

Report: July 2009

The AIDS
Support Grant:
Making a
difference?

Executive Summary

In 2008/09 NAT (the National AIDS Trust) carried out a review of the AIDS Support Grant to identify how the Grant is being used by local authorities and to highlight examples of good practice. The review involved 106 local authorities (out of a possible 150) as well as 30 voluntary sector organisations supporting people living with HIV.

Findings:

- The importance of this unique source of funding which is providing social care services to many people living with HIV in England. The survey discovered that many of the services funded by the Grant were those that people living with HIV identified as most needed. Many services are open to anyone in that area with an HIV diagnosis, a factor which is particularly important when you consider the fluctuating nature of HIV and the difficulty many people have in accessing mainstream social care support.
- Some local authorities are adopting innovative approaches to social care service design and partnership working. This illustrates what can be done with the Grant when local partners come together.
- The need to continue to ring fence **HIV social care funding.** There was a clear sense from respondents that services may not continue if the Grant was no longer ring fenced.
- Areas where improvement is needed. Of particular concern was the fact that half of local authorities had not carried out any form of needs assessment before deciding how to use their Grant.
- An absence of reporting and transparency measures about how the Grant is used in the majority of local authorities. The continued reduction of central reporting requirements on the Grant has not been matched in the majority of local authorities by improved accountability to local communities, certainly in terms of the way the Grant is used.

Recommendations:

The report ends with specific recommendations for local authorities, the Department of Health (DH) and for people living with HIV and the voluntary sector organisations that support them.

The overarching recommendations are summarised below - detailed recommendations can be read in full at page 23.

- Maintain and increase ring fenced funding to meet the social care needs of people living with HIV. The report highlights both the continuing and significant level of need for social care support, as well as the range of social care services provided through the Grant. This demonstrates how vitally important it is to maintain ring fenced funding for social care for people living with HIV.
- Improve local authorities' needs assessment processes. The review revealed that many local authorities need to carry out proper needs assessments for HIV services involving people living with HIV and the organisations that support them in the process.
- Share and develop models of good practice and partnership working. The report identified some examples of good practice and partnership working but both the DH and local authorities could do more to share innovative approaches and ensure good practice around partnership working is built on.

- Improve accountability and transparency about how the Grant is used. The lack of accountability and transparency about the way local authorities spend the Grant was one of the most concerning findings from the review. Local authorities need to do more to inform their local community about how money ring fenced for the social care needs of people living with HIV is used.
- Include HIV social care needs in the wider local agenda. Current Government policies place an increasing emphasis on local government identifying local priorities. It is therefore vital that local authorities, people living with HIV and the voluntary and community sector organisations that support them, ensure HIV is considered when carrying out wider assessments of need (for example Joint Strategic Needs Assessments) and when setting local priorities.

Introduction

Since the AIDS Support Grant (ASG) was introduced in 1989 both the social care needs of people living with HIV, and the social care infrastructure that is designed to meet these needs, have changed dramatically.

Though improvements in treatment mean that many people living with HIV can expect to live into old age, social care needs have changed, not disappeared. The ASG therefore remains a unique and important source of funding for this community.

However, the drive to reduce the reporting burden of local authorities to central Government has led to a reduction in the monitoring of the Grant and reduced reporting as to how the funding is spent.

NAT therefore decided to undertake a review of how the Grant is used by local authorities. As a policy organisation that receives no ASG funding and does not deliver services on behalf of local authorities, NAT felt well placed to conduct this review.

The decision to review the ASG coincided with the DH's announcement in December 2007 of an increase in funding for the Grant of an additional £17.6m or 20% over three years.1

This welcome increase in funding made it even more important to have a picture of how local authorities are using the

NAT's review also aimed to identify examples of good practice and to develop recommendations for local authorities about how the Grant can be used to have the maximum impact for people living with HIV in the future.

This report begins by setting the review in the context of wider social care reforms in England. It looks briefly at the specific social care needs of people living with HIV before analysing the findings of the review in detail, setting out examples of good practice.

The report ends with a series of recommendations setting out what steps need to be taken to secure and improve social care for people living with HIV in the future.

What is social care?

The DH define social care as:

"the wide range of services designed to support people in their daily lives and help them play a full part in society.

It includes a range of practical services such as home care, day centres and residential and nursing homes.

It can include practical assistance to help individuals overcome barriers to inclusion, such as supported entry into work for an individual with a mental health problem, a personal assistant to enable a disabled person to lead a full and active life or supporting a person with a learning disability to play a full part in their local community.

It can include support in managing complex relationships and emotional distress.

Social care includes services directly commissioned by the local authorities and those services which an individual or family organise and commission themselves."2

^{1:} This increase meant that the Grant allocation from 2008 - 11 is as follows: 2008/09 - £19.8 million; 2009/10 - £21.8 million; 2010/11 - £25.5 million.

^{2:} Department of Health (2005), Independence, Well-being and Choice, www.dh.gov.uk.

1. A brief overview of social care

The DH estimate that at any one time 1.5 million people in England are relying on social care workers and support staff for assistance. Serving these people are 25,000 employers from the public, voluntary and private sectors with over one million staff. The provision of social care is the responsibility of the 150 local authorities across England (Northern Ireland, Scotland and Wales have a different social care infrastructure). Local authorities spend over £10 billion a year on social services (approximately 70% on community care services for adults and 30% on services for children). This funding is sourced partly from funds raised through council tax and partly through the Revenue Support Grant allocated by central Government.3

1.1 Social care assessment

Local authorities ask individuals to go through an assessment process to decide if they qualify for council funded care and support. In 2003 the DH produced guidance on this assessment process, Fair Access to Care Services (FACS).4 This provides a framework for councils setting their eligibility criteria for adult social care assessments. This framework was designed to lead to fairer and more consistent eligibility decisions about social care across England. The framework has four eligibility bands (critical, substantial, moderate and low) based on individuals' needs and associated risks to independence. The pressure on local authority budgets means that most people are only eligible for social care if their needs are assessed to be 'critical' or 'substantial'. In January 2008 the Commission for Social Care Inspection (CSCI) was asked by the DH to undertake a review of these eligibility criteria. In their subsequent report, Cutting the cake fairly, they highlighted the need to ensure that everyone can access an assessment of their support needs.5 They also recommended a revision of the current eligibility criteria to increase transparency and consistency so there is a common framework for deciding who is a priority for publicly funded support. The Government's response to this review recognises the need for 'a transparent, open and fair system' and commits to working with key partners to revise existing guidance.6

Currently there are several models of paying for social care. Some people pay for all social care services themselves, others make a contribution to their care with the local authority paying the rest and others rely solely on the local authority to fund their care (for example 70% of older people living in care homes get all or some of their costs met by their local council).

1.2 Planning and regulating social care

Until recently CSCI regulated, inspected and reviewed all adult social care services in the public, private and voluntary sectors in England. The Commission was responsible for Comprehensive Performance Assessments (CPA) and allocated local authorities a performance rating (the star rating) for adult social care. Under the CPA system local authorities were awarded 0 to 4 stars based on the quality of their services and their management. Highly-rated councils and their partners were granted extra freedom over what they could do.

In April 2009 the new Care Quality Commission (CQC) took over the responsibilities of CSCI, the Health Care Commission and the Mental Health Act Commission.

The CPA system has now been replaced by the Comprehensive Area Assessment (CAA) where local authorities are assessed on their performance against outcome-focused national indicators. Local authorities work with partners to select and agree 35 indicators from a list of 198, which set out their priorities for action. This forms the basis of a three year Local Area Agreement (LAA) between the local authority and central Government. A number of the national indicators relate to social care, for example NI 132, timeliness of social care assessment and NI 133 timeliness of social care packages.

The process of developing an LAA involves local authorities bringing together local stakeholders in a Local Strategic Partnership (LSP).7 The LSP then works together with the local authority to carry out a Joint Strategic Needs Assessment (JSNA). The DH's core dataset signposts local authorities to a range of existing data sources to assist with the assessment process (including data on the number of new HIV diagnoses and number of late diagnoses).8 The assessment process should provide local authorities with the evidence they need to select national indicators for their LAA. JSNA should also be used to guide commissioning of services.9

^{3:} Department of Health website, www.dh.gov.uk.

^{4:} Department of Health (2003), Fair Access to Care Services, www.dh.gov.uk.

^{5:} CSCI (2008), Cutting the cake fairly: CSCI review of eligibility criteria for social care, www.carestandards.

^{7:} Local Strategic Partnerships (LSPs) are non-statutory, multi-agency partnerships, which match local authority boundaries. LSPs bring together at a local level the different parts of the public, private, community and voluntary sectors with the aim of allowing different initiatives and services to support one another so that they can work together more effectively.

^{8:} Department of Health and the Association of Public Health Observatories (2008), The JSNA Core Dataset, www.dh.gov.uk.

^{9:} For more information on Joint Strategic Needs Assessments see: Department of Health (2007), Guidance on Joint Strategic Needs Assessments, www.dh.gov.uk.

Local authorities' performance against their LAA is measured by the CAA process, led by the Audit Commission and involving the CQC and other Inspectorates. Part of the CAA assesses how local authorities have involved local communities in determining their priorities and local decision making. JSNAs are also a key piece of evidence considered during the CAA. The first CAAs will be available in November 2009.

Additional overview and scrutiny procedures are in place (set up under the Local Government Act 2000) that allow non-executive councillors to hold the local authority executive to account for their performance and the performance of the authority. Overview and scrutiny committees are free to undertake reviews into a wide range of subjects and members of the public are increasingly being encouraged to suggest topics for review. Since 2000, subsequent legislation has broadened the remit of scrutiny committees and they can now scrutinise the performance of NHS trusts, including primary care trusts (PCTs).

The policy of bringing decision making closer to the community has also led to the development of Local Involvement Networks (LINks) which aim to give people a stronger voice in how their health and social care services are delivered. LINks are intended to find out what people want, monitor local services and to use their powers to hold them to account (for example, they can refer issues to local scrutiny committees if they have concerns which are not being addressed).

1.3 The 'personalisation' agenda and the future of social care

The Government has set out to modernise the way social care is delivered. They have developed a 'personalisation' agenda which puts an emphasis on people choosing their own support and controlling how resources are spent on their care. The Direct Payments and Individual Budgets initiatives are key levers in achieving this control.

The aim of these initiatives is to give more flexibility in how services are provided. Individuals are given money in lieu of social care services, giving them choice and control over how their care is delivered. The law has been changed so that it is now a duty for local authorities to make direct payments. This means that councils must make a direct payment to eligible individuals who are able to provide consent. 10 Direct payments should be discussed as a first option at each assessment and each review. Individual Budgets build on Direct Payments; the difference is that Individual Budgets include a number of income streams brought together to give the individual a joined-up package of support and reduce the need for multiple assessments.

The Government is also considering the future of social care. The Government's recent report The Case for Change: Why England Needs a New Care and Support System, highlights the fact that in the next 20 years the number of people aged 85 and over will double.

In addition to rising life expectancy, advances in treatment mean that disabled people can live longer and healthier lives. There are consequences to these successes and the report projects that by 2028 an additional 1.7 million people will require social care support. The DH estimates (based on Personal Social Services Research Unit projections) that this will leave a funding gap of more than £6 billion by 2027 which raises questions about the sustainability of the current social care system.11

The Government's recently published Green Paper on the future of social care builds on previous proposals setting out reforms to promote independence and control for those in need and improve assessments and information and advice. There is an increased focus on joined-up work between health, housing and social care services. It also looks at the question of affordability for taxpayers, exploring options for a new settlement between individuals, family and the state.12

^{10:} Direct payments can be made to disabled people aged 16 or over, to people with parental responsibility for disabled children and to carers aged 16 or over in respect of carer services

^{11:} Department of Health (2008), The Case for Change: Why England needs a new care and support system.

^{12:} Department of Health (2009), Shaping the future of care together, www.dh.gov.uk.

2. HIV and social care

The improvements in treatment mean that the social care needs of people living with HIV are changing. Many people no longer need support to the same extent as they did in the past as new treatment options enable them to live active and full lives. However, people are surviving into old age and are likely to have more complex social care needs in the future.

Recent Health Protection Agency (HPA) figures show that of the people living with HIV accessing health care in the UK in 2007, 15% were over 50. The number over 50 accessing care has grown from 1,679 in 1997 to 8,722 in 2007.13

Despite improvements in treatment, there are times when the health of people living with HIV may fluctuate and they need help. A recent research report looking at social and economic hardship among people living with HIV found that 41% of black African heterosexual women and 39% of black African heterosexual men did not have enough money to cover their basic needs.14 In addition, 20% of black African heterosexual women and nearly 15% of black African heterosexual men had moved home at least three times in the previous three years.

The study discovered that for black Africans living with HIV in the UK, social problems are at least as important in shaping their lives as their HIV status. Although the study found that white homosexual men were less likely to report social and economic hardship, one in ten said they did not have enough money to cover their basic needs.

The recent report from Sigma Research, What do you need?, summarises the findings of their national survey of needs of people living with HIV. 15 16 The findings reveal that over 70% of respondents had had problems with anxiety and depression and self confidence in the last year.

Of those that had experienced anxiety or depression related problems, 56% felt further help or support would be useful (and 23% had not received any help with their problems). Additional counselling and access to local support groups were just some of the examples people gave of the extra services they would like to see.

Sigma's findings around mental health needs are of particular concern given the significant evidence of the impact of mental health problems and the associated stress on treatment adherence and wellbeing.

Although HIV treatment is very effective, at least 95% adherence to treatment is required. Even one or two missed doses can be seriously problematic both for efficacy of therapy and in preventing drug resistance. In a mortality audit conducted by the British HIV Association (BHIVA) for 2004/05, 27 deaths out of a total of 387 were directly attributable to poor adherence to treatment.17

What do you need? also identified concerns about self-care and household chores; 27% of respondents had ongoing problems in this area and felt that further help or support would be useful. Within this, specific suggestions included receiving greater support to navigate the complex social care system and improving communication between clinicians and social care providers.

"Over 70% of all respondents had had problems managing anxiety or depression in the previous year."18

^{13:} Health Protection Agency (2008), HIV in the United Kingdom: 2008 Report, www.hpa.org.uk.

^{14:} Elford J, Ibrahim F, Bukutu C, Anderson J (2008), Social and economic hardship among people living with HIV in London, HIV medicine 2008: 9:616-624

^{15:} Weatherburn P, Keogh P, Reid D, Dodds C, Bourne A, Owuar J, Hammond G, Jessup K (2009), What do you need? 2007-2008: findings from a national survey of people living with HIV, www.sigmaresearch.org.uk.

^{16:} Sigma do point out that their sample has a relatively low proportion of black African respondents, especially among women. Even so, these findings still reveal an interesting pattern of need within target populations and broad patterns across the sample, particularly around mental health needs.

^{17:} BHIVA (2006), Mortality Audit September 2004 –October 2005, www.bhiva.org.

3. The AIDS Support Grant

The ASG is seen to be a particularly important funding resource for people living with HIV as there is concern that people living with HIV have difficulty in accessing appropriate mainstream social care.

Publicly funded social care is not normally allocated to a medical diagnosis but to support the social care needs that people present. The ASG is an exception which does allow resources to be allocated for HIV specific services.

The Grant was introduced in 1989 as part of the DH's measures to help local authorities manage the needs of people living with HIV. The DH decides how much Grant to allocate to each local authority by using a 70:30 ratio formula; 70% of available funding is allocated to authorities on a pro rata basis depending on the number of people diagnosed with HIV in their area, and 30% of the available funding is allocated to provide extra support to women and children as they are considered to have more complex social care needs.

This is a relatively new funding formula; originally funding was allocated according to the number of people with an AIDS diagnosis in an area. As treatment improved, this was changed to include people diagnosed with HIV and then adapted to take account of the perceived greater care needs of women and children.

In 2008/09 the size of grants given to local authorities ranged from £2,000 (Rutland) to £860,000 (Lambeth). A DH circular set out the aims of the Grant as follows:

- To enable Social Services Departments to draw up strategic plans, based on local population needs assessments, for commissioning social care for people living with HIV and AIDS; and
- To enable Social Services Departments to finance the provision of social care for people with HIV and AIDS and where appropriate, their partners, carers and families.19

Although the aims emphasise the drawing up of strategic plans, the recent Government move to reduce the administrative burden on local authorities means that no evidence of strategic planning is required. The need for local authorities to provide detailed expenditure plans was abolished from 2003.

Under the CPA assessment process local authorities that were performing well receive a set of freedoms, with the aim of providing an incentive for all authorities to improve.

Local authorities with a CPA score of three or four have no conditions attached to their ASG payment.20 In 2008, 83% of local authorities achieved a CPA score of three or four. 2

Until 2008/09 local authorities with a CPA score of one or two and an ASG of over £50,000 were required to complete a final statement to ensure the Grant has been expended for the purposes intended. However, this statement required minimal reporting and provided limited accountability.

FACT

In 2008/09 the size of the Grant given to local authorities ranged from £2,000 to £860,000.

The move away from monitoring was an important factor in NAT's decision to review how the Grant is being used. The review of the Grant looked at the year 2007/08 and 2008/09. It is of note that in the year 2008/09 all reporting requirements were lifted as part of the transition between the CPA process and the CAA. It is currently unclear whether, when the CAA system is in place, some reporting requirements will be put back in place.

The DH facilitate regional HIV social care forums to assist local authority social care commissioners and practitioners in sharing best practice and information about use of the Grant.

In addition to the ASG, £3.1 million is available to local authorities for HIVrelated housing and capital projects in the form of the HIV capital grant. Local authorities can submit applications to the DH for funding. Housing schemes that enable people living with HIV to live independently are given particular priority.²²

^{19:} Department of Health (2007), AIDS Support Grant for social care for people living with HIV/AIDS: Financial year 2007/2008, Local Authority Circular, www.dh.gov.uk.

^{20:} Note that Comprehensive Performance Assessments have been replaced by Comprehensive Area Assessments.

^{21:} Audit Commission (2008), CPA - The Harder Test, www.audit-commission.gov.uk.

^{22:} Department of Health (2009), AIDS Support grant for social care for people living with HIV/AIDS: Financial year 2009/2010, Local Authority Circular, www.dh.gov.uk.

4. The AIDS Support Grant review

4.1 Methodology

Phase one

The first stage of the review process involved interviewing a range of stakeholders who have been involved with the Grant. These included DH officials, local authority social care commissioners, HIV specific social workers and voluntary sector organisations.

Phase two

The findings from these interviews led to the development of a questionnaire. The questionnaire was piloted with six local authority commissioners and then amended.

Phase three

The final version of the questionnaire was endorsed by the Association of Directors of Adult Social Services and sent to the HIV social care commissioner in each local authority in England. The questionnaire stated that all responses would be anonymised. A copy of the questionnaire is available on request.

Phase four

Following the methodology used to develop the local authority questionnaire, a questionnaire for voluntary sector organisations was designed and piloted. The questionnaire was then sent out to 150 voluntary sector organisations; one in each local authority.

4.2 Sample description

A total of 106 local authorities responded to the questionnaire. This was a response rate of 71% of the local authorities who received the Grant at the time.

Of those local authorities that responded, 35 were local authorities with a CPA score of four (33%), 47 had a score of three (44%), 23 had a score of two (22%) and one had a score of one (1%).23

This is roughly in line with the distribution of CPA scores amongst local authorities across England as a whole, where in 2007, 55 had a CPA score of four (37%), 69 had a score of three (46%), 23 (15.5%) had a score of two and two had a score of one (1.5%).

In terms of percentage of the ASG funding, those that responded to the questionnaire accounted for 81% of the amount of ASG in 2008/09. The table opposite sets out the reported CPA score of the local authorities that responded.

Although questionnaires were also sent to voluntary sector organisations in every English local authority area, the response rate was not as high as for local authority respondents. Thirty voluntary sector organisations responded. This was a response rate of 20%. Of the thirty respondents, 22 provided services in local authorities that had also responded to the questionnaire; nine were based in local authorities that had not responded.

Clearly the responses from voluntary sector organisations have some limitations. Whereas the local authority is solely responsible for the ASG in their area, the voluntary sector respondents will only have a limited view of how the ASG is used in their area. Also, the small number of responses means that it is not possible to draw firm conclusions, instead these findings should be seen as a snapshot of the experiences of some voluntary sector organisations at this time.

4.3 Research findings

The level of reporting required by the DH varies according to the CPA score of local authorities. NAT decided to analyse the findings from the local authority questionnaires according to their CPA score to see whether the need to report back on activities to the DH had any relation to the quality of social care provided. In addition we were interested to identify whether the CPA score of a local authority was a good predictor of the quality of their HIV social care provision.

NAT also compared the findings of those local authorities that receive large amounts of ASG funding (with large populations of people living with HIV) with those that receive smaller grants (with smaller populations of people living with HIV) to see whether this impacted on the way the Grant was used.

The analysis revealed that, with the majority of questions, neither the CPA score nor the size of grant was a good predictor of the content of a local authority's response. Where it did appear to influence the response, this is indicated in the discussion below.

TABLE 1

Summary of CPA score of local authority (LAs) respondents				
CPA score	CPA score	CPA score	CPA score	Percentage of
of four	of three	of two	of one	Grant represented
35 LAs	47 LAs	23 LAs	1 LA	81%

4.3.1 Knowledge of the local community

The questionnaire began by looking at local authority commissioners' knowledge of the number of people living with HIV in their area. SOPHID data which provides this information is easily available from the Health Protection Agency (HPA).²⁴ However only six local authorities (5%) referred to this data as a source (or had an exact match with the HPA figure indicating that they had used it as a source).

More encouragingly, nearly a third (32%) of local authorities' estimates of the number of people living with HIV within their area were within 5% of the SOPHID data, indicating a good knowledge of their local HIV population.

Fourteen local authorities were not able to provide an answer (13% of respondents). Others estimated a number that was very different from the SOPHID data. To give two examples, one local authority's figure was 62% lower than the SOPHID data (279 rather than 736) whilst another was 67% higher than the SOPHID data (1659 rather than 995).

These findings are concerning as they indicate that many local authorities are unaware of the data available to help them with planning needs assessments and the commissioning process. Figures provided were often based on service user numbers indicating that many local authorities had not considered people who were not accessing services but may have unmet needs.

Where local authorities provided a number significantly higher than the SOPHID figure based on known service users, this could indicate that people resident in another local authority were accessing their services. In some cases it is possible that the SOPHID data did not reflect the current population because of a recent increase in the number of people living with HIV moving into the area.²⁵ But this cannot account for the very large disparities seen in some local authorities' responses.

GOOD PRACTICE

One local authority was concerned about the lack of African people coming forward to access support services. They used the ASG to fund an **African Community Outreach Worker who has** played a key role in identifying people living with HIV who need support and who are now being assisted with a range of services from housing support to personal care.

4.3.2 Grant allocation formula

The questionnaire looked at whether local authorities felt the Grant allocation formula was equitable.

As set out previously, 70% of the Grant is allocated according to the number of people living with HIV in an area. The other 30% is allocated according to the number of women and children in that area, as they are considered to have higher social care needs.

Eighty percent of local authority respondents felt that the allocation formula was equitable; 20% disagreed.

There was no notable difference in the views of local authorities with a CPA score of one, two, three or four, though those with larger grants (over £400,000) were less likely to question the effectiveness of the allocation method than those with smaller grants.

Several of those that did feel that there was a problem with the allocation formula cited grave concerns around the accuracy of SOPHID data, particularly its inability to keep up-todate with changes in the population.

One local authority stated: "It would be better if the allocation system was able to take into account some estimate of the transient population, for example students, migratory workers and asylum seekers."

One London borough noted the additional cost of providing services for black African communities because they are 'hard to engage with'. They indicated that local authorities with large black African populations should be granted additional funding to compensate for this cost.

Several respondents felt the Grant allocation process should be based on a needs assessment submitted by each local authority.

They noted that a local authority with a large number of people living with HIV 'doing well' could have lower social care costs than another area with a smaller population with greater social care needs (for example a local authority with a black African community where people are often diagnosed late and may have significant social care needs).

Others noted that the current method did not account for people who access services across county borders.

4.3.3 Department of Health guidance

The questionnaire also asked whether the DH provided sufficient guidance for the use of the Grant.

Overall, 79% stated that the current guidance was sufficient. Local authorities with a CPA score of one or two were more likely to request further advice.

One local authority felt that more specific guidance might ensure the money went to the people it is intended for: "The guidance is vague, it does not help with commissioning as it is so flexible and means money does not always get to the people it needs to get to."

Another respondent requested examples of innovative services that other local authorities had commissioned, particularly ideas for joint working with PCTs.

It was of concern that, as set out opposite, one local authority respondent felt that perceived lack of guidance allowed local authorities to spend the money on other areas.

4.3.4 Is ASG funding always spent?

Fourteen percent of local authorities had not spent their entire ASG allocation. Where local authorities gave reasons for this, these included fluctuating need, cases where a service had been agreed but the provider had pulled out at the last minute and the desire to roll money over to pay for a multi-year contract.

More worryingly, one local authority had not used the Grant because there was no commissioner in post.

In contrast 25% of local authorities supplemented ASG funding with other funding sources to pay for social care for people living with HIV, most commonly from wider adult social care funding streams.

Local authorities with a CPA score of three or four were more likely to use other funding streams than one and two star authorities.

I feel that authorities think that they can spend the ASG on what they want, especially if they are a three star authority. I feel the ASG is used to support generic services when it could be used more creatively and constructively for services for people with HIV. It seems to me that the DH is not clear itself what it wants local authorities to spend money on.

A local overview

One local authority gave an overview of how they use the Grant in their area to provide social care services.

Key to success is partnership work between health colleagues, social care providers and voluntary organisations. There is a fulltime specialist social worker who works solely with people living with HIV.

If people need help, the first stage is a community care assessment which identifies what someone's needs are.

The next stage is to develop a care-plan with aims and objectives to help that person live as independently as possible in the community. The care-plan is then put into place and reviewed with the service user on a regular basis.

In addition two voluntary sector organisations (part funded by the Grant) provide services to anyone with an HIV diagnosis in the area.

They offer a range of services including: peer support; immigration, benefit and return to work support; adherence support; drop-in sessions; outof-hours services (for example home visits); complementary therapies; hardship grants; and respite breaks.

4.3.5 Needs assessments

NAT was particularly interested to see whether local authorities had carried out a needs assessment before deciding how to use their ASG funding.

The number of local authorities unaware of SOPHID data already indicates that many social care commissioners are unaware of important tools available to them when looking at what needs there may be within their community.

The findings from the questionnaire found that 51% of local authorities had carried out a needs assessment (see graph 1).

Whilst it is encouraging to see that half of those who responded had carried out a structured assessment, it is clearly of concern that 49% had not, particularly given the recent focus on the need for local government to carry out needs assessments (for example JSNAs).

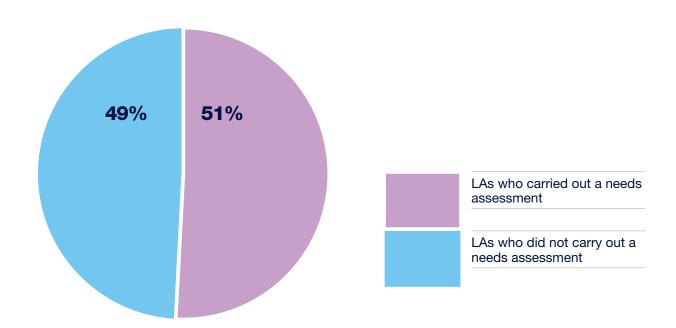
This trend was reflected across local authorities and there was little difference between local authorities with a CPA score of one, two, three or

However, it was reassuring that the two local authorities that received more than £600,000 who responded had both carried out a needs assessment.

49% of local authorities had not carried out a needs assessment.

Where a needs assessment had taken place, 43% of local authorities had consulted with people living with HIV and the voluntary sector, and a further 39% had consulted with health and social care staff.

Graph 1



Of the organisations that responded to the voluntary sector questionnaire, a third of organisations were aware of a needs assessment being carried out by their local authority, and in most cases had been involved in the process.

The questionnaire went on to ask respondents whether they felt their local authority could improve the planning process behind the use of the ASG.

One voluntary sector respondent indicated that planning for how the ASG would be spent happened too late in the year and caused unnecessary pressure because of the lengthy and complicated tendering processes that followed.

Another organisation felt the local authority put too much funding into statutory services that the local ethnic minority communities do not want to or cannot access - they felt more money should be put into innovative community services.

One organisation noted that because their local authority received a relatively small Grant it was seen as a low priority, which meant that insufficient planning was put into how the money was used.

By contrast, another organisation was encouraged by the planning process and felt there was nothing more that could be done:

"It's very refreshing to have a Commissioner who is on the ball and has a real commitment to improvements for people living with HIV."

GOOD PRACTICE

One local authority commissioned the Institute for Health Research at the University of Luton to undertake an assessment of the support needs of people living with HIV in their county. The research involved mapping of local services, a survey and in-depth interviews with people living with HIV and a focus group with specialist HIV service providers.

Another local authority used the DH's guidance, How to guide: sexual health needs assessment to structure their assessment. The process included focus groups, individual meetings, key informant interviews, data reviews, user consultation, community representation, service mapping and site visits.

4.3.6 What services is the ASG funding?

The questionnaire findings reveal the wide range of services being funded by the Grant (see graph 2). Nearly two thirds (63%) of local authorities were providing personal care for people living with HIV through the Grant. Almost half (47%) were providing respite care; this was less common in local authorities with smaller grants. This pattern was echoed with residential care. Overall just under a third (29%) of local authorities provided residential care funded by the Grant but this was more common in local authorities with a bigger grant (over £200,000).

In contrast 91% of local authorities provided counselling services for people living with HIV. Peer support was also widely available, with 82% of local authorities providing this.

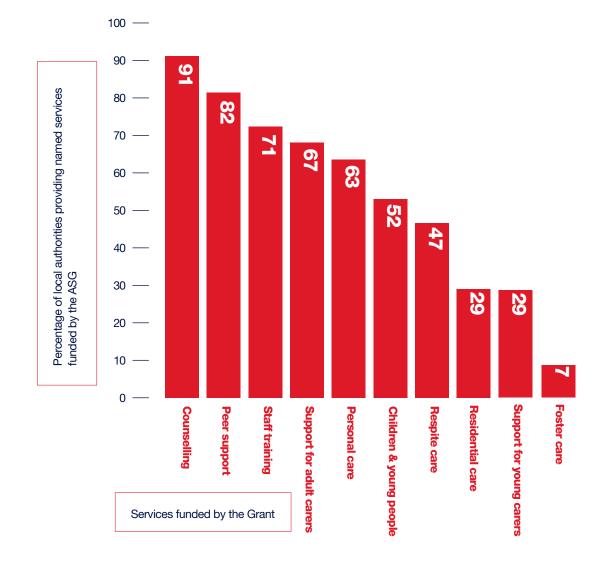
The questionnaire also looked at services for children and young people. Over half of local authorities (52%) provided services for this group, with almost a third (29%) providing support for young carers. Foster care was provided by a minority of local authorities (7%). It is unclear how the recent structural separation of adult and children's services has impacted on services funded by the ASG for either group.

Support for adult carers for people living with HIV was more common with two thirds (67%) of local authorities providing services for this group.

Staff training was also funded by the Grant in 71% of local authorities. Local authorities provided very little information about what this involved.

The ASG funds counselling services for people living with HIV in 91% of local authorities.

Graph 2



The questionnaire also asked local authorities to highlight innovative projects and practices made possible because of the ASG. Some of the examples provided are detailed in the side bar.

Voluntary sector organisations were asked to identify areas where further support was required for people living with HIV. Areas included housing and welfare support, job seeking support, respite care and counselling.

The DH have made clear the Grant is not to be used for the provision of prevention services. However, over half of respondents (56%) had used the Grant for wider HIV activities beyond the provision of social care. Of those, 26% indicated that they had used the Grant for prevention activities (often around World AIDS Day).

4.3.7 HIV specific social workers

Historically HIV specific social workers have had an important role in the social care provision for people living with HIV. However, anecdotal evidence suggests that these roles are disappearing as services are mainstreamed.

The findings from the questionnaire revealed that 58% of local authorities currently use the Grant to provide HIV specific social workers.

The provision of HIV specific social workers was more common in local authorities with grants over £200,000.

Some responses did indicate a move towards mainstreaming, with HIV specific social workers being phased out and people living with HIV being referred to generic social workers.

GOOD PRACTICE

Reaching out

One local authority use part of their AIDS Support Grant to fund a blood borne virus nurse to run a satellite clinic within their specialist prescribing service (part of their drug services). This innovative post ensures that service users living with HIV who are less likely to engage with mainstream social care services are able to access the support they need.

Taking a break

In a different local authority the ASG is used to fund residential retreats for people living with HIV and their families. The weekends involve peer support, complementary therapy and the chance for people to relax away from the difficulties of every day life.

Caring for carers

After carrying out a survey to look at the experiences and needs of carers of people living with HIV, one local authority decided to bring local HIV organisations and carers organisations together to develop a more joined up approach to providing services. They organised an information sharing and networking event at which these organisations were able to share good practice and knowledge, giving everyone a really good understanding of the issues for carers of people with HIV.

4.3.8 Who is providing services and how are they funded?

The questionnaire also looked at the percentage of funding that went to local voluntary sector organisations.

One concern is that any future reduction in the Grant may cause severe financial problems for these organisations. This concern is illustrated in the findings from the voluntary sector questionnaire responses where 93% received ASG funding as part of their income.

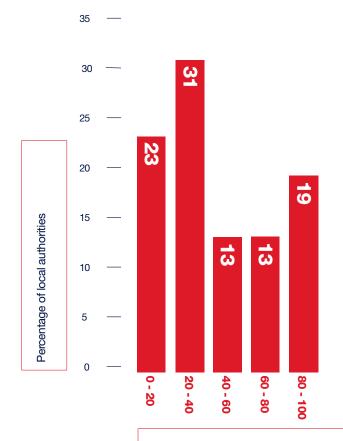
Fourteen percent of those local authorities who responded to this question, (12 local authorities), gave 100% of their grant to voluntary and community sector organisations. These local authorities were more likely to receive smaller grants, with 11 of the 12 having a grant of £100,000 or less.

The remaining local authorities used a substantial proportion of their grant to fund services provided by the voluntary sector. Nearly a quarter (23%) used 20% of their ASG to fund this sector, almost a third (31%) used 20-40%, 13% used 40-60%, 13% gave 60-80% and 19% gave 80% or more (see graph 3 below).

Funding the private sector was far less common with only 29 local authorities funding this sector. However, it is of note that two London local authorities with grants over £300,000 used 80% or more of their grant to fund private sector providers.

Funding was provided to external organisations in a variety of ways. Over a third (36%) of local authorities were funding services through a grant. The other main method of funding was through contracts.

Graph 3



Percentage of ASG used to fund voluntary sector organisations

In 1998 the Compact, an agreement between Government and the voluntary and community sector in England, set out guidelines for how both parties should work together.

The Compact highlights the importance of local authorities providing voluntary sector organisations with stable contracts to enable services to plan ahead and provide stability for their client group:

"Longer term planning and financial arrangements often represent better value for money than one year agreements by providing greater financial stability and by reducing the amount of time and effort wasted on applying for new funds or renegotiating contracts."26

However, 36% of local authorities used annual contracts when funding voluntary sector organisations. One voluntary sector organisation that receives 100% of its funding from the ASG in the form of annual contracts, noted the difficulty this uncertain funding mechanism causes for forward planning.

Some local authorities recognised the limitations of this funding method. noting that they were using this as a temporary measure whilst a full needs assessment was carried out.

More positively, 35% of local authorities used three-year contracts.

4.3.9 Partnership working

DH guidance highlights the importance of local authorities working in partnership with social services, housing, health commissioners and providers, voluntary and independent providers and service users and carers.

The questionnaire found that almost two thirds (60%) of local authorities had used the Grant to fund partnership work.

Most partnerships involved working with the local PCT, though several local authorities mentioned working with the voluntary sector.

Partnership working was more common in local authorities with a CPA score of three or four than those with a score of one or two. Some examples of partnership working provided by respondents are given in the side bar.

GOOD PRACTICE

In one area the local authority and PCT are working together to increase the impact of the ASG. They are joint funding a Children and Families HIV project worker to support children and parents at the point of diagnosis.

The project also includes a teen support group undertaking a range of activities as well as one to one support. In addition, the project works with the fpa to ensure parents have the support they need in talking to children living with HIV entering adolescence about sexual health.

In another area, the council are working in close partnership with THT, with shared premises and facilities and staffing arrangements, and professional social worker supervision of all aspects of HIV social care.

In another region several local authorities, PCT commissioners and local service providers have come together to form a partnership. They work together to provide HIV health and social care services that complement local clinical services for HIV. The partnership has created a range of services including "health trainers", community support staff who work within clinics to support adherence and patient-identified needs.

Outcomes and service user feedback are monitored and an integrated service network with clear care pathways has been developed. A **New Service Development Fund** ensures that provision is made to meet HIV-related needs not already covered as robust evidence of such need emerges.

4.3.10 Service evaluation and accountability

The questionnaire looked at whether local authorities evaluate services funded by the ASG. Encouragingly, 82% of local authorities had done some form of evaluation. In most cases this involved scrutiny of service providers and meetings to ensure that contracts were being delivered effectively.

Local authorities were also asked about what information they provided to the general public, including people living with HIV, about how the ASG is being used.

Twenty nine percent of local authorities said that there were no public monitoring or scrutiny processes in place. A further 29% ticked 'don't know'. Only 43% had any kind of public monitoring or scrutiny process in place. Of those local authorities that provided examples, the majority referred to Freedom of Information Act proceedings (which are actually available to any member of the public in any local authority).

It is of concern that local authorities felt that use of the Freedom of Information Act was an appropriate way to expect members of the public to find out about how the Grant is used, given the lengthy procedures involved. This indicates a lack of commitment to transparency. Other examples given included Council Scrutiny meetings and information displayed on council websites. There were two examples of good practice. One local authority's Local Involvement Network (LINk) had a specific sexual health and HIV workstream. Another local authority has set up an HIV Users Forum which scrutinised services funded by the ASG.

Although only 43% of respondents said that scrutiny processes were available, the Freedom of Information Act (FOI) allows anyone to make an inquiry into how the ASG has been used. Two organisations that responded to the voluntary sector questionnaire had actually made FOI requests to identify how the Grant was being used in their area.

One organisation described the outcome of their FOI request:

"Our FOI request showed the local authority are spending a large portion of funding on a residential drug rehab service who have no positive people in their care. They also fund another voluntary organisation who have ceased to provide services for people with HIV."

GOOD PRACTICE

In one area the Local Involvement Network (LINk) has committed to having HIV as an integral part of their work by setting up a specific workstream on sexual health and HIV. with a Sexual Health representative on the LINk steering group. This means that the local community have the opportunity to feedback on what they think about HIV health and social care services and influence future service development, including services funded through the ASG.

4.3.11 Impact of social care reforms on the ASG

The introductory section of this report outlined the developments in social care delivery. The questionnaire looked at how these changes are reflected in the way the ASG is used.

Direct payments were being used in 24% of local authorities, though this was mainly in local authorities with grants between £200,000 and £600,000. Local authorities with very large or small grants were less likely to be using direct payments in relation to the ASG.

One local authority commented that they had reservations about moving towards using direct payments as "it would be a threat to joint working with the voluntary sector.'

Local Area Agreements (LAA) and national indicators now play a pivotal role in how local authorities prioritise their activities and funding. Although there is not a specific performance indicator about HIV there are several which relate to social care including NI 130, NI 135 and NI 136, as well as NI 124 which refers to supporting people with a long-term condition.27



82% of local authorities had done some form of evaluation of how the Grant is used in their area.



NAT were interested to see whether local authority social care commissioners felt that the social care needs of people living with HIV were reflected in their current LAA or whether they should be in future agreements.

Overall, 32% of respondents felt that the social care needs of people living with HIV were currently included in their local authorities' LAA. However, 21% ticked 'don't know' and less than half of respondents (49) answered the second part of the question about whether people living with HIV should be included in the future, perhaps indicating a lack of knowledge about these reforms.

Of those that did respond, 53% felt that if it was not already included, it should be included in the future. Respondents gave reasons as to why it should be included as well as why it should not be. One local authority respondent felt that currently people living with HIV were not recognised as a group with specific needs and that it was therefore important to include them in the LAA.

Another noted "... it [HIV] should be an LA and PCT priority to ensure that we address inequalities in health." In contrast, a respondent from an area with low HIV prevalence felt HIV was not a priority given other competing issues. Others felt that HIV should not be picked out specifically as it should be covered by other indicators that look at general public health and social care needs.

4.3.12 Eligibility criteria

The questionnaire also looked at the eligibility criteria for people living with HIV accessing social care services.

As detailed in the introductory section, many people with social care needs, including people living with HIV, will not meet the very high thresholds councils set using the FACS criteria. This means that, although they may have significant needs, they may not be able to access services.

NAT wanted to find out if social care services funded by the ASG have different eligibility criteria to mainstream social care services. The findings from the questionnaire revealed that 45% of local authorities asked people living with HIV to go through a FACS assessment, using the standard eligibility criteria and thresholds, to see if they were eligible for local authority social care services and funding, despite the existence of 'ring fenced' funding for this group.

It is of note however that several local authorities who stated that people living with HIV had to go through the FACS system to access social care, elsewhere indicated that a substantial proportion of their grant funded voluntary sector services that are accessible to anyone with an HIV diagnosis. Follow up telephone conversations confirmed that, whilst the eligibility criteria for accessing local authority statutory services were the same for people living with HIV as other council residents, voluntary sector services funded by the Grant were open to everyone with an HIV diagnosis in their area.

Over half (55%) of local authorities indicated that they had different eligibility thresholds for ASG funded services. One local authority noted: "Clients are currently eligible due to their diagnosis as the ASG is ring fenced to the client specialism therefore automatically entitling them to a service from the local authority."

Another stated:

"As the funding is different from mainstream service provision we are able to be flexible in how our services are provided and to whom."

It was put most clearly by one local authority that said: "We do not assess for eligibility for social care funded by ASG, as often needs may fall below critical and substantial."

This suggests that access to these services for some people may not be automatic if the ring fencing was removed.

The questionnaire gave local authorities, who did consider the eligibility criteria for ASG services to be different from that for mainstream services, the opportunity to comment on whether they thought this was appropriate.

Several local authorities highlighted the stigma and discrimination that is unique to HIV which they felt merited the additional support. Others felt that the potential cost benefit of keeping people well and adhering to treatment justified the different eligibility criteria. One local authority felt the unique support was necessary given the particular care required by people with a fluctuating condition. Others mentioned the importance of considering wider public health.

One local authority felt that people living with HIV would be unwilling to access mainstream statutory social care services and that the funding enabled them to fund non statutory services which people living with HIV would access. Another respondent felt that, although eligibility may appear to be lower, the reality is different:

"Some who are not familiar with the needs of people with HIV might think from the outside that they access services more easily, however I think it's about understanding what the impact of the needs are and thus when to intervene."

In contrast, two local authorities felt strongly that the lower eligibility was not justified. One respondent said:

"In the past many people with HIV have had lower eligibility thresholds. Personally I feel this is unfair. Many illnesses are unpleasant and have social consequences, but the sufferers are subject to the same eligibility criteria as other potential service users."

4.3.13 The future of HIV social care services

There has been a clear move away from specific 'ring fenced' grants, most recently witnessed in the changes to the Supporting People Grant. NAT wanted to find out whether local authorities believed that the services they provided, currently funded by the 'ring fenced' ASG, would continue to be funded if ASG funding ended or was mainstreamed into local area base grants.

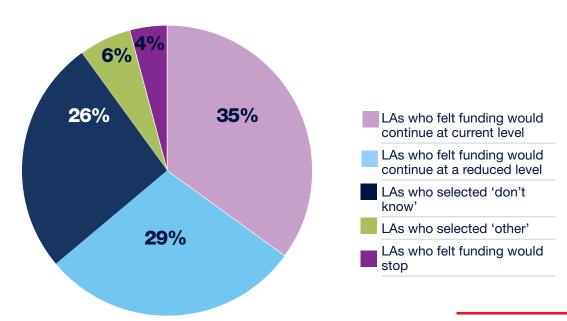
Just over a third (35%) of local authorities felt that they would continue to fund the services at the current level if the Grant was no longer ring fenced. Just under a third (29%) felt that whilst services would continue to be funded, it would be at a reduced level. Four percent felt that services would no longer be funded at all (with 26% selecting 'don't know' and 6% selecting 'other') (see graph 4 below).

Clearly the fact that only just over a third felt certain that social care services for people living with HIV would continue to be provided at the current level, should the Grant no longer be ring fenced, is a cause for concern (particularly given the impact of the end of ring fencing on HIV prevention funding).28 In addition, the current financial climate may mean that local authorities are under even greater pressure to use non ring fenced funding in other areas.

Voluntary sector respondents were also asked if they felt services would still be funded if the Grant was no longer ring fenced. Only 8% felt that services would continue to be funded at the same level. Fifty percent felt that services would continue, but at a reduced level, with 8% predicting that their services would stop altogether. The remaining 34% were unsure of the impact of the end of ring fencing on funding for HIV social care services.

Only just over a third felt certain that social care services for people living with HIV would continue to be provided at the current level should the Grant no longer be ring fenced.

Graph 4



5. Conclusion and recommendations

The findings from NAT's review of the ASG reveal that the Grant is being used to fund a wide range of social care support services for people living with HIV. Many of these services are the types of service highlighted as needed in the recent research report What do you need?. Within these services there are some examples of innovative good practice, with local authorities working in partnership with PCTs and the voluntary sector to reach out to people who may not choose or be able to access mainstream social care support.

However, the findings also indicate that there are clear areas for improvement. Of particular concern are the issues of needs assessment, contracting arrangements and transparency.

It is of real concern that so few local authorities are aware of SOPHID data and that only 51% had carried out a needs assessment in relation to planning service provision funded by the ASG.

It was also of concern that less than half of local authorities had taken any steps to inform people living with HIV and the general public about how they were using the Grant. The combination of this lack of transparency and the reduction of reporting requirements from the DH means that people living with HIV and the organisations that support them remain unconvinced that the Grant is always used effectively, even when in many local authorities it is.

The instability for service providers and service users caused by current contracting arrangements was also a cause for concern; as was the need to ensure the skills and expertise of HIV specific social workers are not lost in any move towards mainstreaming of services.

In the longer term, the findings underline the importance of maintaining ring fenced funding for social care for people living with HIV. If the Grant were to end in 2011 there is widespread concern that in many local authorities the standard and amount of provision for people living with HIV would reduce, if not disappear altogether. Experience of the end of other ring fenced health budgets suggests this may be the case.29

At the same time, the social care needs of people living with HIV may well increase as people live into old age. Given the unique problems faced by people living with HIV, a stigmatised and long-term condition, this could have serious consequences for these individuals and their families, particularly as many may not be able to access mainstream support.

The introduction of Local Strategic Partnerships, LINks, Joint Strategic Needs Assessments and Local Area Agreements as well as the emphasis on citizen empowerment should be welcomed as an attempt to ensure local services and priorities reflect local need.

However, for stigmatised conditions such as HIV there is a concern that providing funding/services for people living with HIV will be unpopular with the local population and consequently may not be reflected in priorities, regardless of need.

In addition, given that many people living with HIV are seen as 'hard to reach' and come from communities that already face discrimination (particularly gay men and black Africans) it may be difficult to persuade these individuals to speak up and get involved in setting local priorities.30 This makes the continuation of a ring fenced social care grant for people living with HIV particularly important.

Opposite is a series of recommendations for local authorities, the DH and the voluntary sector based on the findings of this report that aim to maintain and improve the current social care provision for people living with HIV.

5.1 Recommendations

Local authorities:

- Should conduct needs assessments before planning and commissioning HIV social care services funded by the ASG. The assessment process should include analysis of SOPHID data and involve a range of partners from PCTs, HIV healthcare workers, social care workers, people living with HIV and voluntary organisations supporting them. The assessment should not be done in isolation but should link into Joint Strategic Needs Assessments and wider local planning.
- Should agree three-year service plans, underpinned by a commitment to the appropriate level of resources, for HIV-related social care on the basis of needs assessments - this will bring greater clarity and stability for people living with HIV and service providers.
- Should improve transparency about how the Grant is used (for example making information available on local authority websites). They should not expect the public to rely on the Freedom of Information Act to access information about the Grant.
- Should ensure that the Grant is included in their local scrutiny arrangements to improve openness and transparency about how the Grant has been used, and to evaluate its effectiveness locally.
- Should ensure the needs of people living with HIV are considered when conducting wider needs assessments, including Joint Strategic Needs Assessments, and when selecting National Indicators or local targets for Local Area Agreements.
- Should ensure they consider including people living with HIV and organisations supporting them when setting up their Local Strategic Partnerships.

LINks should ensure they include people living with HIV within their membership.

Department of Health (DH):

- Should maintain and increase levels of ring fenced social care funding for people living with HIV post 2011.
- Should review whether the ASG allocation ratio needs to be amended to reflect the high level of social care need in some economically deprived communities.
- Should provide clearer guidance on how social care needs assessments should be carried out, drawing on comparable work in other areas such as sexual health. Any guidance should include good practice examples from local authorities who have successfully completed this process in the past.
- Should work with local authorities to provide and disseminate further examples of the type of service the ASG can fund, particularly examples of innovative partnership working.
- Should work with the regional HIV social care forums and others to identify best practice in transparency around the use of the Grant and its impact.
- Guidance provided by the DH and other Government bodies around Local Strategic Partnerships, Joint Strategic Needs Assessment. Local Area Agreements, and LINks should encourage local authorities to engage with individuals and communities who may not traditionally become involved in these processes, including people living with HIV.

People living with HIV and the organisations supporting them:

- Should ask their local Overview and Scrutiny Committee to review how the local authority is using the ASG if they have concerns about the way the funding is being spent.
- Should consider using Freedom of Information Act requests to find out more about how the ASG is used by their local authority if other transparency measures are not in place and their local authority are not willing to provide information.
- Should consider imaginative ways to engage with local authorities and get involved with Local Strategic Partnerships and Joint Strategic Needs Assessments to influence social care needs assessment and planning processes.
- Should encourage and support people living with HIV to play a part in LINks.

Social Care Institute for **Excellence (SCIE):**

Should consider how it could capture best practice in social care supporting people living with HIV and develop tools to disseminate this.



www.nat.org.uk

About NAT

NAT is the UK's leading charity dedicated to transforming society's response to HIV. We provide fresh thinking, expert advice and practical resources. We campaign for change.

SHAPING ATTITUDES.

CHALLENGING INJUSTICE.

CHANGING LIVES.

All NAT's work is focused on achieving four strategic goals:

- Effective HIV prevention in order to halt the spread of HIV
- Early diagnosis of HIV through ethical, accessible and appropriate testing
- Equitable access to treatment, care and support for people living with HIV
- Eradication of HIV-related stigma and discrimination.

NAT New City Cloisters 196 Old Street London EC1V 9FR

T: +44 (0)20 7814 6767 F: +44 (0)20 7216 0111 E: info@nat.org.uk W: www.nat.org.uk NAT would like to thank the following people for their insight and contributions to the ASG review process:

The Regional HIV Social Care Forums, Barbara Disney, Matthew O'Dwyer (Department of Health), Paul Elfick (Buckinghamshire County Council), Maurice Hebert, Jane Hillier, Chris Morley (George House Trust), Andrew Pearmain (Essex County Council), Maggie Powell, Lisa Power (Terrence Higgins Trust) and Steve Slack (Centre for HIV and Sexual Health, Sheffield).

National AIDS Trust is a registered Charity No. 297977 and a Company Limited by Guarantee (registered in England and Wales) No.2175938. Registered office: Target Winters Ltd, 29 Ludgate Hill, London, EC4M 7JE

© National AIDS Trust (2009). All rights reserved. No part of this publication may be copied or transmitted in any form or by any means without the National AIDS Trust's permission.