



The Case for Social Care for People with HIV

The need of many people with HIV for social care is well understood and accepted

From the outset of the HIV epidemic it has been acknowledged that people with HIV have a high level of social care need. This is well known amongst people with HIV themselves, healthcare and social care workers and the HIV voluntary sector, and is also clearly accepted by the Government. In 2010 the Government announced that there would remain a budget allocation specifically for HIV social care within the local authority grant (the only remaining condition-specific budget-line), rising from £25.5 million in 2010/11 to £36.2 million in 2014/15.

Social care need amongst people with HIV has changed over the last 30 years but remains substantial

Over the last 30 years social care needs for people with HIV have changed, but they have not gone away, they remain substantial and very frequently experienced. In the early days of the epidemic social care was often around supporting people with a terminal condition, and their carers.

Now there are still, for some, physical needs which require care support, but there are also, for example, widespread psychological/emotional support needs,¹ often linked to questions of stigma, disclosure, the shock of diagnosis, and social isolation. A high proportion of people with HIV now have parental responsibilities - social care supports parents with HIV in dealing with social isolation and the demands of their caring role.²

There are also needs related to poverty and associated issues, be it housing, benefits needs, financial problems, and dealing with the immigration system. People with HIV are disproportionately affected by poverty - between 2006 and 2009 one in six of all people with diagnosed HIV had to approach the Hardship Fund (a charitable fund providing emergency cash support for urgent cases of need) for assistance. On average their income after housing costs was £42 per week.³

There are a wide range of services social care can provide which assist people with HIV in living independently and playing a full part in society

Social care can be provided in many forms - specialist social workers, who give invaluable assistance to improve access to other services (such as housing and benefits), peer support, counselling, personal care, support for carers and respite care. In addition to generic local authority social care services there has been innovative use of specialist social care workers and voluntary sector organisations to provide tailored support.⁴

¹ For more information see NAT, *Psychological support services for people living with HIV* (2010), Harding, R Lampe FC, Norwood S, et al. *Symptoms are highly prevalent among HIV outpatients and associated with poor adherence and unprotected sexual intercourse*. *Sex. Transm Infect* (2010), Sigma Research, *What do you need? 2007-2008: findings from a national survey of people living with HIV* (2008) (www.sigmaresearch.org.uk)

² See 'Responsibility for children' in NAT and THT 2010 *Poverty and HIV 2006-2009*

³ NAT and THT 2010 *Poverty and HIV 2006-2009*

⁴ See NAT 2009 'The AIDS Support Grant: Making a difference?' and NAT 2011 *The role and impact of social care support for people living with HIV*

Social care for people with HIV makes a difference as to how well people manage their condition

In a survey of HIV clinicians undertaken by NAT, the significant majority stated that social care helped their patients, for example in coping with diagnosis, adhering to treatment, in psychological and emotional well-being, and in meeting physical care needs. A wide range of services were found to be helpful including specialist social work support, peer support, counselling, support for carers and personal care.⁵

Social care for people with HIV reduces the likelihood of them passing HIV on to sexual partners

Clinicians responding to the NAT survey cited safer sex as one of the benefits of social care for people with HIV. Support in coming to terms with diagnosis and in disclosure of status, as well as in improved mental and emotional well-being, are all linked to safer sex. Another key benefit of social care is support in adherence to medication.⁶ It is proven that people with HIV who adhere to their treatment and so achieve an undetectable viral load are extremely unlikely to pass HIV on to sexual partners. On the other hand, those who do not adhere to treatment see viral load increases which make them more likely to transmit HIV.⁷

Social care for people enables people with HIV to play a full, active and productive part in society

Thanks to advances to treatment people with HIV can now play a full and productive part in society. Social care can assist individuals in getting through difficult periods, or in coming to terms with their condition and any ongoing health challenges. A key NHS Outcome Indicator will be employment rates among people with long-term conditions, including people with HIV. Well-judged social care can assist in the reintegration of people with long-term conditions into society, allowing them to make productive contributions to the local community as employees, volunteers and family members.

Social care for people with HIV reduces costs to the public purse which would otherwise arise from severe ill-health and further HIV infections

Social care means people adhere better to their treatment and manage their condition well. Poor adherence and condition management can result in treatment failure and serious ill-health which cost far more both in terms of the drugs needed and in terms of stays in inpatient care.

It is estimated that one HIV transmission in the UK results in a direct lifetime healthcare costs of between £280,000 and £360,000, and this does not take account of associated social and economic costs of that person's ill-health nor costs relating to any other people that person may pass HIV on to. Good social care for people with HIV is part of good HIV prevention - failures in social care can bring high costs as a result of increased HIV transmission.

⁵ NAT 2011 '*The role and impact of social care support for people living with HIV*

⁶ Harding, R Lampe FC, Norwood S, et al. *Symptoms are highly prevalent among HIV outpatients and associated with poor adherence and unprotected sexual intercourse.* Sex. Transm Infect (2010)

⁷ See NAT 2011 '*HIV treatment as prevention*'

The current challenge

Social care services are being cut across many local authorities, and are being limited only to the most severely disabled individuals. There are reports of specialist HIV social care services being cut. There is a real danger that social care for people with HIV becomes inaccessible. The case needs to be made strongly that -

- The combination of physical, psychological and social factors mean that people with HIV very frequently have social care needs, which should be addressed
- The Government has made clear that it is not intended or acceptable to limit social care to only the most acute cases⁸ - social care has a vital preventive function
- There is an increased emphasis on effective coordination of social care and healthcare, especially for people with long-term conditions - local authorities need to explore with HIV clinics how social care locally can best be integrated with healthcare for people with HIV and how best it can support people in staying well
- There will be in the long-run increased costs to local health and social services from failures to meet lower level social care needs now
- Part of the local authority Formula Grant is earmarked (although not ring-fenced) for HIV social care - this means local authorities should undertake some assessment of HIV social care need in their area and how best to meet it. It means spending the allocated sum as intended on HIV social care or having a good evidence-based reason for any variation
- Assessment of local social care need should involve collecting views and information from people with HIV, voluntary sector organisations, local HIV clinics and other relevant healthcare providers on the need for and impact of social care for people with HIV
- Local authorities should consider, if necessary, pooling HIV specialist social care amongst a number of local authorities. This pooled HIV specialist social care would achieve cost savings and continue to provide expertise for complex cases and for social worker training purposes.
- Local authorities should also use high quality voluntary sector services to provide low threshold open-access social care support for people with HIV

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⁸ Department of Health 2010 'A Vision for Adult Social Care: Capable Communities and Active Citizens' p.9, para.3.2