



HIV SCOTLAND'S RESPONSE TO THE HEALTH AND SPORT COMMITTEE CALL FOR VIEWS ON THE PUBLIC BODIES (JOINT WORKING) (SCOTLAND) BILL

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

This Bill is of particular relevance to people living with HIV, given its implications for health and social care and initial emphasis on the needs of the aging population. Since the introduction of antiretroviral therapy, people living with HIV are enjoying healthier longer lives; 1 in 5 people with HIV in the UK is now over 50¹ and a 2011 study² found that the prevalence of certain conditions typical of aging (e.g. cardiovascular disease, liver disease, hypertension) in people living with HIV was more typical of HIV negative people aged 10-15 years older. The same study also points to the need for earlier detection of non-infectious comorbidities, which this Bill could play a vital role in addressing. Furthermore, people living with HIV may be more likely to access multiple services across a range of settings e.g. health, social care, social work, welfare, housing and criminal justice.

The Bill also has the potential to ensure that individuals, communities and the third sector are meaningfully involved in the planning, design and delivery of public services. However, HIV Scotland believes that the provisions in the Bill require to be strengthened if this potential is to be realised and to ensure a genuine focus on the needs and rights of individual patients and service users.

QUESTIONS

- **Do you agree with the general principles of the Bill and its provisions?**

HIV Scotland fully supports the policy ambitions and principles outlined within the Policy Memorandum, such as the delivery of joined up and person-centred care. However, within the Bill itself the overarching 'general principles' are unclear; instead there are a set of 'integration planning principles' and 'integration delivery principles' set out within different sections. It is also unclear which principles are to be seen as driving this legislation, whether it be the *"the underlying principle... that Health Boards and local authorities must take joint and equal responsibility for the delivery of nationally agreed outcomes..."* or *"the desire to embed a person-centred approach to public service delivery of health and social care."*

HIV Scotland firmly believes that any reform to public services must be driven by the need to place the person at the heart of the services they receive, however the principles contained within the Bill at present do not go far enough to ensure that the focus will truly be on the individual patient or service user. A far better approach would be to explicitly set out guiding principles at the start of

¹ Health Protection Agency (2011) 'HIV in the United Kingdom: 2011 Report' (www.hpa.org.uk/webc/HPAwebFile/HPAweb_C/1317131685847).

² Guaraldi, G. Et al. (2011) 'Premature Age-Related Comorbidities Among HIV-Infected Persons Compared With the General Population', *Clinical Infectious Diseases*, 53, pp. 1120-1126.

the Bill, placing a duty on the relevant public bodies to adhere to principles such as involvement, collaboration and the fulfilment of individual's rights (e.g. independent living and access to quality and effective services) when acting on their functions under the Bill. We would refer to the Social Care (Self-directed Support) (Scotland) Act 2013 as an example of good practice in this regard. This Act established a legal framework for people to have greater choice and control over the support they receive, with principles such as independent living being set out on the face of the legislation.

- **To what extent do you believe that the approach being proposed in the Bill will achieve its stated policy objectives?**

The Bill appears largely focused on the technical aspects of integration, placing a strong emphasis on the desired structural change. However, the integration of health and social care is a means to an end and not an end in itself. The integration of services alone will not be enough to better deliver outcomes for individuals and produce better quality services equipped to meet their needs. In order to achieve these ends, it will be absolutely essential that the people accessing services are meaningfully involved in their design and delivery but the provisions in the Bill relating to the involvement of service users and communities are currently weak.

The significant contribution of the voluntary sector towards meeting the policy objectives must also be recognised, with the voluntary sector being included as a full and equal partner. The voluntary sector has a key role to play, both in supporting commissioners to procure services that are responsive to peoples' needs and provide value for money, and in the delivery of effective and innovative health and social care provision. The voluntary sector is also well placed to engage people and communities and give them a voice in decisions which affect them. Unless the Bill is strengthened in this regard, the potential for it to achieve the stated policy objectives will be greatly lessened.

One of the stated policy objectives is to *"improve the quality and consistency of services"*. The fact that the Bill allows for integration authorities to progress integration using several different models may result in significant inconsistencies between localities. This could have implications for the consistency of support for people living with HIV who may travel beyond their local service(s) to access care. Furthermore, depending on the delegation model adopted and the effectiveness of its implementation, there could remain serious disconnects. For example, disconnects could be widened between child and adult services where a 'delegation between partners' model is employed in relation to these services.

- **Please indicate which, if any, aspects of the Bill's policy objectives you would consider as key strengths**

HIV Scotland welcomes attempts to deliver joined up care which delivers better outcomes for patients, service users and carers. The fact that the Bill introduces a requirement for health and social care partners to integrate their services and budgets, prepare and publish strategic plans and engage in strategic commissioning certainly goes further than previous attempts to foster integration.

We also greatly welcome the introduction of nationally agreed outcomes for health and social care, which if properly developed and implemented could go far to ensure that all partners are working together towards the delivery of better outcomes for individuals and communities.

- **Please provide details of any areas in which you feel the Bill's provisions could be strengthened**

As stated above, the development of national health and wellbeing outcomes and published integration plans could help to bring about improvements in the delivery of public services. However, this will only be the case if the people accessing these services and the third sector are meaningfully involved in their development. The term 'consultation' used throughout the Bill is not strong enough to ensure that this will happen; a much greater emphasis must be placed on involvement and collaboration, with the voluntary sector being positioned as an equal partner in strategic planning and the design/delivery of services. Unless the provisions of the Bill are strengthened in this regard, there is a real danger that the national health and wellbeing outcomes will not reflect the needs people accessing services and that voluntary sector involvement will become tokenistic within the new arrangements. This is especially so given that the third sector will be a non-voting member of the HSCP Committees.

In relation to integration plans, the Bill could be greatly strengthened by placing a duty on Health Boards and local authorities to evidence/report how they have involved communities and the third sector in their development. Furthermore, there is little detail in the Bill about how or whether integration authorities will be held accountable for progress against the agreed national outcomes and strategic plans, or how poor performance will be identified and addressed in a timeous manner.

The plans to integrate adult health and social care services are not limited to older people's services but are intended to extend to all adult health and social care services. HIV Scotland believes that the proposals would greatly benefit from clarity as to when and where the proposals for integration are intended to be progressed.

HIV Scotland would also like to see human rights and a rights-based approach being given more prominence within the Bill. This could be achieved by setting out clear overarching rights-based principles as described earlier in this response.

- **What are the efficiencies and benefits that you anticipate will arise for your organisation from the delivery of integration plans?**

This Bill presents an opportunity to ensure that services across all sectors can be better aligned to joint outcomes, focused on the needs of individuals and communities. HIV Scotland is aware of a number examples of good practice in this regard, where effective joint working has delivered significant efficiencies for all partners and, critically, better outcomes for individuals.

Waverley Care is a national charity that works with people living with HIV and hepatitis C. One of their projects is the running of Milestone House, a short term residential support unit. This service is currently being comprehensively redesigned and reshaped in collaboration with the local authority and the NHS to focus more on 'step-up' and 'step-down' care. Multi agency referral pathways are being designed, with funding being allocated to the new service by both the local authority and health board. Waverley Care also runs an African Health Project that provides a variety of holistic support services ranging from housing and immigration to health. An important aspect of this is work with Africans, both living with HIV and not, is support to access health services and navigate a sometimes complex NHS system. This is particularly vital for recent migrants who are completely unfamiliar with the system and often have low levels of treatment-literacy. This is an 'at risk' population that is often only able to access services because of the support of the third sector. This delivers clear benefits, not only in ensuring the best use of NHS resources, but also in terms of the preventative approach put forward by the Christie Commission; taking demand out of the system over the longer term.

Positive Help is a charity which offers volunteer led practical help to those affected by HIV and hepatitis C in Edinburgh and the Lothians. Positive Help's befriending service offers a life line to

children and young people who are either living with HIV or hepatitis, or whose parent/s have HIV or hepatitis C. By establishing trust and relationships with young people and their families, Positive Help not only provides a vital support which better enables people to live in their local communities and enjoy an improved quality of life, but any problems can be identified at an early stage and the families linked to the appropriate support. This again demonstrates the way in which the voluntary sector can engage people and communities who may not normally come to the attention of statutory services, ensuring that their needs are identified and addressed at the earliest possible opportunity.

Another example of good practice is Gay Men's Health (GMH), the only Scottish organisation that delivers community based services run by and for gay and bisexual men. To steer the work it does, GMH consults widely and frequently with its volunteer base and the whole community, enabling new trends and health needs to be quickly identified and addressed. GMH also works with NHS Boards to increase the choice and variety of sexual health services that gay and bisexual men can access, offering HIV testing within community settings to increase awareness, and early identification, of HIV in a risk group.

However, building on this type of success will require that joint strategic commissioning is taken forward in such a way that it prioritises preventive support and recognises the third sector as a key partner. If this is not the case, there is a very real risk that existing areas of good practice could be undermined by the integration proposals.

- **What effect do you anticipate integration plans will have on outcomes for those receiving services?**

The answer to this question depends heavily on the extent to which the outcomes of people receiving health and social care services come to be reflected in the national health and wellbeing outcomes. At present, HIV appears to be largely missing from national and local outcomes and performance monitoring mechanisms. HIV Scotland is hopeful that the integration plans will provide an opportunity to address this oversight and ensure the inclusion of people living with or at risk of HIV in the design and delivery of services.

The development of shared outcomes and better integrated services may present new opportunities to better promote and evaluate public health and prevention efforts to reduce HIV transmission. For example, it could help to align efforts to increase the proportion of people with HIV being identified at an early stage of infection. The overall proportion of late diagnoses remains high in the UK, in 2011 this comprised 47% of people newly diagnosed with HIV.³ People diagnosed late have a tenfold increased risk of dying within a year of diagnosis. The findings of a recent Scottish study support more routine HIV testing outside of a specialist setting, particularly for patients in high-risk populations.⁴

The integration plans could also serve to ensure that people working across sectors and settings have a greater awareness and understanding of HIV and related issues. This could be achieved, for example, through developing joint training packages and co-locating staff and services.

If you have any questions or comments regarding this response please contact Aidan Collins, HIV Scotland Head of Policy and Campaigning at aidan.collins@hivscotland.com

³ Health Protection Agency (2012) 'HIV in the United Kingdom: 2012 Report' (http://www.hpa.org.uk/webc/hpawebfile/hpaweb_c/1317137200016)

⁴ L Goodall and C Leen, *Scott Med J* (2011) 'Late diagnosis of HIV: could this be avoided?'