

## CONSULTATION QUESTIONS

### The Carer's Assessment: Carer's Support Plan

Question 1: Should we change the name of the carer's assessment to the Carer's Support Plan?

Yes

No

#### Comments:

HIV Scotland supports changing the name of the carer's assessment to the Carer's Support Plan in order to better communicate a person centred approach, whereby the carer is supported to have a high quality of life. In addition, changing the name in this way could be beneficial in encouraging more carers to access the support they need, especially where people may feel stigmatised by the use of the term 'assessment' or have had negative experiences of assessments when applying for welfare benefits.

Question 2: Should we remove the substantial and regular test so that all carers will be eligible for the Carer's Support Plan?

Yes

No

#### Comments:

HIV Scotland believes that removing the substantial and regular test would better account for the impact that illness and disability can have on people's lives, and enable more people who would benefit from carers support to access it.

The needs of people living with and affected by HIV are wide-ranging and can involve a variety of health and social care issues. There has been great progress in treatment and care for people with HIV, bringing significant improvements to both clinical outcomes and to the lives of people living with HIV. Although these improvements have changed the lives of many, there remains large numbers of people who have poor treatment responses and remain chronically unwell, both physiologically and psychologically. People living with HIV may also experience significant fluctuations in their health over time due to their condition or the side effects of medication, meaning they can require different levels of support at different times and from different people. As such, many carer's may not provide substantial care on a regular basis but still have caring responsibilities such that they would greatly benefit from support. The proposed Carer's Support Plan could apply to a wider group of carers and could also be adapted to ensure that any support provided is appropriate and tailored to individual needs.

Question 3: Should we remove that part of the existing carer assessment process whereby the cared-for person is a person for whom the local authority must or may provide community care services/children's services?

Yes

No

Comments:

HIV Scotland particularly welcomes proposals to remove parts of the existing carer assessment process whereby the cared for person must be receiving community care services for the carer to receive support. People living with HIV have a wide variety of needs and don't necessarily receive community care services. This change would mean that all carers of people living with HIV would be able to access support if they required it.

Question 4: Should we introduce two routes through to the Carer's Support Plan – at the carer's request and by the local authority making an offer?

Yes

No

Comments:

Question 5: Should we remove from statute the wording about the carer's ability to provide care?

Yes

No

Comments:

Question 6: Should we introduce a duty for local authorities to inform the carer of the length of time it is likely to take to receive the Carer's Support Plan and if it exceeds this time, to be advised of the reasons?

Yes

No

Comments:

When accessing support, people must be fully informed of both their rights and the process of how they will receive support. Ensuring that people are fully informed about the length of time it takes to process a claim could help to minimise the anxiety and stress associated with applying for support. The proposed duty could also help to improve accountability and transparency. Carers should be empowered to hold local authorities to account if they fail without reason to deliver a support plan in the agreed time period.

It is disappointing that the possibility of introducing timescales for the undertaking of the Carer's Support Plan has been ruled out on the grounds that this must be determined locally. To ensure equality of access across Scotland, HIV Scotland believes that there should be a defined timescale for Local Authorities to undertake an assessment and also to provide services that carers are eligible for.

Question 7: How significant an issue is portability of assessment for service users and carers?

Comments:

Question 8: Should the Scottish Government and COSLA with relevant interests work together to take forward improvements to the portability of assessment?

Yes

No

Comments:

### Information and Advice

Question 9: Should we introduce a duty for local authorities to establish and maintain a service for providing people with information and advice relating to the Carer's Support Plan and support for carers and young carers?

Yes

No

Comments:

HIV Scotland supports proposals to place a duty on local authorities to provide carers with appropriate advice and information. Information can be empowering for carers as it can assist them to make more informed decisions about what support would be beneficial for them. Furthermore, easy access to information could help potential carers and people living with HIV to plan for support which they might need in the future.

It is estimated that by 2015 50% of all people living with HIV will be over 50, with a national study of ageing and HIV <sup>1</sup> (50 Plus) finding that this group report twice as many other long term health conditions as people who are not living with HIV. It is therefore likely that there will be an increase in the number of carers for this group who require support and it is critical that effective communication and advice services are established.

The consultation document notes that information for carers has not always been delivered in a way which carers can easily access or understand. HIV Scotland believes that strengthening the effectiveness of information provision will require an evaluation of information sharing formats, not just an increase in the number of information resources available. Resources should be designed in partnership with carers, to ensure that they best fit the needs of the people using them. It must also be made clear that Local Authorities should seek to work in partnership with the third sector and carer support services to provide information and advice, in order to avoid duplication and make best use of resources.

It will also be important that information provision for carers is not entirely digitally based. The 2012 Ofcom Communication Market report found that approximately 30% of people in Scotland did not have access to broadband at home. This figure rose to 60% in households with an annual income below £17,000.

Question 10: Should we repeal section 12 of the Community Care and Health (Scotland) Act 2002 about the submission of Carer information Strategies to Scottish

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<sup>1</sup> A national study of ageing and HIV (50 Plus), Joseph Rowntree Foundation, 2011

Ministers, subject to reassurances, which are subject in turn to Spending Review decisions, about the continuation of funding to Health Boards for support to carers and young carers?

Yes

No

Comments:

### Support to Carers (other than information and advice)

Question 11: Should we introduce a duty to support carers and young carers, linked to an eligibility framework?

Yes

No

Comments:

HIV Scotland believes that a *duty* to support carers would be greatly preferable to the existing discretionary power to support carers and young carers. However, the introduction of an eligibility framework does raise some concerns. For example, if the eligibility criteria is too restrictive it could greatly undermine the extent to which the proposed Carers Legislation will enable more people who would benefit from support to access it.

HIV Scotland understands that the eligibility framework would be set out in regulations or guidance rather than in primary legislation. As such, we would expect that the eligibility criteria would be developed through consultation with carers, communities and carers organisations. Any criteria should be specific to the needs of carers and account for factors such as the carer's health and employment status.

If a duty to support carers and young carers is introduced, it will be vital that local authorities have a discretionary power to support carers and young carers where they do not meet the criteria for the eligibility framework.

Question 12: Alternatively, should we retain the existing discretionary power to support carers and young carers?

Yes

No

Comments:

Question 13: Should we introduce a duty to provide short breaks?

Yes

No

Comments: See points pertaining to eligibility criteria provided in response to question 11.

## Stages and Transitions

Question 14: Should we issue statutory guidance on the Carer's Support Plan which will include guidance for those undertaking the Carer's Support Plan on managing stages of caring? This would apply to adult carers only. (For young carers, practice guidance will be developed to support management of a Child's Plan through the stages of caring).

Yes

No

Comments:

Question 15: Should new carers' legislation provide for young carers to have a Carer's Support Plan if they seem likely to become an adult carer? Any agreed support recorded in the Carer's Support Plan would be put in place after the young carer becomes a (young) adult carer.

Yes

No

Comments:

## Carer Involvement

Question 16: Should there be carer involvement in the planning, shaping and delivery of services for the people they care for and support for carers in areas outwith the scope of integration?

Yes

No

Comments:

HIV Scotland fully supports the principle that carers should be involved in the shaping and delivery of services. However, we believe that HIV services should be focussed on the best interests of people living with HIV and when planning health and social care services, the needs of the carer should not be prioritised over those of the person being cared for.

There are some of examples of good practice involving people living with HIV in service planning. For example, there is a very successful patient involvement group based at the Brownlee Centre in Glasgow. HIV Scotland also welcomes proposals in the Scottish Government's Community empowerment Bill to better engage with communities in the planning and delivery of services.

Question 17: Should we make provision for the involvement of carers' organisations in the planning, shaping and delivery of services and support falling outwith the scope of integration?

Yes

No

In particular, HIV Scotland would like to see the third sector included as an equal partner in the planning, shaping and delivery of service.

Question 18: Should we establish a principle about carer and young carer involvement in care planning for service users (subject to consent) and support for themselves in areas not covered in existing legislation?

Yes

No

Comments:

Question 19: What are your views on making provision for young carer involvement in the planning, shaping and delivery of services for cared-for people and support for young carers?

Comments:

### Planning and Delivery

Question 20: Should we introduce statutory provision to the effect that a local authority and each relevant Health Board must collaborate and involve relevant organisations and carers in the development of local carers strategies which must be kept under review and updated every three years?

Yes

No

Comments:

Question 21: Should we introduce statutory provision to the effect that local authorities with Health Boards must take steps to ensure, in so far as is reasonably practicable, that a sufficient range of services is available for meeting the needs for support to carers and young carers in the area?

Yes

No

For the proposed Carers Legislation to be effective, it will be essential that its implementation is supported by resources and the provision of quality services. The consultation document identifies that there is an underdeveloped market of providers to support carers with counselling, advocacy, short breaks and other forms of support. A statutory duty could therefore potentially help to develop and support the market.

### Identification

Question 22: Should there be no legislative provision for GPs or local authorities to maintain a Carers Register in order to support the identification of carers?

Yes

No

**Comments:**

HIV Scotland believes that placing a duty on GPs and local authorities to maintain carers register could be beneficial in helping more carers to access the support they are entitled to. However, for this to succeed it will be important that best use is made of existing processes and that the maintenance of the register is not time-consuming or onerous for GPs.

Furthermore, a register will not in itself mean that more carers are supported. Any register would have to be accompanied by guidelines around how to better identify carers and encourage people who have previously not wanted to be identified by support services to come forward. It can be particularly difficult for third sector organisations to identify young carers who may need support and a register might allow GPs and local authorities to refer these young people on to further services more easily.

While carers should be encouraged to identify themselves, it is paramount that the privacy of carers is maintained and that any system safeguards against the unwanted disclosure of a person's caring status or information about the health of the person being cared for. Preventing unwanted disclosure can be of particular importance to people living with HIV because of the stigma associated with the condition.

More detail is required with regards to who might have access to the carers register, how it would be used to point carers to particular services and assurances as to how people could maintain control over their information.

Question 23: Should the Scottish Government ensure that good practice is widely spread amongst Health Boards about the proactive use of Registers of Carers within GP practices?

Yes

No

**Comments:**

Question 24: Should the Scottish Government ask Health Boards to monitor compliance with the core contractual elements of the GP contract?

Yes

No

**Comments:**

**Carer and Cared-for Person(s) in Different Local Authority Areas**

Question 25: What are the views of respondents on the lead local authority for undertaking the Carer's Support Plan and agreeing support to the carer where the carer lives in a different local authority area to the cared-for person(s)?

**Comments:**

Question 26: What are the views of respondents on which local authority should cover the costs of support to the carer in these circumstances?

Comments:

Question 27: Should the Scottish Government with COSLA produce guidance for local authorities?

Yes

No

Comments: