
HIV Scotland submission to the Social Security Committee on Social Security (Scotland) Bill.

About HIV Scotland

HIV Scotland is the national HIV policy organisation for Scotland. We exist on behalf of all those living with and at risk of HIV to ensure that Scotland has responsive policies, quality services and a supportive environment that enable people living with or at risk of HIV in Scotland to live healthy and fulfilling lives.

Statistics about HIV in Scotland

- As of 31st March 2017, there are 5,287 people diagnosed as living with HIV in Scotland, with the highest number of new diagnoses within Greater Glasgow and Clyde, and Lothian.¹
- It is estimated that one in six people living with HIV in Scotland are unaware of their status.²
- There were 306 new cases of HIV were reported in 2016.³ This represents the first significant drop (approximately 20%) in new cases for over a decade.
- It is estimated that 30% of those individuals diagnosed with HIV currently living in Scotland are aged 50 and over.

1. The Scottish Government has chosen to put most of the rules about the new benefits in Regulations. Q. Do you have any views on this approach?

Whilst acknowledging the Scottish Government's assertion that placing the rules within Regulations will ensure rules can be amended "*to reflect changes in economic and social conditions*" there should be a greater level of detail about the rules placed in the Bill itself. The nature of placing rules in Regulations means the Government will have the ability to change the fundamental aspects of the social security system with no public consultation and could create significant problems with consistency. We believe this places the Bill at odds with the Scottish Government's commitment to have a system based on human rights and involves people who will be in receipt of devolved payments. HIV Scotland would support the inclusion of a wider parliamentary scrutiny that is broader than only MSPs approving or not approving changes to Regulations. We support the call made by the ALLIANCE to provide Committees with the power to scrutinise proposed changes to Regulations when are laid before parliament.

¹ [HIV infection and AIDS: Quarterly report to 31 March 2017 \(ANSWER\)](#), Health Protection Scotland, June 2017

² [Why Get Tested](#), HIV Testing Week Scotland

³ [HIV infection and AIDS in Scotland: HIV infection and AIDS: Quarterly report to 31 December 2016 \(ANSWER\)](#), Health Protection Scotland, March 2017

HIV Scotland has conducted extensive consultation activity with people living with HIV to ascertain their opinions, based on experiences of the existing social security system, on how the new Scottish agency should operate. The consensus among people living with HIV is that HIV is not properly understood within the context of social security and that the devolution of powers offers an opportunity to remedy this. We welcome the Scottish Government's commitment to a system based on "*dignity and respect*". However, the Bill does not contain information about how the agency will alleviate the fundamental problems within the existing system. People living with HIV have expressed the considerable stress and anxiety both the application and assessment processes cause, which has an impact on their overall health. The Bill should therefore be more explicit in detailing how the Scottish Government intends to better support people through what will be the key components of the new system.

2. The Bill proposes that the Scottish social security system will be based on seven principles. **Q. What are your views on these principles and this approach?**

HIV Scotland welcomes the seven principles that have been placed within the legislation.

Specific comments:

Social security is an investment in the people of Scotland.

Over the past ten years there has been no significant decrease in the number of new HIV infections, with an average of one new infection every day. Late diagnosis of HIV can have a significant impact on the health and wellbeing of individuals, some of whom require access to social security benefits at different times for various reasons; to stay in work, maintain their health, wellbeing and independence, or to meet basic living costs. The rate of late diagnosis in Scotland during 2015 was 45%.⁴ In addition, people living with HIV are disproportionately affected by poor mental health, with around one in three people living with HIV having symptoms of depression at some point in their lives.⁵ Therefore, the commitment for social security to be an investment in the people of Scotland is a welcome step to reinforce that social security should be regarded as a safety net for people at any point in their life.

Social security is a human right. It is essential to accessing other human rights.

Human rights form the bedrock of empowerment, enable people to advocate for themselves and have meaningful involvement in Scotland's response to HIV. By adopting a human rights framework for our laws, policies and services, people living with and at risk of HIV can be empowered to make choices about their own lives and to participate fully in their communities.

In order to strengthen the role of human rights within the context of social security, we would propose that there is reference to international human rights law and existing conventions. In the Policy Memorandum, the Scottish Government details the aspiration not to be "*criticised by the UN, or an equivalent organisation, for failing to guarantee a right to social security.*" HIV Scotland supports this ambition but believe it should be more robust than merely seeking to avoid international criticism, there should be a commitment to establishing a world leading human rights approach to social security. Such an approach would include the rights of asylum seekers who are currently going through the asylum system in the UK. Whilst the Scottish Government has no jurisdiction over this area of policy, the Social Security Bill provides an opportunity to ensure that people living with HIV and seeking asylum are

⁴ [Late diagnoses in Scotland](#), Health Protection Scotland, 2016

⁵ [Depression and HIV](#), Terrence Higgins Trust

better supported irrespective of their immigration status and do not experience destitution.

Respect for the dignity of individuals is at the heart of the Scottish social security system.

People living with HIV continue to experience stigmatising attitudes when accessing services. The UK Stigma Index 2016 revealed that a third of respondents living in Scotland worried about being treated differently to other patients at the GP and dentist.⁶ Stigma and awareness of the modern day realities of HIV, have also been identified as a significant concern by people living with HIV in regards to accessing the existing social security system. Reports of intrusive questions and unknowledgeable staff conducting assessments are a common occurrence.

HIV Scotland would therefore urge the Scottish Government to provide further detail on what the terms “*dignity*” and “*respect*” will mean for claimants and what procedures will be put in place to allow individuals to seek redress if these principles are not being fully upheld. Consideration should also be given to address stigmatising attitudes towards those who access social security payments.

The Scottish social security system will be designed with the people of Scotland, and based on evidence.

The establishment of the Experience Panels has been a welcome development to involve people in the design of the new system. However, there is limited detail on the future role of the panels. We would recommend that these panels are regarded as an important tool to meaningfully involve people in shaping the new system and should have adequate resources allocated to support that activity. Furthermore, this principle should be enhanced by recognising the importance of access to independent advocacy and support for those most vulnerable to participate in any engagement work.

Q. Are there other principles you would like to see included?

3. The Bill proposes that there will be a publicly available social security ‘charter’. This will say how the Scottish Government will put the seven principles above into practice. It will also say what is expected from people claiming benefits. A report on the charter will be produced by the Scottish Government each year.

Q. Do you agree with the idea of the charter? Please explain the reason for your answer.

HIV Scotland supports the idea of the charter as could be a useful resource to define the principles of the new system. This charter should be co-produced by people who will access the new system and designed in an accessible format. We would recommend that the charter takes a rights-based approach and includes specific information on how claimants can seek to exercise their rights at all times during their interaction with the new system. The Policy Memorandum states the charter will be “*used as an instrument to facilitate a ‘two-way’ dialogue between users and the Scottish Government*” This should be strengthened to recognise the role of the Experience Panels and ensure that people in all communities have an opportunity to be supported and meaningfully involved in this dialogue.

Q. Is there anything specific you would like to see in this charter?

- Clear information about how claimants can fully exercise their human rights when accessing the system.

⁶ [HIV in the UK: Changes and Challenges; Actions and Answers The People Living With HIV Stigma Survey UK 2015 Scotland](#), Stigma Index UK, 2016

- Details of how claimants can complain if they believe that the principles in the charter have been breached.
- Details of independent support and advocacy services that are available to assist claimants.

4. The Bill proposes rules for social security which say:

- how decisions are made and when they can be changed
- how to apply and what information people have to provide
- how decisions can be challenged
- when overpayments must be repaid
- what criminal offences will be created relating to benefits.

Q. Do you have any comments on these rules?

Redetermination: We have concerns about the process of redetermination set out in the Bill. As stated in the submission by the Scottish Campaign on Welfare Reform (SCoWR), this proposed process retains key characteristics of the current UK mandatory redetermination process. HIV Scotland welcomes the commitment to providing short term assistance to claimants when an appeal is being considered. However, the continuation of a process that involves a second stage consideration before access to an independent hearing is provided remains problematic. We acknowledge that the Scottish Government has proposed that redetermination will have clear timescales and the claimant will be kept informed throughout the process. From our engagement with advocacy workers, it is clear that the number of people who wish to proceed to a subsequent appeal is low and this has been attributed to the stress of the undergoing a mandatory redetermination process. We believe this stress and traumatic experience results in people living with HIV choosing not to make a second application and potentially not receiving the support they are entitled to.

Overpayments: We echo the comments made in the submission by SCoWR regarding the provisions in the Bill to automatically recover benefit overpayments, even if these result from official error. Whilst the policy intent is to not to recover overpayments that have occurred in error by the agency, the Bill does not contain powers to create Regulations on the circumstances when recovery would or would not take place.

Offences: Whilst it may be unintentional, the wording in the Bill as introduced concerning offences is unnecessarily punitive. The Bill does not contain provisions to consider genuine error on the part of the claimant, nor does it recognise that fraud within the existing social security system represents 1.1% of estimated total fraud in the UK.⁷ In line with the Scottish Government's commitment to a system based on dignity and respect, the wording within the Bill should be amended to form a more rights-based approach that better takes into account individual circumstances when addressing suspected offences.

5. The Scottish Government will take over responsibility for some current benefits. The Bill does not explain how they will work in detail. This will be set out in Regulations at a later date. The current benefits which will be run by the Scottish Government are:

- disability assistance (including disability living allowance, personal independence payment, attendance allowance and severe disablement allowance)
- carer's allowance

⁷ [Fraud and Error in the Benefit System](#), Department for Work and Pensions, UK Government, December 2016

- winter fuel payments
- industrial injuries disablement benefit
- cold weather payments
- funeral payments
- sure start maternity grants

Q. What are your thoughts on the schedules in the bill in regard to these benefits?

Under the Equality Act 2010, a person is considered to have a disability from the day of being diagnosed with HIV.⁸ Although HIV is no longer a terminal illness, it is now considered to be a chronic condition. HIV Scotland would therefore call for inclusion of chronic illnesses within the schedules in the Bill. We have concern that the wording “*physical or mental impairment*” is not explicit enough to also include people living with a chronic condition.

6. The Bill proposes that a new type of short-term assistance will be introduced. This will be for someone who is challenging a decision to stop or reduce a Scottish benefit.

Q. What are your views on this proposal?

We welcome the introduction of a short-term assistance for people who wish to appeal a decision. However as previously stated, we have concerns about the proposals for a mandatory redetermination process that this assistance would be linked with. A key concern that has been raised with us concerns access to mobility vehicles during the course of an appeal being made. There must be measures put in place to ensure that people can continue to have access to such vehicles throughout the entirety of an appeal.

7. The Bill includes the power for the Scottish Government to be able to top up ‘reserved’ benefits (ones controlled by the UK Government), but does not say how these will be used. The Scottish Government also has the power to create new benefits. This is not included in the bill.

Q. Do you agree with these proposals?

8. The Bill proposes that carer’s allowance should be increased as soon as possible to the level of jobseeker’s allowance (from £62.10 to £73.10 a week).

Q. What are your thoughts on this proposal?

One third of people living with HIV in the UK are aged 50 and over and there has been an increasing rate of new diagnoses of older people in the past nine years (9% in 2006 to 17% in 2015).⁹ A study into older people living with HIV found that 88% of participants had not made financial plans to fund future social care needs.¹⁰ It is therefore likely there will be a need for an increased number of carers for people who require support. HIV Scotland supports the proposed increase to Carer’s Allowance, however there should be an aspiration to take into account the actual cost of providing care full-time. Moreover, the Scottish Government should proactively seek to increase the take-up of Carer’s Allowance through identifying carers who may be eligible.

9. The Bill proposes that discretionary housing payments continue as they are. They will still be paid by local authorities. The Bill does not require any local authority to have a discretionary housing payments scheme but if they do, they must follow Scottish Government guidance on running it.

⁸ [Equality Act \(2010\)](#), UK Government

⁹ [HIV in the UK – 2016](#), Public Health England, December 2016

¹⁰ [Uncharted Territory: A report into the first generation growing older with HIV](#), Terrence Higgins Trust, January 2017

Q. Do you agree that discretionary housing payments should continue largely as they are?

We note that there continues to be no statutory obligation for local authorities to provide DHPs, nor universal approach to how assessments are conducted to decide on entitlement. People living in private rented housing within urban areas face significantly higher levels of rent than those in social housing, yet DHPs do not take into account this difference. Policies should be put in place to better recognise the actual cost of housing and ensure there is long-term continuity of DHPs by local authorities.

Q. Do you have any other views on the proposals for discretionary housing payments?

10. Q. Is there anything else you want to tell us about this Bill?

- HIV Scotland would like to draw the Committee's attention to a report by the National AIDS Trust on the roll-out of PIP and how it has affected people living with HIV.¹¹ This report found that people living with HIV are:
 - Less likely to be awarded PIP following reassessment.
 - Less likely to receive an increase in their rate of benefit when moving from DLA to PIP.
 - More likely to receive a decrease in their rate of benefit when moving from DLA to PIP.

The present assessment process for PIP is not working for people living with HIV and we would urge the Scottish Government to take into account the findings of this report when drawing up Regulations concerning disability benefits.

- We have concerns about the wording that social security assistance "*may or may not take the form of money*". Whilst we acknowledge the Scottish Government intends to use this provision to offer choice to the claimant, there should be more robust wording in the Bill to make clear that access to cash is a guaranteed right.
- One of the biggest challenges in the current social security system is the increasing pressures on independent advocacy and support services. People living with HIV often rely upon third sector organisations to support them with applications and during the assessment process. We would call for greater clarity on the role of advocacy and support within the new system and how people will be signposted to these services.

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¹¹ [PIP and HIV: How Personal Independence Payment is working for people living with HIV](#), National AIDS Trust, July 2017