House of Lords: Select Committee on HIV and AIDS in the United Kingdom

Call for Evidence 18th February 2011:

A joint Response from the Association of Directors of Adult Social Care and the Local Government Association:

The **Association of Directors of Adult Social Services** (ADASS) represents Directors of Adult Social Services in Local Authorities in England. As well as having statutory responsibilities for the commissioning and provision of social care, ADASS members often also share a number of responsibilities for the commissioning and provision of housing, leisure, library, culture, arts and community services within their Councils.

ADASS members are jointly responsible through the activities of their departments for the well-being, protection and care of their local communities and for the promotion of that well-being and protection through the use of direct services as well as the co-ordination of and liaison with the NHS, voluntary agencies, private companies and other public authorities.

ADASS members have leadership responsibilities in Local Authorities to promote local access to services and to drive partnership working to deliver better outcomes for local populations. They participate in the planning of the full range of council services and influence Health Service planning through formal and informal partnership arrangements.

Local Government Association (LGA) – is the voice of the local government sector. We work with and on behalf of our membership to deliver our shared vision of an independent and confident local government sector, where local priorities drive public service improvement and every councillor acts as a champion for the people they represent. The 422 authorities that make up the LGA cover every part of England and Wales. Together they represent over 50 million people. They include county councils, metropolitan district councils, English unitary authorities, London boroughs, shire district councils and Welsh unitary authorities, along with fire authorities, police authorities, national park authorities and passenger transport authorities.

Monitoring:

a. **how robust is the current system for monitoring the number of people with HIV in the UK**

b. **will the proposed public health reforms impact on this system**

c. **could anything be done to improve monitoring**

d. **what groups in particular are at risk from HIV**

a. The extent of current national (and local) monitoring of HIV/AIDS activity and prevalence rates is fragmented, reflecting the limited extent of national strategy, the degree of local flexibility in how HIV/AIDS services are organised and delivered, and the extent of "denial" and associated under reporting within community groups .

It is noted that Adult Social Care, through the application of Fair Access to Care criteria, only accounts for approximately 10% of the anticipated HIV/AIDS population

In terms of national analysis, it is noted that there are a number of collections which assist in understanding the extent of HIV/AIDS prevalence, although these returns are either based upon surveys or retrospective activity collections, resulting in a degree of statistical error in the calculations (particularly when the stigma associated with HIV/AIDS conceals numbers of individuals with HIV/AIDS from these collections). This analysis is summarised in the Health Protection Agency Annual Report on HIV [Health Protection Agency- HIV in the United Kingdom 2010 Report](#)

B The proposed PH Outcome Framework includes a HIV/AIDS measure (Proportion of persons reporting with HIV at a late stage on infection) within Domain 4 (Prevention of Ill Health). This will enhance the profile of HIV/AIDS within the remit of Public Health focus.

C. There are several recommendations to improve monitoring, namely:

- Specific reference to HIV/AIDS monitoring within the scope of the Joint Strategic Needs Assessment (JSNA), the production of which is to be a statutory duty for the Health and Wellbeing Board (HWB). Furthermore, GP consortia will be required to have regard to the JSNA in their commissioning plans.

- Strengthened role of Health Watch and the Health and Wellbeing Boards to hold providers and commissioners to account for health and social care outcomes and health inequalities detailed in the Healthy Lives, Healthy People and the Public Health Outcomes Framework consultation

D. Groups at risk- HIV remains prevalent in the **gay community**, which is at odds with the public perception that HIV/AIDS is reducing as a consequence of improvements in medical treatment. Additionally, as acknowledged by the Department of Health ([DH paper- HIV and Aids in African Communities: Jan 2005](#)) HIV/AIDS is increasingly prevalent amongst the **Black African community,** although issues relating to stigmatisation and "denial" within this community masks the extent of prevalence.

Prevention

> a. **Is government policy sufficiently focused on HIV prevention**
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> b. **Have the right groups been targeted in recent prevention campaigns**
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> c. **To what extent have prevention initiatives targeted at injecting drug users been successful**
>
> d. **How could prevention initiatives be better delivered and evaluated**

A. Prevention: - Since the mid 1990's when the Government embraced a high profile preventative campaign,   the welcomed advancements in medical treatment have change emphasis towards the medical model of treatment. This shift is believed to have had limited effectiveness in prevention and we draw on three trends to support this view: first, the continued incidence of HIV/AIDS (See HPA - HIV in the United Kingdom 2010 Report); the increasingly poor public awareness; and the changing nature of the groups being affected.

B. Effectiveness of targeting. There are several groups that, it is suggested, would benefit from preventative campaigns. These are:

- **Marginalised groups within Gay Community** HIV/AIDS - 'awareness' and services are still clustered in places with substantial and influential gay populations at the expense of more isolated and less connected groups, dispersed across the country

- **Black Africans -** as previously noted, this community is experiencing increased prevalence of HIIV/AIDS, compounded by reluctance within this community to recognise this increase, combined by ongoing discrimination towards Black and Ethnic Minority communities.

- **Vulnerable adults-** As a consequence of demographic changes**,** there are increasing numbers adults with physical disabilities and learning disabilities, and older people, who are eligible for social care services, and who are experiencing and expressing higher expectations regarding choice and independence. Adult Social Care fully supports these outcomes, through personalisation.

D. Prevention Initiatives - the proposals in the Public Health White Paper, give local authorities a more central, leadership and coordination role in prevention strategies. They can do this by including in their strategies a range of related local services such as housing, education, youth services and social care to significantly contribute to early prevention and behavioural change initiatives, particularly for vulnerable families and young people.

D. Evaluation - we note that it is extremely challenging to measure success of prevention initiatives, even when it is widely accepted that prevention is better than cure. The absence of any reliable measure which assesses upstream social and economic impact, combined by the difficulties in attributing accountability for interventions and the fact that the vast majority of upstream benefits are likely to be experienced by completely different organisations at a later point, undermines incentives to conduct preventative activity.

The Department of Health, through its recent Outcome Framework consultations has recognised the importance of "outcome measures", although we note that the proposed set of measures do not address the issue of preventative benefits and we will continue to work with the Department of Health to tackle this.

Testing

a. **Are current testing policies adequate across the country**
b. **What can be done to increase take-up rates**

A. Current Testing Policies: The current arrangements are Councils are best placed to target their testing programmes to their communities.

B. Take-up rates: There are a variety of influences which can impact upon the success of take-up rates. These are as follows:

- **Stigma of setting;** Given the sensibilities and potential stigmatisation experienced by HIV/AIDS individuals, the context of the setting is critical. In terms of Social Care (through which individuals can be encouraged to undertake tests) although most councils operate Single Access Points, it is recognised that HIV/AIDS specialist teams also operated more "sensitive" low key access arrangements to encourage engagement and referral.

- **Accessibility;** It is suggested that new models of accessing HIV testing could be considered to include retail settings i.e. chemists. This may reduce barriers to" take up" associated with clinical settings as well as encourage new ways of regarding HIV/AIDS in a more socially accepting way, although any such approach needs to take into account access to pre/post - test counselling.

- **Front line differences:** Despite many examples of excellent partnership working, there is some tension between the 'medical' and 'social' models in HIV care, which impacts upon the referral pathways to testing ,treatment and social care support.

- **Routine testing;** Alongside the current offer for HIV Testing made to pregnant women as part of their antenatal care, it is suggested the offer of routine testing could be extended for all new GP patients (the new GP Consortia may create further opportunities) as well as all STI Testing to also include routine HIV Testing , although any routine approach has to take into account whether this itself creates barriers to people coming forward for testing.

- **Insurance Guidelines;** It is suggested that the Government should clarify guidelines to Insurance companies and citizens as to HIV/AIDS testing requirements.

Treatment

a) **How can the NHS best commission and deliver HIV treatment**

b) **What impact might the proposed new commissioning reforms have on HIV treatment**

c) **In what setting can treatment most effectively be delivered**

A. In terms of commissioning HIV treatment, social care is critical partner in the care pathway. Firstly in terms of successful intervention and prevention activity (in partnership with Public Health) to reduce incidence; secondly in creating the supporting framework for adherence to treatment programmes (i.e. emotional support) and third, sustained recovery or successful maintenance of long-term conditions associated with HIV/AIDS through improved life choices and chances (access to services, info and advice) – **no point treating symptoms only , you must also treat the cause.**

B. The new reforms places the NHS at the centre of commissioning and there is concerns as to the level of awareness that the NHS has of the offer that Social Care can make to supporting people with HIV/AIDS and their carers, as well as the range of preventative work undertaken by Social Care.

C. As previously noted, the stigma of institutional clinical settings (hospitals / clinics) is believed to create barriers to individuals presenting themselves for HIV/AIDS testing or treatment. Social Care can provide the supportive holistic framework to assist individuals (and local communities) in breaking down these barriers and to seek (or sustain) an improved quality of life.

Cost

- Have cost considerations been satisfactorily balanced with Public Health imperatives in HIV

  i.   Prevention policy; and

  ii.   Treatment policy

- Is research funding correctly prioritised

Although the Public Health White Paper includes improved outcome measures for HIV/AIDS and a Health Premium will be introduced to incentivise a reduction in health inequalities (possibly including improved outcomes for HIV/AIDS), it is not clear if HIV/AIDS will be prioritised over other competing outcomes. We also have associated concerns of how to attribute improvements in Health Inequalities relating to HIV/AIDS and that Health And Wellbeing Boards will not be able to "direct" GP Consortia commissioning intentions. That said, GP consortia will be required to have regard to the JSNA and the Joint Health and Wellbeing Strategy in developing their plans, both of which will need to identify and address the challenges related to HIV/AIDS.

Further, it is noted that the National HIV Strategy was refreshed in 2009, although it is not clear as to status of this strategy in the context of the Government's approach to HIV/AIDS.

Stigma

> a. **What impact does stigmatisation of those with HIV have on those infected and on addressing HIV as a public health problem**
>
> b. **Where are the problems of stigmatisation most acute**
>
> c. **What measures are currently taken on tackle HIV stigmatisation? What more should be done**

A. From the perspective of Social Care we note the increasingly close association between mental ill health and HIV/AIDS. This association is results from isolation and low expectations experienced by people with HIV/AIDS, particularly by marginalised groups within the wider HIV/AIDS community.

B. The stigmatisation of people with HIV/AIDS is most acute within the Black African community, driven by a culture of denial within the community itself. This can further isolate and marginalise Black African people with HIV/AIDS and it is an area to which Adult Social Care is addressing through it's presence within the community setting and the broader community cohesion programmes undertaken by councils, although it is recognised that further work is required to acquire the full community confidence in accessing social care services and support. This confidence is highly dependent upon customer experience of a seamless, coherent and focused service, and reinforces the need for an integrated approach.

C. Social care is well positioned to tackle stigma head on as opposed to the medical model operated within health, which is restrictive to the treatment of conditions. The historical basis for HIV-specialist social care, specifically the prejudice and discrimination and consequent stigma and shame experienced by people with HIV/AIDS, remains as much of a factor in many of their lives.

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Supplementary Questions:

1. Under new arrangements, local authorities will be responsible for commissioning a full range of sexual health services, but not HIV treatment and care. Do you believe that this distinction in commissioning is justified?

a. Is there a case to be made for a holistic approach to all genitourinary medicine services?

b. Is there any danger of service fragmentation arising from the new arrangements, thereby undermining the control of STIs and HIV? Specifically, how will the national network of HIV/GUM services be maintained?

1   Local Authorities have historic experience of promoting public health, which can be equally applied to commissioning HIV/Sexual health promotion

a. Social care is critical to successful intervention (and prevention) in partnership with health. Social care provides the supporting framework for adherence to treatment programmes (i.e. emotional support) and   sustained recovery through improved life choices and chances (access to services, info and advice) – **no point treating symptoms only , you must also treat the cause.**

   It is noted the social care has not undertaken commissioning of medical treatment, so this distinction would seem justified from a pragmatic perspective. However, keeping treatment & social care integrated as a holistic solution based upon mutual understanding and respect is key

b. Fragmentation HIV/GUM services is more likely when commissioned through health where the medical model dominates and there is limited awareness of the value of social care input. The limitations of explicit national expectations is likely to exasperate current post code lottery of service availability.

> 2. Are local authorities ready for the delegation of public health responsibilities? How do you think that governance arrangements will ensure the quality of clinical services commissioned?
>
> a. Is there any risk of local politicisation of public health issues, particularly around a stigmatised condition such as HIV?

2. There remains significant concern as to the inter-relationships between Public Health and Local Authorities. The Public Health White Paper is still al live consultation, and the Health and Social Care Bill does not mention the responsibilities of Public Health England and how it will operate with the National Commissioning Board, GP Consortia or Health and Wellbeing Boards.

We have already noted concerns as to HealthWatch and the Health and Wellbeing Boards not having statutory powers to hold commissioners to account. Further, the role of CQC as regulator of quality is perceived as becoming more withdrawn from front line engagement and increasingly reliant upon desk top analysis

The role of NICE to develop and introduce Quality Standards across NHS, Adult Social Care and Public Health is welcomed, but there is concern that the emphasis will be based upon the health model. Although this may address issues relating to commissioning of clinical standards, the critical value of social care input must also be addressed and we welcome opportunities to work with NICE in developing holistic Quality Standards.

2a, Stigma remains prevalent and ever changing (for example, new communities experiencing HIV/AIDS). Commissioning of HIV /AIDS and STI are very likely to result in fragmented services, particularly where commissioning is to be dependent upon local awareness.

It is suggested there is a programme of awareness (amongst professionals and the public) and that national expectations are clearly expressed to direct service development, but balanced with local flexibility (Localism), combined with a refreshed HIV Strategy.

In terms of supporting full service availability, it is suggested that Local Authorities safeguard the commissioning of niche "Cinderella" services and that the NHS and GPs should work with their Local Authority partners to ensure that services for people with HIV/AIDS do not slip through the cracks.

3. The Health and Social Care Bill has a strong focus on integrated working, with a lot of emphasis placed on a seamless experience for the patient. How could this work in practice, using HIV and sexual health services as an example?
3.   Many areas of good practice already exist and there are increasing patterns of integrated services across the country. It is noted that HIV services tend to enjoy enhanced collaboration when they are closely focused upon the needs and interests of service users within a "practice" rather than a "strategic" setting, and such settings can lead to further innovative solutions to collaborative working, benefiting service users and the wider community.

4. Under existing arrangements in areas such as in Manchester, Primary Care Trusts have formed voluntary regional networks for commissioning HIV and STI services. To what extent do you anticipate that local authorities will seek to do the same?
4. Voluntary regional network are very likely to expand within Local Authorities

5. How will local authorities maintain focus on HIV/STI prevention work, given the many competing priorities that new public health responsibilities will bring; especially given that money saved on expensive HIV treatment will benefit the national NHS budget, rather than the balance sheets of local authorities?

5. The proposed move towards an Integrated Outcome Framework (as described in DH Business Plan 2011-15) could create synergy across NHS, Public Health and Adult Social Care and create opportunities to work collaboratively, and this may equally create a platform to maintain a focus upon preventative work.

Further, it is suggested that the HIV Strategy is refreshed to provide clear national expectation upon the level and quality of HIV/AIDS services, to be then designed and commissioned locally.

The shift towards increasing pooled budgets and integrated commissioning teams, plus the development of both "Total Place Budgets" and measures which describe the economic / social impact of preventative interventions, can all help to address the current limitations of working collaboratively on "upstream costs", although there is no universal approach.

It is suggested that further work is conducted nationally to establish a transparent methodology to achieve enhanced efficient and effective use of public money across organisational boundaries, and this should also cover the inclusion of a social/economic impact measure within the Integrated Outcome Framework to incentivise prevention, rather than responding to "failure demand" characterised by the existing set of national measures.

In terms of moving towards pooled budgets (as opposed to shared budgets), it is important that the role of prevention is clearly recognised and discharged. and that there should be equality of decision making between commissioners of prevention and of treatment.

The proposed introduction of "payment by results" within the Health and Social Care Bill, presents opportunities to incentivise prevention and early intervention, but this needs to be predicated upon clear national (and local) expectations, which are still in development. Any financial rewards system (payment by results) needs to take into account the multiple influences upon the health choices and outcomes of individuals, and the rewards need to be balanced with resources to support communities that have the least assets and the greatest challenge in relationship to addressing health inequalities.

In terms of preventative initiatives taken by councils, it is suggested that the main area of focus should be young people, through the schools curriculum. There is concern however that the current curriculum does not fully address HIV/AIDS awareness (only 60 minutes dedicated within year 9) and the proposed opportunities for the emerging Academies and Free Schools to have more discretion over their curriculums, which when seen in the context of concerns of local awareness of HIV/AIDS, raises further questions about an effective "national" preventative programme.

6. Under the arrangements proposed in the Health and Social Care Bill, increased patient and public engagement is proposed. One avenue for this is through a national HealthWatch England structure, with local authority-funded local units. What role do you envisage for these Local HealthWatch organisations, especially for HIV where local prevalence may be low?

a. Do you consider there to be any conflict of interest in local authorities funding an organisation that holds the services that they commission to account?

6. HealthWatch needs to align its work programme with the local JSNA and relevant Health and Wellbeing Strategies and consequently ensure it's membership is inclusive of all groups, including those marginalised groups (likely to include people with HIV/AIDS) identified within the local JSNA. This membership should also include links to representative groups to ensure wide coverage.

B. There are potential conflicts, but these can be addressed through procurement and contract arrangements with HealthWatch. Local Councils are accustomed to identify and mitigate against conflict of interests and fund a range of organisations engaged in conflict resolution, i.e. Service User Panels, Neighbourhood Assemblies etc.

7 Much of the responsibility for public health has been delegated locally, but there are designated roles in the Health and Social Care Bill for a number of central bodies: Monitor in economic regulation; the Care Quality Commission in quality control; NICE in quality guidance. Is there any concern over the potential degree of input from central bodies into devolved responsibilities?

7. Whilst we support the important functions these central bodies hold, particularly in the context of providing a transparent national framework to support improved outcomes for citizens and local populations, we are concerned that there remains a degree of ambiguity as to the balance between national and local direction/discretion.

We support a balance which clearly allows for a high degree of local discretion and minimal national interference and we seek assurance that resources will be available to ensure that local decisions are appropriate to meet requirements expressed by local people.