support and services provided by third sector organisations, this approach must be extended to many more client groups and locations to provide a truly effective response.
WHICH BENEFITS DO PEOPLE RECEIVE AND WHY?

The UK social security system is extremely complex with an array of benefits being introduced at different times, each with their own rules and eligibility criteria, and sometimes interacting in complicated ways. As such, there can be confusion over the types of benefits people are entitled to and why.

People living with HIV and hepatitis may require welfare benefits at different times and for different reasons - whether it be to stay in work, maintain their health and independence, or simply to meet their basic living costs. A large proportion receive multiple benefits, often being administered by different agencies, such as Employment and Support Allowance (administered by the Department for Work and Pensions), or Housing Benefit and Council Tax Reduction (administered by local authorities).

The benefits being accessed by the greatest overall proportion of people living with HIV, hepatitis or both in Scotland identified in this report are Employment and Support Allowance (64%) and Disability Living Allowance (62%). The separate proportions of respondents with HIV or hepatitis claiming each benefit are set out in Figure 1 below.

The fact that Employment and Support Allowance and Disability Living Allowance are the benefits being claimed most by this group reflects the impact that blood borne viruses may have on a person’s ability to work as well as the extra costs associated with individual care and mobility needs.

The key welfare benefits being claimed are outlined in the following pages, alongside overall percentages of people living with HIV, hepatitis or both who were surveyed in Scotland who indicated they accessed each.

The welfare benefits covered are:

- Employment and Support Allowance;
- Disability Living Allowance;
- Housing Benefit;
- Council Tax Reduction;
- Income Support;
- Incapacity Benefit;
- Child Benefit;
- Child Tax Credit;
- Carer’s Allowance;
- Personal Independence Payment;
- Job Seeker’s Allowance; and
- Working Tax Credit.
### FIG 1: Proportion of people surveyed with HIV and hepatitis accessing welfare benefits, grouped by condition

<table>
<thead>
<tr>
<th>Benefit</th>
<th>Percentage of HIV</th>
<th>Percentage of Hepatitis</th>
</tr>
</thead>
<tbody>
<tr>
<td>Employment and Support Allowance</td>
<td>56% (18)</td>
<td>82% (9)</td>
</tr>
<tr>
<td>Disability Living Allowance</td>
<td>69% (22)</td>
<td>45% (5)</td>
</tr>
<tr>
<td>Housing Benefit</td>
<td>56% (18)</td>
<td>64% (7)</td>
</tr>
<tr>
<td>Council Tax Support</td>
<td>47% (15)</td>
<td>36% (4)</td>
</tr>
<tr>
<td>Income Support</td>
<td>28% (9)</td>
<td>36% (4)</td>
</tr>
<tr>
<td>Incapacity Benefit</td>
<td>19% (6)</td>
<td>27% (3)</td>
</tr>
<tr>
<td>Child Benefit</td>
<td>16% (5)</td>
<td>18% (2)</td>
</tr>
<tr>
<td>Child Tax Credit</td>
<td>16% (5)</td>
<td>18% (2)</td>
</tr>
<tr>
<td>Carer’s Allowance</td>
<td>12% (4)</td>
<td>9% (1)</td>
</tr>
<tr>
<td>Personal Indep. Payment</td>
<td>6% (2)</td>
<td>9% (1)</td>
</tr>
<tr>
<td>Job Seeker’s Allowance</td>
<td>3% (1)</td>
<td>9% (1)</td>
</tr>
<tr>
<td>Working Tax Credit</td>
<td>3% (1)</td>
<td>9% (1)</td>
</tr>
</tbody>
</table>
Benefits people reported accessing:

- **Employment and Support Allowance (ESA)** provides financial support to people who can’t work or have a limited capacity for work because of sickness or disability. To receive ESA claimants must complete a survey (including opportunity to provide medical evidence). Most claimants then take a face-to-face Work Capability Assessment with an independent healthcare assistant.

- **Disability Living Allowance (DLA)** is a tax-free benefit for disabled children and adults to help with extra costs they may have because of their disability. It is given at different rates depending on how a person’s disability affects them and has two components: the care component and the mobility component. It is due to be phased out between 2013 and 2017.

- **Housing Benefit** is intended to help meet housing costs for rented accommodation. It can pay for part or all of a person’s rent depending on their income and circumstances. It is paid to people in or out of work.

- **Council Tax Reduction** replaced Council Tax Benefit from April 2013. It is intended to help people pay their council tax if they are on a low income.

- **Income Support** provides extra money to help people on a low income. It is intended for people either not working or working less than 16 hours a week who don’t have to sign on as unemployed e.g. a lone parent or carer. People may also receive Income Support if they are signed off and getting statutory sick pay from their employer.
Incapacity Benefit was given to people below the state pension age who could not work because of illness or disability, and who had made enough national insurance contributions to qualify. It has now been replaced by ESA, although at the time of writing some claimants had yet to be transferred.

Child Benefit is given to parents or other people who are responsible for bringing up a child under the age of 16.

Child Tax Credit is given to help with the costs of bringing up a child under the age of 16. It can be claimed by people in or out of work.

Carer’s Allowance is a benefit for people who are giving regular and substantial care to disabled people in their own homes. It is a taxable benefit and forms part of a person’s taxable income.

Personal Independence Payment (PIP) helps toward the extra costs arising from a long term ill-health condition or disability and is based on how a person’s condition affects them. It is not means-tested or subject to tax and it is payable to people who are in or out of work. It will gradually replace Disability Living Allowance (DLA) by 2017.

Job Seeker’s Allowance is a benefit for people who are unemployed but capable of work. To get Jobseeker’s Allowance people also have to meet several other conditions, which includes showing that they are actively looking for work.

Working Tax Credit is a payment to provide extra support for people who are working but on a low income.
When the present welfare reforms come into full effect, there will be over £1.6bn less in the Scottish economy as a result: the equivalent to around £480 per year for every adult of working age. However, successive governments have altered aspects of the whole system over the years and some of the changes affecting people now were first introduced prior to 2012. The complexity of the system, coupled with the scale and pace of reform, can often cause confusion over what changes are occurring, as well as when and who they are affecting.

### WHAT ARE THE CHANGES AND WHO ARE THEY AFFECTING?

**MAIN BENEFITS CHANGES**

<table>
<thead>
<tr>
<th>UNDER-OCCUPANCY RULE (BEDROOM TAX)</th>
<th>&gt; Since 1 April 2013, working-age social tenants in receipt of Housing Benefit will experience a reduction in their entitlement if they live in housing that is deemed to be too large for their needs (14% for one extra bedroom and 25% for two).</th>
</tr>
</thead>
<tbody>
<tr>
<td>TRANSFER FROM INCAPACITY BENEFITS TO EMPLOYMENT AND SUPPORT ALLOWANCE</td>
<td>&gt; Employment and Support Allowance (ESA) replaced incapacity benefits (Incapacity Benefit (IB), Income Support (claimed because of a disability) and Severe Disability Allowance) for people making new claims from October 2008. Most existing incapacity benefit claimants have now been reassessed for ESA using the Work Capability Assessment.</td>
</tr>
<tr>
<td>TRANSFER FROM DISABILITY LIVING ALLOWANCE TO PERSONAL INDEPENDENCE PAYMENT</td>
<td>&gt; Personal Independence Payment (PIP) started to replace Disability Living Allowance (DLA) from June 2013 in Scotland. PIP has different entitlement criteria to DLA, intended to make decision making more consistent, while saving 20% of working age expenditure. This change is being rolled out gradually and it is expected that all existing DLA claimants will have been invited to claim PIP by 2017.</td>
</tr>
<tr>
<td>THE BENEFIT CAP</td>
<td>&gt; Since 15 July 2013 there is a limit on the total amount of benefit payable to most people of working age, ranging from £350 - £500 per week depending on individual circumstances.</td>
</tr>
</tbody>
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## Jobseeker’s Allowance and/or Employment and Support Allowance Sanctions

A new sanction regime for Job Seeker’s Allowance (JSA) and Employment Support Allowance (ESA) came into effect in 2012. The highest level sanctions are now for three months for the first failure to comply, six months for the second and three years for the third. Only claimants subject to ‘all work-related requirements’ - currently those on JSA - will be subject to the highest two levels of sanction. ESA sanctions are open ended and last until a person is deemed to have complied with the relevant conditions, although there may also be a fixed period sanction.

## Time Limiting of Employment and Support Allowance

There are two types of ESA: contributory ESA (which is paid where people have made enough national insurance contributions) and income-related ESA (which is paid where a person’s income and capital are low enough). Payment of contributory Employment and Support Allowance in the Work Related Activity Group is now limited to a 12-month period. This came into effect at the end of April 2012.

## Changes to Community Care Grants

Since 1 April 2013, Community Care Grants have been replaced with a new scheme called the Scottish Welfare Fund, which is delivered by local councils.

## Changes to Crisis Loans

Since 1 April 2013, Crisis Loans have been replaced with a new scheme called the Scottish Welfare Fund, which is delivered by local councils.

## Plans to Introduce Universal Credit

The progressive roll out of Universal Credit began in November 2013 in Scotland. It replaces six main benefits with a single monthly payment for people in work or out of work. Universal Credit brings a significant shift in conditionality arrangements and a new sanctions regime. It is expected that the rollout of Universal Credit will be complete by 2017.
**FIG 2:** Proportion people (living with HIV, hepatitis or both) and services surveyed in Scotland affected by reform.

<table>
<thead>
<tr>
<th>Reform Category</th>
<th>Percentage of Respondents (HIV, hepatitis or both)</th>
<th>Percentage of Services Affecting or Affected Service Users</th>
</tr>
</thead>
<tbody>
<tr>
<td>Under-occupancy rule (Bedroom Tax)</td>
<td>36% (10)</td>
<td>93% (14)</td>
</tr>
<tr>
<td>Transfer from IB to ESA</td>
<td>32% (9)</td>
<td>80% (5)</td>
</tr>
<tr>
<td>Transfer from DLA to PIP</td>
<td>18% (5)</td>
<td>67% (10)</td>
</tr>
<tr>
<td>ESA and JSA sanctions</td>
<td>7% (2)</td>
<td>73% (11)</td>
</tr>
<tr>
<td>The Benefit Cap</td>
<td>4% (1)</td>
<td>33% (5)</td>
</tr>
<tr>
<td>Time limits on ESA</td>
<td>7% (2)</td>
<td>53% (8)</td>
</tr>
<tr>
<td>Community Care Grants changes</td>
<td>18% (5)</td>
<td>60% (9)</td>
</tr>
<tr>
<td>Crisis Loans changes</td>
<td>11% (3)</td>
<td>60% (9)</td>
</tr>
<tr>
<td>Introduction of Universal Credit</td>
<td>14% (4)</td>
<td>47% (7)</td>
</tr>
</tbody>
</table>

**IN FOCUS: Under-occupancy rule**

The under-occupancy rule for Housing Benefit has affected the greatest proportion of individuals living with viral hepatitis, HIV or both (36%), and service providers and their clients (93%), according to survey responses.

Many respondents commented that the under-occupancy rule failed to account for the lack of single bedroom housing stock available in parts of Scotland, and disproportionately affected vulnerable people.

Two years ago HIV Scotland and Hepatitis Scotland recommended that where a person with a blood borne virus was forced to share accommodation as a result of welfare reform, possible measures to decrease the risk of involuntary disclosure of their status should be investigated. This has not yet been acted upon and it clearly continues to be a key concern, with implications for the human rights of the individuals concerned including the right to respect for private and family life, home and correspondence.

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13 Hepatitis Scotland and HIV Scotland, People living with hepatitis C and HIV: Their views on welfare reform, June 2012

14 Human Rights Act 1998, Article 8: “Everyone has the right to respect for his privat and family life, his home and his correspondence.”
**FIG 3:** Proportion of people surveyed affected by the under-occupancy rule, and services affected or with affected clients, grouped by type.

<table>
<thead>
<tr>
<th>Category</th>
<th>Percentage</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>People living with HIV</td>
<td>36%</td>
<td>(8)</td>
</tr>
<tr>
<td>People living with viral hepatitis</td>
<td>22%</td>
<td>(2)</td>
</tr>
<tr>
<td>Services for people with HIV, hepatitis or both</td>
<td>93%</td>
<td>(14)</td>
</tr>
</tbody>
</table>

**INDIVIDUAL EXPERIENCES:**

> “In my local area housing associations made a conscious decision to build two bedroom homes rather than one due to cost effectiveness. This means tenants are going to be penalised under the ‘bedroom tax’ but actually have no way of changing their circumstances.”

  - Person living with HIV

> “The bedroom tax has caused a great deal of stress and hardship to our clients who are unable to downsize to smaller flats and who are too vulnerable to have a lodger rent a room in their house.”

  - Service provider

> “Bedroom tax has affected all clients. A lot cannot move into one bedroom houses as there are none available. Also some parents are separated but do have access to their children and need a spare bedroom to facilitate overnight stays; this is not taken into account.”

  - Service provider
IN FOCUS: **Transfer from incapacity benefits to Employment and Support Allowance**

Employment and Support Allowance (ESA) replaced incapacity benefits (Incacity Benefit [IB], Income Support [claimed because of a disability] and Severe Disability Allowance) for people making new claims from October 2008.

Most existing incapacity benefit claimants have now been reassessed for ESA using the Work Capability Assessment.

The transfer from incapacity benefits to ESA has affected the second highest overall proportion of individuals living with HIV, viral hepatitis or both (32%) and services and their clients (80%), according to survey responses.

The separate figures for people living with HIV or hepatitis - as well as services - affected are set out in Figure 4 below.

FIG 4: Proportion of people surveyed affected by the transfer to Employment and Support Allowance, and services affected or with affected clients, grouped by type.

<table>
<thead>
<tr>
<th>People living with HIV</th>
<th>27% (6)</th>
</tr>
</thead>
<tbody>
<tr>
<td>People living with viral hepatitis</td>
<td>33% (3)</td>
</tr>
<tr>
<td>Services for people with HIV, hepatitis or both</td>
<td>80% (12)</td>
</tr>
</tbody>
</table>

A large number of respondents commented on the Work Capability Assessment, believing it to be inadequate to assess the impact of blood borne viruses on a person’s ability to work. In particular, it was felt that the Work Capability Assessment was unable to account for the fluctuating nature of people’s conditions or the side-effects of medication.

The Work Capability Assessment was also raised as a key area of concern in the 2012 report, alongside a recommendation that measures be taken to make it a more evidence-based examination of current work capability\(^\text{15}\). This has not been addressed and examples of the negative and damaging impact of the Work Capability Assessment on people living with blood borne viruses in Scotland are explored further in the next section of this report.

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\(^{15}\) Hepatitis Scotland and HIV Scotland, ‘People Living with Hepatitis C and HIV: Their Views on Welfare Reform’, June 2012

www.hivscotland.com
About the Work Capability Assessment

The Work Capability Assessment identifies how a claimant’s health condition or disability affects their ability to work and is used to determine entitlement to benefit. It is intended to distinguish between: people who can work; people who could work at some point with the right support (the Work-Related Activity Group); and people who cannot work (the Support Group).

People applying for Employment and Support Allowance will initially be asked to complete a questionnaire about how their illness or disability affects them, and they can also provide medical evidence to support their claim. In most cases, people will also be asked to attend a face-to-face assessment with an independent healthcare professional. During the face-to-face assessment, the healthcare professional will discuss a person’s medical history and activities undertaken in a typical day. A number of physical and mental health functions are considered within a range of activities and points are awarded on the basis of limitations with respect to each function. The physical health functions include a person’s ability to move around, to use their hands, and continence etc, while the mental health functions include someone’s ability to undertake personal actions such as planning, organising, and problem solving, and ability to get around or engage in social contact etc.

A final decision on a claimants’ benefit entitlement is then made, based on all evidence provided during the claim. People who are deemed to be fit for work are advised to claim Jobseeker’s Allowance; people who may be able to work in the future are placed into the ESA Work Related Activity Group; and people thought currently unable to return to work are put in the ESA Support Group.

INDIVIDUAL EXPERIENCES:

> “The Work Capacity Assessment process is obviously flawed and blatantly biased. I was sent for an assessment and was subsequently told that my ESA payments were stopped. On appeal this was restored.”
  - Person living with hepatitis C

> “The ATOS medical was intrusive. I know they have to ask but the types of questions and the focus were not right, because they are only based on the one day you see them. Tried to appeal but got too ill so couldn’t pursue it and gave up. They need a doctor who knows about illness not just basing it on that one meeting.”
  - Person living with HIV

> “My fear is that I’ll be FORCED to find paid employment which I currently cannot do for health reasons.”
  - Person living with HIV

> “Variable and fluctuating conditions when being assessed for Employment Support Allowance are not fully being taken into account.”
  - Service provider
IN FOCUS: Transfer from Disability Living Allowance to Personal Independence Payment

Personal Independence Payment (PIP) started to replace Disability Living Allowance (DLA) from June 2013 in Scotland.

Personal Independence Payment has different entitlement criteria to Disability Living Allowance, intended to make decision making more consistent, whilst saving 20% of working age expenditure.

The transfer from DLA to PIP has so far directly affected 18% of people living with HIV, viral hepatitis or both, according to survey responses, and 67% of specialist services and their clients.

The separate figures for people living with HIV or hepatitis - as well as services - affected by this change are set out in Figure 4 below.

FIG 5: Proportion of people surveyed affected by transfer from DLA to PIP, and services affected or with affected clients, grouped by type.

<table>
<thead>
<tr>
<th></th>
<th>People living with HIV</th>
<th>People living with viral hepatitis</th>
<th>Services for people with HIV, hepatitis or both</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>18% (6)</td>
<td>33% (3)</td>
<td>67% (10)</td>
</tr>
</tbody>
</table>

Unlike the broad criteria for DLA, PIP entitlement is assessed using a points-based test. The method of deciding claims is also significantly different: while DLA relied on a paper claim form, with supporting evidence requested from the claimants’ healthcare professionals if needed, the PIP assessment involves a referral to an independent healthcare professional.

Most claimants must attend a face-to-face consultation, which is unlikely to be undertaken by a specialist in the claimants’ condition.

There is no equivalent to the DLA lowest rate care component, meaning that some people may not qualify for the new benefit.

Many people living with blood borne viruses are concerned that the assessment for PIP will replicate the failings of the Work Capability Assessment, particularly in its ability to account for fluctuating conditions. Many are also afraid of losing out on vital support when PIP is rolled out to their area.
INDIVIDUAL EXPERIENCES:

> “The migration from Incapacity Benefit was very stressful and took 7 months, and I am already stressed about the PIP assessment even though that is still some time off, because it seems to be punishing the disabled by withdrawing support.”
  - Person living with HIV

> “I am struggling to maintain a semblance of a normal life but with the economics of my situation it would take but a short loss of benefit to leave me house bound (PIP concerns me the most at present).”
  - Person living with hepatitis B and C

> “The introduction of PIP worries me terribly as I believe my income will decrease.”
  - Person living with HIV
IN FOCUS: Conditionality and sanctions

The Welfare Reform Act 2012 brings with it a significant shift in conditionality arrangements and a tougher sanctions regime. This is intended to reflect the principle of Universal Credit that people who can work, must look for work.

Claimants of Universal Credit will have to accept a claimant commitment outlining what work-related requirements they must meet while receiving support or risk being sanctioned.

A number of changes have also been made in respect of other Department for Work and Pensions benefits - such as Job Seeker’s Allowance (JSA) and Employment and Support Allowance (ESA) - including an increase in the length of sanctions that can be applied.

FIG 6: Proportion of people surveyed affected, and services with clients affected, by JSA/ESA sanctions, grouped by type.

<table>
<thead>
<tr>
<th>Type</th>
<th>People living with HIV</th>
<th>People living with viral hepatitis</th>
<th>Services for people with HIV, hepatitis or both</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>9% (2)</td>
<td>0% (0)</td>
<td>73% (11)</td>
</tr>
</tbody>
</table>

A new sanction regime for JSA and ESA came into effect in 2012. The highest level sanctions are now: three months for the first failure to comply; six months for the second; and three years for the third.

Only claimants subject to ‘all work-related requirements’ - currently those on JSA - will be subject to the highest two levels of sanction. ESA sanctions are open ended and last until a person is deemed to have complied with the relevant conditions, although there may also be a fixed period sanction.

Relatively few individuals living with HIV, viral hepatitis or both (7%) reported being affected by sanctions in the survey. However, a significant proportion of service providers (73%) reported that their service or service users have been affected.

Comments given pointed to the fact that people may be unfairly sanctioned where they are unable (as opposed to unwilling) to comply with conditions e.g. due to a lack of understanding of the sanction process or practical and personal barriers to ensure compliance.
INDIVIDUAL EXPERIENCE:

> “One client in particular has had their benefit frozen... because they failed to attend three appointments. To be fair they attempted to attend two appointments. They had to take two buses... could not find the appeals office... and were 20 minutes late so were not taken for the appointment. The second time the bus was delayed and they were 10 minutes late, again they were refused that appointment. They were unable to attend the 3rd appointment due to a sickness bug.”

- Service provider
WHAT IMPACT ARE THE CHANGES HAVING?

The welfare reforms have come into force across Scotland and it increasingly clear that the most deprived areas will take the biggest financial hit. This has serious implications for people with blood borne viruses, especially hepatitis C, as they are disproportionately located in areas in Scotland where there is low economic activity and high levels of unemployment.

IMPACT ON PEOPLE LIVING WITH HIV AND HEPATITIS

The impact of the reforms has been wide ranging and affected all aspects of people’s lives. Survey respondents highlighted the serious nature of these effects. These are set out and explored below in the graphs, examples of individual experiences and sections, considering the the impact on health, poverty and daily living, and isolation and stigma in particular.

FIG 7: Impact individuals surveyed (living with HIV, viral hepatitis or both) report reforms have had on their lives.

<table>
<thead>
<tr>
<th>Problem</th>
<th>Percentage</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Poorer mental health</td>
<td>58% (18)</td>
<td></td>
</tr>
<tr>
<td>Poorer physical health</td>
<td>48% (15)</td>
<td></td>
</tr>
<tr>
<td>Struggle to pay gas/electricity bills</td>
<td>45% (14)</td>
<td></td>
</tr>
<tr>
<td>Struggle to buy food</td>
<td>39% (12)</td>
<td></td>
</tr>
<tr>
<td>Can’t afford to see friends/family</td>
<td>35% (11)</td>
<td></td>
</tr>
<tr>
<td>Have had to borrow money</td>
<td>35% (11)</td>
<td></td>
</tr>
<tr>
<td>Can’t afford to work</td>
<td>23% (7)</td>
<td></td>
</tr>
<tr>
<td>Can’t afford to attend medical appointments</td>
<td>16% (5)</td>
<td></td>
</tr>
<tr>
<td>Struggle to pay rent</td>
<td>16% (5)</td>
<td></td>
</tr>
<tr>
<td>No noticeable change</td>
<td>10% (3)</td>
<td></td>
</tr>
</tbody>
</table>
FIG 8: Impact service providers surveyed report reforms have had for service users living with HIV, hepatitis or both.

<table>
<thead>
<tr>
<th>Issue</th>
<th>Percentage</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Poorer mental health</td>
<td>86%</td>
<td>(12)</td>
</tr>
<tr>
<td>Housing problems</td>
<td>86%</td>
<td>(12)</td>
</tr>
<tr>
<td>Poorer physical health</td>
<td>79%</td>
<td>(11)</td>
</tr>
<tr>
<td>Debt</td>
<td>79%</td>
<td>(11)</td>
</tr>
<tr>
<td>Reduced income</td>
<td>79%</td>
<td>(11)</td>
</tr>
<tr>
<td>Difficulties accessing services</td>
<td>64%</td>
<td>(9)</td>
</tr>
<tr>
<td>Increased isolation</td>
<td>57%</td>
<td>(8)</td>
</tr>
<tr>
<td>No impact</td>
<td>0%</td>
<td>(0)</td>
</tr>
</tbody>
</table>

Welfare Reform Committee 2nd Report, 2013 (Session 4), The Impact of Welfare Reform on Scotland, Scottish Parliament Paper 303 Session 4

Hepatitis Scotland and HIV Scotland, People Living with Hepatitis C and HIV: Their Views on Welfare Reform, June 2012
Impact on individuals: health

Welfare reforms have had a significant, negative impact on the physical and mental health of people living with blood borne viruses in Scotland. Many people living with HIV, hepatitis or both said that the stress and anxiety of dealing with the reforms has had a direct effect on their physical health and their ability to manage their own care and treatment. Service providers noted that the changes have led to an increased need for support from health and social care services.

INDIVIDUAL EXPERIENCES:

> “I live with AIDS Dementia, Crohn’s Disease, and Irritable Bowel Syndrome. Stress and anxiety really affects my illness. I live hand to mouth each week financially.”
  - Person living with HIV

> “Loss or reduction of benefits (or the threat of this) has been extremely stressful for lots of patients, a couple have been suicidal.”
  - Service provider

> “They have caused our service users to have deteriorating health outcomes which puts increased pressure on other services, statutory, voluntary and primary and secondary care. Money saved here is lost there and vice versa.”
  - Service provider

The Work Capability Assessment is repeatedly identified as an area of particular concern, with many survey respondents describing the intense stress and uncertainty people experience as a result the assessment process.

INDIVIDUAL EXPERIENCES:

> “With advanced liver disease but one of the health issues making working impossible for me, the current ESA assessment did nothing but enforce the depression I suffer.”
  - Person living with hepatitis B and C

> “One of my patients became so very afraid of being assessed that he was very socially avoidant, totally depressed and spent most of his time in bed thinking of ending his life.”
  - Service provider
“High anxiety about welfare reform is prevalent among my client group. This is widespread and deep rooted. It is escalated when any correspondence from DWP arrives, but is exponential when the Work Capability Assessment Form arrives. This anxiety results in poorer physical health as well as poorer mental health.”

- Service provider

Several respondents commented that levels of substance misuse had increased as people struggled to cope with the effects of welfare reform. Some also expressed concern that people may be reluctant to take medication due to fears that they could lose vital support as a result.

INDIVIDUAL EXPERIENCES:

“...[The Work Capability Assessment]... results in huge stress for the people concerned. This stress leads to poorer physical and mental health. Some people I have supported have increased drug use leading up to and during assessment.”

- Service provider

“Stress and anxiety have increased... and in the case of substance misuse, people may increase their substance misuse to self-medicate their anxiety.”

- Service provider

Welfare reforms have also made it harder for some people with blood borne viruses to access essential services, treatment and care, keeping people’s lives in a state of crisis and even making it hard to afford transport to essential appointments. While in some areas support services exist that provide transport and similar assistance, this is not consistently available.

A Healthcare Travel Cost Scheme does operate in Scotland to assist people on low incomes to travel to hospital appointments and other NHS premises for NHS-funded treatment. However, people are often unaware of this support and it is not always promoted to the people who may benefit from it. Furthermore, this scheme does not cover travel to services out with the NHS.
INDIVIDUAL EXPERIENCES:

> “Service users have advised workers that the changes have left them unable to afford transport to/from appointments.”
  - Service provider

> “Since the introduction of the welfare reforms, I have not had a single client either go for testing or enter the HCV treatment process - too many crises and too much uncertainty to undertake treatment.”
  - Service provider

> “Changes in welfare reforms have impacted negatively on people’s ability to access treatment.”
  - Service provider
Impact on individuals: poverty and daily living

Many people living with blood borne viruses may face financial disadvantage and for some people, small changes in circumstances can lead to a rapid deterioration into poverty\textsuperscript{18}. It is therefore vital that they are supported to work when they are able and provided with financial support when they are unable.

Many people living with HIV, hepatitis or both describe struggling to pay for basic necessities such as food, utility bills and rent as a result of the welfare reforms. This is a particular issue when benefits are stopped suddenly, and also impacts on people’s health and ability to manage their condition.

INDIVIDUAL EXPERIENCES:

> “I am very worried about rising heating and food bills.”
  - Person living with HIV

> “People are unable to eat. They either eat or choose heating for the house. They cannot afford both.”
  - Service provider

> “To access hep c treatment, people need to attend many appointments at hospital; they need to not be underweight, have a good diet (due to medication), they need a warm house... and to be in safe stable housing. Treatment can last up to a year. Crises due to lack of money affect diet, ability to pay heating, mental health and their support network of friends and family who may be faced with the same problems.”
  - Service provider

Nutrition plays an important role in the health of the immune system and its ability to fight infections. As such, ensuring good nutrition can be particularly important for people living with HIV during the time before they start HIV treatment and - as HIV medication can cause changes to the way the body metabolises some fats and sugars - once treatment has started\textsuperscript{19}.

Similarly, good nutrition and living conditions can be particularly important for people accessing treatments for viral hepatitis; people taking protease inhibitor medications for example must have high fat meals on an 8 or 12 hourly basis.

Hepatitis C medication can be expensive and for maximum effectiveness there needs to be a strict adherence to prescription protocols, which may include dietary requirements. The fact that a large proportion of people surveyed are borrowing money or accessing foodbanks - implying that they are unable to maintain diets - undermines some of the economic and social imperatives for treating people with this illness. It is also important to note that while food banks provide a lifeline for some people, they are not likely to provide the kind of fresh, nutritious food people with blood borne viruses need.

\textsuperscript{18} Terrence Higgins Trust, HIV and Poverty, 2014
\textsuperscript{19} NAM, HIV treatment, metabolic changes and nutrition, from www.aidsmap.com
INDIVIDUAL EXPERIENCES:

> “I had to borrow money and had to go to the food bank.”
  - Person living with HIV

> “I hardly ever gave out food parcels to clients. Previously on average I would gave a food parcel out once a year. Since the benefit changes I find myself giving out a food parcel at least once a fortnight. If someone’s benefit is frozen for three months what are they supposed to do?”
  - Service provider

> “Welfare changes together with increasing fuel bills have left many clients unable to afford food - we have made numerous food bank referrals and at least one food bank has closed due to being unable to meet demand.”
  - Service provider

> “Benefits are often stopped suddenly/discontinued during appeal and this leaves our clients having to choose between food and buying electricity. We have been able to help with emergency food boxes but this is far from an ideal situation.”
  - Service provider
Impact on individuals: isolation and stigma

A significant proportion (35% of those surveyed) of people living with HIV, viral hepatitis or both are unable to afford to see their friends and family as a result of the welfare reforms. The majority of service providers (57%) report increasing social isolation among their service users.

INDIVIDUAL EXPERIENCES:

> “Clients are continuously fearful of losing benefits and nervous about attending interviews. People have become more isolated and mentally more unstable.”
  - Service provider

> “Poverty, debt, poor health, discrimination, all lead to increased social isolation.”
  - Service provider

Several individuals reported negative media reporting of welfare issues had increased stigmatisation of welfare recipients and disabled people. Some people felt ostracised as a result and had experienced discrimination within their local communities. The stigma associated with claiming benefits had also deterred some people from accessing the support to which they were entitled.

INDIVIDUAL EXPERIENCES:

> “Isolation due to stigma and fear that people will think they are scroungers.”
  - Service provider

> “There is an increase in discrimination and stigma for disabled people. I have heard my service users remark on comments heard on the bus for instance about free bus passes.”
  - Service provider

> “People are confused and don’t want to claim benefits as they are worried about media and how the community feels about issue.”
  - Service provider

> “‘Scrounger’ narratives in the media have affected many clients - some now will not apply for PIP despite being entitled - especially if they have a less visible disability e.g. mental health issues, BBVs.”
  - Service provider
Individuals living with blood borne viruses and the services that support them overwhelmingly describe a welfare system that is leaving increasing numbers of people without access to any support at all, while those who may qualify for support are forced to engage with a system that lacks compassion and fails to treat them with dignity or respect.

This is consistent with research into the impact of welfare reforms on people with blood borne viruses in England: a recent survey of 287 people diagnosed with HIV across England found that two-thirds were affected by benefit changes, with nine out of ten reporting poorer health and limited access to HIV care as a result.20

IMPACTS ON SERVICES FOR PEOPLE LIVING WITH HIV, HEPATITIS OR BOTH

FIG 9: Impact service providers surveyed report that welfare reforms have had on their services.

<table>
<thead>
<tr>
<th>Service Impact</th>
<th>Percentage</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Greater demand for service</td>
<td>71%</td>
<td>10</td>
</tr>
<tr>
<td>Increased need for staff training/development</td>
<td>64%</td>
<td>9</td>
</tr>
<tr>
<td>People not able to afford/access service</td>
<td>36%</td>
<td>5</td>
</tr>
<tr>
<td>Strained relationships with service users</td>
<td>29%</td>
<td>4</td>
</tr>
<tr>
<td>No impact</td>
<td>0%</td>
<td>0</td>
</tr>
</tbody>
</table>

Impact on services: increased demand
A significant proportion of service providers (71%) report an increase in demand for their service as a result of welfare reforms. This relates not only to those services which have a specific remit to provide welfare support and assistance but also to health and social care services.

INDIVIDUAL EXPERIENCES:

> “The welfare reforms are very punitive and strike at the heart of community life... impacting negatively on carers, friends and families who support each other. In turn, this means more people turn to already stretched resources in social work and third sector organisations.”
  - Service provider

> “Demand on services is greater, stress level is higher.”
  - Service provider

Staff are increasingly being asked to provide supporting evidence for benefit claims, which has implications for staff time and resources. There has also been an increase in the amount of time being spent supporting people in relation to appeals.
Impact on services: diverting resources
Responding to the effects of welfare reform has meant that some services have been forced to divert time and resources from other vital areas of their work. Several service providers commented that as a result they are finding it more difficult to focus on their core activities supporting people in relation to their general health and wellbeing.

INDIVIDUAL EXPERIENCES:

> “The main impact has been the increase in clients wanting letters to support their appeals. Even when they manage to get a welfare officer to represent them more information is required about the client and often at very short notice e.g. the next day! Clients... put the staff members name forward as a representative at an appeals tribunal... This is a huge amount of work that is not the nurse’s role... but because you care you feel unable to neglect that specific need for the client as they have no one else to advocate for them.”
  - Service provider

> “Lots of requests for help completing forms and letters of support - this is very, very time consuming.”
  - Service provider

> “We have seen a big spike in the provision of emergency food parcels we have given out and an increase in lift requests to attend benefits hearings.”
  - Service provider

> “Time constraints mean other areas of work are being neglected.”
  - Service provider

> “There has been a refocusing of our work on benefits related crisis rather than recovery”
  - Service provider

> “It has become a major area of work for us that takes up a disproportional amount of time.”
  - Service provider
Impact on services: developing knowledge and skills

Service providers (64%) report an increased need for staff training and development as a result of welfare reforms. Even where training was made available to staff, the scale and pace of reforms meant that some services struggled to keep staff abreast of changes and were limited in the support that they could offer.

INDIVIDUAL EXPERIENCES:

> “The biggest challenge is the uncertainty of the changes. As an organisation we are not fully aware of what changes are happening when and who they will affect. As such we can only offer limited information support to clients and usually refer clients on for proper support and advocacy.”
  - Service provider

> “The timetable has been rushed and it has not always been possible for the appropriate staff members to fit in training within their current workload.”
  - Service provider

> “The speed of the reforms are not allowing services, let alone individuals’ time to understand them and adjust.”
  - Service provider
The pace and complexity of welfare reform has led to a significant degree of uncertainty, confusion and anxiety. Access to clear, quality sources of information and support is critical to enable people to navigate the welfare system and receive the support they need and to which they are entitled.

**Access and availability**

Over half of people living with HIV, viral hepatitis or both (55%) surveyed do not feel there is enough information and support available explaining welfare reforms. Many commented that information on specific changes and elements of the system could be difficult to find or simply did not exist.

**FIG 10:** Views of people surveyed living with HIV, viral hepatitis or both in Scotland on whether there is enough information and support available on welfare benefits.

- **I don’t know**
  - 55% (21)
  - 16% (6)
  - 29% (11)

- **I feel there is enough information**
  - 55% (21)

- **I feel there is not enough information**
  - 16% (6)

- **29% (11)**
Some people felt that the information and support which did exist was not relevant to their specific needs and circumstances.

INDIVIDUAL EXPERIENCES:

> “I think there should be more information/awareness as I don’t know what is going to happen until it happens.”
  - Person living with hepatitis C

> “I need more information about what to do if sanctioned.”
  - Person living with HIV

> “I have difficulty finding information on special changes.”
  - Person living with HIV

INDIVIDUAL EXPERIENCES:

> “Because of memory problems, I can’t work out what I did get and if it’s changed as things keep changing.”
  - Person living with HIV

> “It is difficult to know what as someone living with HIV I am entitled to, I’m classed as having a disability however I do not come under any disability benefits etc.”
  - Person living with HIV

> “My local job centre is useless in that they never really help me or give relevant advice that I want. Regular updates would be great - knowing what’s ahead.”
  - Person living with HIV

> “I feel they don’t tell you which benefits you are entitled to.”
  - Person living with hepatitis C
There are some examples of good practice in relation to information provision at a local level. For example, Glasgow City Council has developed a specific welfare section on its website containing information about the welfare reforms, how to apply for locally administered benefits and how to lodge an appeal.

While the availability of information online is vital, this will not be accessible to everyone. A review of the locally administered Scottish Welfare Fund found that applicants had largely relied on the services they were already in contact with to make them aware of supports, such as homeless support workers and third sector welfare rights or housing rights agencies.21

**FIG 11:** Places people surveyed living with HIV, hepatitis or both have accessed support in relation to welfare benefits.

<table>
<thead>
<tr>
<th>Service</th>
<th>Percentage</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health charity</td>
<td>56%</td>
<td>15</td>
</tr>
<tr>
<td>GP</td>
<td>25%</td>
<td>7</td>
</tr>
<tr>
<td>NHS</td>
<td>18%</td>
<td>5</td>
</tr>
<tr>
<td>General advice service</td>
<td>18%</td>
<td>5</td>
</tr>
<tr>
<td>Local authority welfare service</td>
<td>7%</td>
<td>2</td>
</tr>
<tr>
<td>DWP / Jobcentre</td>
<td>7%</td>
<td>2</td>
</tr>
</tbody>
</table>

When asked where they received support or information regarding welfare, over half (54%) of individuals living with blood borne viruses had received support from a health-related third sector organisation; examples given included the Terrence Higgins Trust, Waverly Care and Positive Help. A quarter of respondents had received support from their GP, with 18% accessing support from other NHS services and staff. Local authority welfare rights services and the DWP/Jobcentre were the services accessed by the smallest proportion of respondents (both at 7%).

There were examples of good practice, with several respondents praising the work of the services which supported them – especially community-based support provided on a one-to-one basis.

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21 Scottish Government, Review of the Scottish Welfare Fund Interim Scheme, 2014
Service support and signposting

Provision of clear information about local support services is clearly key - all specialist support services surveyed report signposting people requiring welfare support to other agencies for one element of support or another.

In addition to signposting to other sources of support, many service providers (87%) working with people living with HIV, viral hepatitis or both are providing emotional support in relation to the effect of welfare reforms, alongside providing information (67%) and supporting evidence for benefits claims (60%).

It is therefore critical that services are well resourced and provided with the information they require to effectively support people in relation to welfare issues. However, a large majority of service providers working with people with blood borne viruses (73%) do not feel that there is enough support available to their service to enable them to respond to welfare related issues.

FIG 12: Types of welfare-related support provided by surveyed services for people living with HIV or hepatitis.

<table>
<thead>
<tr>
<th>Service Type</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Signposting to other agencies</td>
<td>100% (15)</td>
</tr>
<tr>
<td>Emotional support</td>
<td>87% (13)</td>
</tr>
<tr>
<td>Providing general information</td>
<td>67% (10)</td>
</tr>
<tr>
<td>Providing supporting evidence for claims</td>
<td>60% (9)</td>
</tr>
<tr>
<td>Advocacy</td>
<td>53% (8)</td>
</tr>
<tr>
<td>Case work (claims, appeals etc)</td>
<td>47% (7)</td>
</tr>
<tr>
<td>Hardship support (food etc)</td>
<td>47% (7)</td>
</tr>
<tr>
<td>Assistance with budgeting etc</td>
<td>40% (6)</td>
</tr>
<tr>
<td>None</td>
<td>0% (0)</td>
</tr>
</tbody>
</table>
Service providers consistently raise concerns about: the resource implications of training and developing staff in relation to welfare issues; increased demand making more it difficult to access support from specialist welfare advice agencies; and a lack of information about reforms.

There are examples of good practice, where health related services have established good working relationships and had regular contact with welfare rights agencies. However, disconnects between health and welfare services do exist in many areas, with concerning results for individuals in need of support.

**INDIVIDUAL EXPERIENCES:**

> “We need far more CAB Welfare rights workers but they are a voluntary organisation and cannot keep up with the demand and have to be selective whom they represent.”
  
  - Service provider

> “It is increasingly difficult for security reasons to advocate on clients behalf with welfare offices. We need more guidance on how to support clients in terms of what info to put into support letters.”
  
  - Service provider
CONCLUSION

The views and experiences of people living with HIV, viral hepatitis or both - and the services that support them - set out in this report show beyond doubt that welfare reforms being implemented at a UK level are not appropriate in a Scottish context, and not at all suitable for people living with blood borne viruses.

As predicted in the HIV Scotland and Hepatitis Scotland 2012 report, ‘People living with hepatitis C and HIV: their views on welfare reform’, the reforms are causing significant uncertainty and anxiety, worsening the mental and physical health of people in grave need, and adding to the burden carried by specialist services that are already stretched and oversubscribed.

Poverty, isolation and stigma have all worsened, and may yet grow worse. The impact of Universal Credit will be felt well beyond 2015; its introduction only began this year in a small number of pilot areas and only for new claimants.

The full impact is unlikely to be felt before 2018.

Ultimately the reforms explored in this report are at odds with efforts and national strategies which seek to improve the lives of Scottish people - including the Sexual Health and Blood Borne Virus Framework’s aim to ensure that ‘people affected by blood borne viruses lead longer, healthier lives’.

The need for a new approach to social security has never been more pressing. Based on all the information presented in this report we make the recommendations set out on the following pages.

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Recommendations

Recommendations for the NHS

➢ Training should be rolled out to front line staff so that they are aware of the welfare reforms, the way they may impact people with blood borne viruses, and their role in providing evidence to support benefits claims.

➢ Health assessments should routinely include questions about whether people require welfare or financial support and staff should be equipped to signpost people to local services appropriately.

➢ Welfare rights advisors should be co-located in NHS facilities through partnership working with the third sector, DWP and local authorities. Links to local authority and third sector service providers must also be developed to facilitate easy access.

➢ Employment and vocational issues should be discussed in assessments and consultations, and form part of treatment and support plans.

➢ Appropriate support for individual travel needs must be investigated for people undergoing or maintaining treatment and attending medical appointments relating to blood bone viruses.

Recommendations for the Department of Work and Pensions and Jobcentre

➢ Communication with regards to benefits must be improved and, through partnership working with the third sector, specific resources should be developed for and targeted towards people with blood borne viruses.

➢ The Work Capability Assessment process is not fit for purpose. Measures must be taken to make it an evidence based-examination of current work capability.

➢ DWP and ATOS staff should receive specialist training on blood borne viruses, including symptoms and side effects of treatment. This should be developed and delivered through partnership working with organisations which have expertise in relation to HIV and viral hepatitis.

➢ Appropriate support for individual travel needs should be investigated for people in rural areas travelling to and from benefit assessments and interviews.

➢ Detailed guidance must be developed and made available to healthcare workers to enable them to provide supporting evidence for benefit claims for people with blood borne viruses.

Recommendations for local authorities

➢ Measures to decrease the risk of involuntary disclosure must be investigated where a person with a blood borne virus is forced to share accommodation as a result of the under-occupancy rule.

➢ Information about the Scottish Welfare Fund and other supports administered by local authorities must be communicated directly to the individuals and communities who may have the greatest need, through partnership working with the third sector, NHS and other key stakeholders.
Recommendations continued

Recommendations for the Scottish Government

- Resources and funding must be provided to community based services which enable quicker interventions for vulnerable people who are struggling to cope, before a crisis point is reached.

- Funding and resources must be provided to advice and support services equipped to provide specific support for people with blood borne viruses.

- The increasing stigma associated with claiming benefits must be addressed. The Scottish Government should resource and work with all partners to develop initiatives which counter harmful, stigmatising media messages.
APPENDICES
WELFARE SUPPORT SERVICES

For specialist advice and information:

WELFARE SUPPORT FROM HIV AND HEPATITIS ORGANISATIONS:

- **Terrence Higgins Trust Scotland**: 0141 332 3838, info.scotland@tht.org.uk, 134 Douglas Street, Glasgow, G2 4HF.
- **Waverley Care**: 0131 558 1425, info@waverleycare.org, www.waverleycare.org
  - Edinburgh: 0131 558 1425; 3 Mansfield Place, Edinburgh, EH3 6NB.
  - Highland: 01463 711 585, 34 Waterloo Place, Inverness IV1 1NB.

NATIONAL WELFARE ADVICE AND INFORMATION SERVICES:

- **Benefit Calculator**: www.gov.uk/benefits-adviser.
- **Citizen Advice Bureau**: www.cas.org.uk.
- **CPAG Scotland Welfare Advice Line (for advisers and service providers)**: 0141 552 0552, advice@cpagscotland.org.uk (Mon-Thur 10am-4pm, Fri 10am-12).

For local support:

WELFARE SERVICES IN ABERDEENSHIRE:

- **Aberdeen Welfare Rights**: 01224 523 203, welfarer@aberdeencity.gov.uk, Hub 1 Lower Ground West, Marischal College, Broad Street, Aberdeen AB10 1AB (Mon-Fri 9am-5pm).
- **Banchory Advice Centre**: 01330 825 551, banchory.advice@gmail.com, Mount Street, Banchory, AB31 5PA (Mon-Fri 10am-4pm).
- **Ellon Advice Bureau**: 01358 724425, www.gordonruralaction.org.uk, Inverthian House The Square, Ellon, AB41 9JB (Mon+Fri 10am-4pm).
- **Huntly Advice Bureau**: 01466 793676, Huntly Business Centre, Gordon Street, Huntly, AB54 8FG.
- **Inverurie Advice Bureau**: 01467 634 421, 49c Market Place, Inverurie, AB51 3PY (Mon+Thurs 10am-2pm).
- **Fraserburgh and District Advice Service**: 01346 515307, fraserburghadvice@aol.com, 10 Commerce Street, Fraserburgh, AB43 9AQ.

WELFARE SERVICES IN ANGUS:

- **Angus Welfare Rights Service**: 0845 277 7778, www.angus.gov.uk, Ravenswood, New Road, Forfar, DD8 2ZW (Mon-Fri 8am-6pm).

WELFARE SERVICES IN ARGYLL AND BUTE:
Welfare support services continued

**WELFARE SERVICES IN AYRSHIRE:**

- **East Ayrshire Advice Bureau**: 01563 544744, 3 John Dickie Street, Kilmarnock, East Ayrshire, KA1 1HW.
- **North Ayrshire Money Matters Team**: 01294 310 456, 3rd Floor, Bridgegate House, Irvine, KA12 8BD (Mon-Thurs 9am-4.30pm).
- **South Ayrshire Welfare Rights**: 0300 123 0900, enquiryandinformationteam.kylestreet@south-ayrshire.gov.uk, Wallace Tower, 172 High Street, Ayr.

**WELFARE SERVICES IN CLACKMANNANSHIRE:**

- **Clackmannanshire Money Advice Service**: 01259 450 000, moneyadvice@clacks.gov.uk.

**WELFARE SERVICES IN DUMFRIES AND GALLOWAY:**

- **Dumfries and Galloway Welfare Rights**: 01387 266 888, www.welferights.net, 63-65 Friars Vennel, Dumfries, DG1 2RQ.

**WELFARE SERVICES IN DUNBARTONSHIRE:**

- **East Dunbartonshire Welfare Rights Service**: 0141 775 3220, 11 Alexandra Street, Kirkintilloch, G66 1HB.
- **West Dunbartonshire Welfare Rights Service**: 0800 980 9070.

**WELFARE SERVICES IN DUNDEE:**

- **Dundee Welfare Rights**: 01382 431167, welfare.rights@dundeecity.gov.uk, Jack Martin Way, Claverhouse East, Dundee DD1 3LA.

**WELFARE SERVICES IN EDINBURGH AND LOTHIAN:**

- **Advice Shop**: 0131 529 4828, advice.shop@edinburgh.gov.uk, 249 High Street, Edinburgh, EH1 1YJ.
- **Community Health and Advice Initiative**: 0131 442 2100, www.chaedinburgh.org.uk, ELS House, 555 Gorgie Road, Edinburgh, EH11 3LE (Mon-Fri 8am-6pm).
- **Community One Stop Shop (Broomhouse)**: 0131 443 6223, www.coss-broomhouse.co.uk, 3 Broomhouse Market, Edinburgh, EH11 3UU.
- **Family Advice and Information Resource (FAIR)**: 0131 662 1962, www.fairadvice.org.uk, 95 Causewayside, Edinburgh, EH9 1QG (Mon-Fri 9am-5pm).
- **East Lothian Welfare Rights Team**: 0131 653 5230, Brunton Hall, Ladywell, Musselburgh, EH21 6AF.
- **Granton Information Centre**: 0131 552 0458, 134-138 West Granton Road, Edinburgh, EH5 1PE, www.gic.org.uk, (Mon-Thurs 9.30-12.30pm).
- **Midlothian Council Welfare Rights Team**: 0131 271 3781, Fairfield House, 8 Lothian Road, Dalkeith, EH22 3AA.
- **West Lothian Council Advice Shop**: 01506 283000, advice.shop@westlothin.gov.uk, South Bridge Street, Bathgate, EH48 1TS (Mon-Fri 8.30am-4pm).
Welfare support services continued

WELFARE SERVICES IN FALKIRK AND STIRLING:

> Council on Disability: 01786 462178, codstirling@talktalkbusiness.net, The Norman McEwan Centre, Cameronian Street, Stirling, FK8 2DX (Mon-Thurs 10am-3pm).
> Falkirk Council Debt Advice Services: 01324 506735, debtadvice@falkirk.gov.uk, Carronbank House, Carronbank Crescent, Denny, FK6 6GA (Mon-Fri 9am-5pm).

WELFARE SERVICES IN FIFE:

  - Glenrothes: 10-12 Pentland Court, Saltire Centre, Glenrothes, KY6 2DA.
  - Kirkcaldy: 15 Wemyssfield, Kirkcaldy, KY1 1XN.
  - St Andrews: St Mary’s Place, St Andrews, KY16 9UY.
  - Cupar: Local County Buildings, St Catherine Street, Cupar KY15 4TA.
  - Leven: Adam Smith College, Levenmouth Campus, Victoria Road, KY8 4RN.
  - Cowdenbeath: 322 High Street, Cowdenbeath, KY4 9NT.
  - Dunfermline: 4 Abbey Park Place, Dunfermline, KY12 7PD.

WELFARE SERVICES IN GLASGOW:

> Castlemilk Law and Money Advice Centre: 0141 634 0313, www.castlemilklawcentre.co.uk, 155 Castlemilk Drive, Castlemilk, Glasgow G45 9UG.
> Drumchapel Money Advice Centre: 0141 944 0507, admin@dlmac.co.uk, Unit 1, KC Edge Commercial Centre, 15 Ladyloan Place, Glasgow G15 8LB.
> Legal Services Agency - Glasgow: 0141 353 3354, www.lsa.org.uk, 3rd Floor, Fleming House, 134 Renfrew Street, Glasgow, G3 6ST.
> Money Matters Money Advice Centre: 0141 445 5221, www.moneymattersweb.co.uk, Orkney Street Enterprise Centre, 18-20 Orkney Street, Glasgow G51 2BX (Mon-Fri 8.30am-5pm, Wed 8.30am-7pm).
> Tannochside Information and Advice Centre: 01698 816427, tiaadvicentre@hotmail.co.uk, 14 Thorniewood Road, Tannochside, Glasgow, G71 5QQ (Mon-Fri 9.15am - 4pm).
> Temple-Shafton Youth Project: 0141 950 1739, 358 Netherton Road, Temple Glasgow G13 1AX.
> Kingsway Court Health and Wellbeing Centre: 0141 959 0129, kingswaycourt@btclick.com, Kingsway Court, Scotstoun, Glasgow G14 9SR (Mon-Fri 9am-5pm).
Welfare support services continued

- **Money matters Inverclyde**: 01475 715965, 195 Dalrimple St, Greenock, Glasgow, PA15 1UN (Mon-Thurs 8.45am-4.30pm, Fri 8.45am-3.30pm).
- **Red Road Family Centre**: 0141 557 5571, rrfamilycentre@hotmail.com, 94 Red Road, Balornock, Glasgow G21 4PH (Mon-Fri 8.30am-6pm).
- **Renfrewshire Law Centre**: 0141 561 7266, www.rlclaw.co.uk, 65-71 George St, Paisley PA1 2JY.

**WELFARE SERVICES IN HIGHLAND:**

- **Highland Council Income Maximisation team**: 0800 090 1004, www.highland.gov.uk/yourcouncil/counciltax/incomemaximisation, income.maximisation@highland.gov.uk.
- **Debt and Money Advice Highland Council**: 0800 090 1004, money.advice@highland.gov.uk.
- **Community Advice and Information Service (Badenoch & Strathspey)**: 01479 810919, 2 Inverewe, Grampian Road, Aviemore, PH22 1RH (Tues: 10am-12noon, Weds: 9am-12noon, Thurs 2pm-4pm).

**WELFARE SERVICES IN LANARKSHIRE:**

- **South Lanarkshire Money Matters Advice Service**: 0303 123 1008, moneymatters.eastkilbride@southlanarkshire.gov.uk, Andrew Street, East Kilbride, G74 1AB (Mon-Thurs 8.45am-4.45pm, Fri 8.45am-4.15pm).
- **Blantyre Money Matters Advice Service**: 0303 123 1008, moneymatters.blantyre@southlanarkshire.gov.uk, David Dale House, Blantyre Area Office, 45 John Street, Blantyre G72 0JG (Mon, Tues & Thurs 8.45am - 4.45pm, Wed 11am – 4.45pm, Fri 8.45am – 4.15pm).
- **Cambuslang Money Matters Advice Service**: 0303 123 1008, moneymatters.cambuslang@southlanarkshire.gov.uk, Cambuslang Gate, 27 Main Street Cambuslang, G72 7EX (Mon, Tues & Thurs 8.45am - 4.45pm, Wed 11am – 4.45pm, Fri 8.45am – 4.15pm).
- **Disability Resource Centre - Clydesdale**: 01555 770123, www.clydesdale-disability-services.org.uk, 32 Hamilton Street, Carluke ML8 4HA (Mon-Fri 10am-1pm).
- **Lesmahagow and District Resource Centre**: 01555 892545, 40-42 Abbeygreen, 40-42 Abbeygreen, Lanark, ML11 0EQ.
- **Cumbernauld Unemployed Workers Centre**: 01236 729520, Community Education Centre, Brown Road, Seafar, G67 1AA (Mon-Fri 9am-4pm).
- **Newmains Advice Centre**: 01698 382661 / 382665, 54 Abernethan Road, Newmains, Wishaw, ML2 9NB (Mon-Fri 10am-3pm).
- **Rochsoles Community Resource Project**: 01236 767896, 63b Rochsoles Drive, Airdrie, ML6 6ST (Mon-Fri 9am-4.30pm).

**WELFARE SERVICES IN MORAY:**

- **Moray Citizens Advice Bureau**: 01343 55088, bureau@moraycab.casonline.org.uk, 30 Batchen Street, Elgin, IV30 1B8
- **Moray Council Welfare Benefits Team**: 0300 123 4561, welfarebenefits@moray.gov.uk (Access by referral from Moray Council departments or Moray Health Care Trust).
## Welfare support services continued

<table>
<thead>
<tr>
<th>Welfare Services in Orkney:</th>
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<tbody>
<tr>
<td><strong>Orkney Disability Forum:</strong> 01856 871515, <a href="http://www.orkneycommunities.co.uk">www.orkneycommunities.co.uk</a>, <a href="mailto:info@odforkney.com">info@odforkney.com</a>, 18 Junction Road, Kirkwall, Orkney KW15 1AV (Mon - Fri 9am-3pm).</td>
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<tr>
<th>Welfare Services in Perth and Kinross:</th>
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<tbody>
<tr>
<td><strong>Perth and Kinross Welfare Rights:</strong> 01738 476900, <a href="http://www.pkc.gov.uk/welfarerights">www.pkc.gov.uk/welfarerights</a>, Pullar House, 35 Kinnoull Street, Perth, PH1 5GD (Mon-Fri 9am-4pm).</td>
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<tr>
<th>Welfare Services in the Borders:</th>
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</thead>
<tbody>
<tr>
<td><strong>Borders Welfare Benefits Service:</strong> 01896 661 394, Galashiels Area Offices, Paton Street, Galashiels, TD1 3AS (Mon-Friday 8am-5pm, Thurs 8am-8pm, Sat 9am-12pm).</td>
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<tr>
<th>Welfare Services in Shetland:</th>
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</thead>
<tbody>
<tr>
<td><strong>Disability Shetland:</strong> 01595 743921, Market House, 14 Market Street, Lerwick, ZE1 0JP (Mon-Fri 10am-5pm).</td>
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<tr>
<th>Welfare Services in Western Isles:</th>
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<tbody>
<tr>
<td><strong>Stornoway Citizens Advice Bureau:</strong> 01851 705 727, 41-43 Westview Terrace, Stornoway, Isle Of Lewis HS1 2HP (Mon, Tues, Thurs and Fri 10am-12.45pm 2pm-3.30pm).</td>
</tr>
<tr>
<td><strong>Benbecula Citizens Advice Bureau:</strong> 01870 602 421, 7 Druim-na-Hairde, Balivanich, Isle of Benbecula HS7 5NE (Mon, Tues, Thurs and Fri 10.30am-12.30pm 2pm-4pm).</td>
</tr>
</tbody>
</table>
Hepatitis Scotland is the national voluntary sector organisation funded by the Scottish Government to help improve responses to viral hepatitis prevention, treatment and support.

Hepatitis Scotland supports and leads the work of voluntary sector groups in partnership with statutory agencies and patients towards:

- reducing the spread of viral hepatitis
- increasing the numbers of people diagnosed with viral hepatitis
- improving access to hepatitis treatment and support
- improving the range and quality of prevention, treatment and care services
- reducing stigma associated with viral hepatitis.

**OUR KEY WORK** focuses on:

- information-sharing with professionals and people affected by viral hepatitis
- training/capacity building and networking - fostering links with a range of services including those working in drugs and sexual health and with vulnerable young people
- patient involvement and representation - exploring the views of those affected by viral hepatitis.
ABOUT HIV SCOTLAND

HIV Scotland is the national HIV policy charity for Scotland: we speak out for people living with HIV. We want a society which is well-informed about HIV and devoid of HIV-related stigma and discrimination.

HIV Scotland provides:

> Knowledge and expertise to help inform and deliver strong policies and effective strategies;
> Expert advice and a voice for HIV in Scotland;
> Information, training and resources;
> Signposting to evidence, expertise and community experience; and
> Opportunities to engage with others in shaping policy and practice.

OUR VISION is a society which is well informed about HIV, devoid of HIV related stigma and discrimination, and where everyone living with or affected by HIV has access to and helps shape excellent services.

OUR MISSION is to ensure that all HIV relevant policy and practice in Scotland is grounded in evidence and in the experience of people living with and affected by HIV.
ACKNOWLEDGEMENTS

> The individuals who shared their stories and made this report possible.

> The services (from across the third sector, NHS, and local authorities) that shared their experiences.

> The organisations and individuals who assisted us with our research, including: Positive Help, Terrence Higgins Trust, and Waverly Care.

> The Scottish Campaign on Welfare Reform and Child Poverty Action Group for their expertise and input.