RESPONSE TO CONSULTATION ON THE FUTURE USE OF RESOURCES DEVOLVED FOLLOWING THE UK GOVERNMENT'S DECISION TO CLOSE THE INDEPENDENT LIVING FUND

HIV SCOTLAND
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WHO WE ARE

HIV Scotland is the national HIV policy charity for Scotland. We want a society which is well-informed about HIV and devoid of HIV-related stigma and discrimination. 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. We maintain meaningful engagement with people living with HIV and demonstrate how their involvement makes a difference.

SUMMARY

HIV is a disability as defined in the Equality Act 2010 from the point of diagnosis. Although many people in Scotland living with HIV can now experience a much better quality of life, there remain many others who are chronically unwell and disempowered. In particular, the complex support needs of people living with HIV who received their diagnosis in the 1980s can often go unmet. At this time, people were told that they were not likely to live more than a few years and even counselled to cash their pension. These same people are now also losing vital support due to welfare reform.

The Independent Living Fund (ILF) is somewhat unique in that it currently bridges the gap between social care and welfare support. The needs of people living with HIV in Scotland are wide-ranging and involve the statutory and third sectors within health and social care. Many people with HIV have particularly significant social care needs that will impact on clinical care and compromise well-being.[1] Furthermore, people are living with HIV into old age and will increasingly need social and clinical support. With complex health problems, fewer financial resources and greater isolation than many of their peers, many people with HIV face major challenges.[2]

As such, the ILF is of great importance to people living with HIV. HIV Scotland is pleased that the Scottish Government's intention is to ensure that current recipients of the ILF do not have their existing funding taken away. However, we do not believe that the ILF is currently well accessed or understood by people living with HIV. We therefore welcome the opportunity to contribute to discussion about possibilities for the future, and wish to consider this within the wider policy context of public service reform and local council budget cuts.

We have limited our response to focus on those questions which we believe have the greatest relevance to the points highlighted above and to people living with HIV.

DETAILED COMMENT

Question 1: *What aspects of the current ILF worked well and what elements did not work so well?*

A key strength of the ILF is that it provides money - over and above the critical level of support offered by local authorities - to help disabled people live an independent life in their communities rather than in residential care. A national study of ageing and HIV (50 Plus) found that three quarters of respondents were concerned about future access to social care such as home help; half of them already reported mobility problems and almost half having difficulties with everyday activities. Many people in

[1] BHIVA Standards of Care for People Living with HIV, 2013

[2] A national study of ageing and HIV (50 Plus), Joseph Rowntree Foundation, 2011

the study expressed anxiety about needing to use residential care because of perceived, and sometimes experienced, prejudice and ignorance about HIV within these services. [3]

However, since 1993 ILF recipients have had to qualify for a certain amount of support from their local authority before they can access the fund which may have created barriers to the fund for many people who could have benefited from it. This is especially so given that access to social care is increasingly through standard local authority assessment, with some local authorities' only meeting critical needs under Scotland's national eligibility guidance. This makes it difficult for many people with HIV to qualify for care, despite having high levels of social care needs. Consequently, accessing financial assistance such as the IFL can also be made much more difficult. In fact, unmet financial and social care needs are common in people with HIV. [1]

HIV Scotland fully recognises that the resources available for the ILF are extremely limited, especially relative to demand. As the consultation states, any future funding released through attrition and by streamlining systems is also unlikely to be substantial. We have not provided comment on how the overall resources might be increased but do highlight below several factors which we believe are important to consider when making decisions about the future focus of any new fund.

Question 5: ***With any available resource, where is the most effective area to target resources which can have the biggest impact on an individual's ability to live more independently?***

The combination of increasingly constrained resources coupled with the varying needs of a changing population of people living with HIV requires that we develop new approaches to meet their needs. Since the introduction of antiretroviral therapy, people living with HIV in Scotland are living longer lives; one-in-five adults accessing HIV care in 2010 was over 50 years old.[4] Increased life expectancy results in an ageing HIV population with an above-average risk of other health conditions e.g. cardiovascular, metabolic, bone and neurological problems. [5] Chronic long-term condition management is therefore becoming increasingly relevant to HIV care.

The consultation document suggests that a future focus of the fund could include prevention and low level support - shifting the emphasis away from waiting for an individual's support requirements to increase before they can access a service. This approach could go far to help resolve some of the aforementioned barriers to access and would also be consistent with the preventative approach put forward by the Christie Commission, taking demand out of the system over the longer term.

Self-management is an example of a preventative approach which could be used to great effect to make best use of resources and also enable people to live more independently. The British HIV Association (BHIVA) has identified that, as with many other long-term conditions, self-management approaches can help people with HIV to gain confidence, skills and knowledge to manage their own health, with resulting improvements in quality of life and independence.[6] BHIVA has stated that, for people with HIV, self-management can help with at least four interconnected major areas:

[3] A national study of ageing and HIV (50 Plus), Joseph Rowntree Foundation, 2011
[4] BHIVA Standards of Care for People Living with HIV, 2013
[5] BHIVA Standards of Care for People Living with HIV, 2013
[6] BHIVA Standards of Care for People Living with HIV, 2013

physical health; mental health; economic inclusion (including access to financial and employment support); and social inclusion. As such, a future fund could be used to assist people to access those interventions which supported them to develop confidence and competencies for living with their illness or disability.

The consultation also suggests that the future fund could be used to overcome short term challenges in an individual's life e.g. seeking employment. This would be a significant move away from the "awards for life" assumption that the current ILF system implies. This approach could help to ensure that greater numbers of people were able to benefit from the fund by reducing/increasing levels of support relevant to individual situations and needs.

Moving away from an "awards for life" assumption might also enable an approach which could better account for conditions which may change or fluctuate over time. For example, support could be awarded at times when a change in a person's condition meant that their social care needs were increased. In relation to HIV, fluctuating symptoms can be the result of HIV infection, HIV treatment, or both. The experience of these fluctuating symptoms is a cause of real distress for some people living with HIV and creates significant barriers to work, daily living and social participation.[7] HIV Scotland believes that these impacts must be considered in relation to the future provision of both benefits and social care.

Whilst a shift towards preventative approaches or away from an "awards for life" assumption has the potential to deliver significant benefits, it also has to be recognised that some people will always have significantly higher social care needs than others and will require greater levels of support in order to maintain an adequate standard of independent living. It is important that the focus of any future fund does not work to the detriment of people with higher levels of need. This again raises the key issue of the limited resources available to sustain and deliver the ILF.

However, the closure of the ILF in its current form provides an opportunity to design a new system to support independent living in Scotland. This will require that we view the future of the ILF in light of current developments at a local, regional and national level and carefully consider how any adverse impacts might be mitigated; for example, reductions in funding for local authorities, changes to Disability Living Allowance, caps on housing benefit and the way in which these might interact to restrict enjoyment of the right to independent living.

Question 6: ***Once funding has been devolved to the Scottish Government, which option do you think will be most appropriate for Scotland?***

The consultation document puts forward a number of options which the Scottish Government has identified as being feasible for the distribution of funding; one of which would involve local authorities administering the Fund in conjunction with their wider social care duties. This has a clear advantage in that local authorities do have existing expertise and obligations in relation to the provision of social care, operating at a local level.

If it is decided that the fund is to be distributed by local authorities then robust guidance and monitoring procedures will be critical in order to prevent geographical variations and to ensure that the funds are being used for their intended purpose. Having local authorities administer the fund could blur the lines between funding intended to support disabled people to pay for support over and above the critical

[7] Fluctuating Symptoms of HIV, National AIDS Trust, 2011

level of support already offered and that intended to meet basic care needs. Furthermore, in the absence of ring-fencing there is a real risk that funding from the ILF will end up going into the general social services pot and becoming lost. The focus of the ILF should be on promoting equality of opportunity for people at home and work, in education and their communities.

Another option proposed within the consultation document is the creation of a new partnership or trust with the third sector. An approach which places disabled people and/or their representative organisations in charge of managing the fund would be consistent with current health and social care policy which seeks to place people at the heart of the services they receive. The third sector is often well placed to facilitate access to support for those most in need, and opportunities for people to manage and coordinate their own support is essential for ensuring a human rights based approach. However, if third sector service providers are to administer welfare this could alter their actual or perceived relationship with the people and communities they support. For example, tensions could be created between service providers and clients in situations where funding could not be provided. A decision to pursue this option should only be reached through a process of extensive consultation with the third sector and communities.