Joint Response from LGA and ADASS: A consultation on extending the legal rights to have personal health budgets and integrated personal budgets

8 June 2018

About the Local Government Association

1. The Local Government Association (LGA) is the national voice of local government. We work with councils to support, promote and improve local government.

2. We are a politically-led, cross-party organisation which works on behalf of councils to ensure local government has a strong, credible voice with national government. We aim to influence and set the political agenda on the issues that matter to councils so they are able to deliver local solutions to national problems.

About the Association of Directors of Adult Social Services

3. The Association of Directors of Adults Social Services (ADASS) is a registered charity which aims to further the interests of people in need of social care by promoting high standards of social care services and influencing the development of social care legislation and policy

4. The membership is drawn from serving directors of adult social care employed by local authorities in England.

5. Our objectives include:

   - furthering comprehensive, equitable, social policies and plans which reflect and shape the economic and social environment of the time.
   - furthering the interests of those who need social care services regardless of their background and status
   - promoting high standards of social care services

Key Messages

6. A person-centred approach is the most important driver of better joining-up health and care services to meet individual's needs. Personal budgets and integrated health budgets are important mechanisms for personalisation, but they are just one approach and will not be right for everyone.

7. An essential prerequisite to any extension of personal health budgets is that everyone in the NHS – from senior NHS leadership to frontline clinicians – is committed to putting the person, not the organisation or professional, at the centre of decision-making.

8. The changes must also lead to meaningful choice for individuals that improves their outcomes. Personal budgets are not an end in themselves. They work well if the market supports genuine choice and people can access information and advice to make informed purchasing decisions. Any extension will need to be appropriately resourced to ensure the support is in place.

9. The resource implications of these policy changes need to be carefully considered and local government must be closely consulted on any such analysis. Resource implications cannot be met from existing budgets and new funding must be made available where necessary.

10. There is an opportunity to build upon local government's extensive experience of social care personal budgets. In addition, the final report from the Integrated Personal Commissioning Programme will be published in September 2018 and it would be sensible to reflect this learning in taking forward the consultation proposals.

11. Adult social care faces a funding gap of £2.2 billion by 2020 and that is just the cost of core pressures including demography, inflation and the National Living Wage. We need an immediate injection of funding to stabilise the here and now as a down-payment on the green paper which must seek to secure the long-term sustainability of this vital service.

Further Information

12. Rather than respond to the individual questions, not all of which are relevant to the LGA and ADASS, we have grouped our comments under a number of key headings

13. **The proposals are a significant opportunity to further catalyse health and social care integration around a person**. Bringing together health and social care has been a constant and dominant policy theme for many decades. Extending integrated personal budgets is one way in which we can further help the shift towards meeting people's complex needs in a more holistic way. ADASS/LGA see this as an opportunity to build on some of the developing integration models with the NHS, and there already exist many tools to establish good joint working. We believe if introduced correctly this may further assist with this journey.

14. **A person-centred approach is the most important driver of better joining-up health and care services to meet individual's needs.** Personal budgets and integrated health budgets are important mechanisms for personalisation, but they are just one approach and will not be right for everyone.

15. There are around 500,000 people using personal social care budgets, but take-up varies between places and groups of people. Barriers to taking up personal budgets include finding the process challenging, a lack of information and support and perceptions about complexity. Think Local Act Personal (TLAP) have produced a suite of resources to help councils ensure that personal budgets are nimble and effective.

16. Personalisation encompasses a wide range of approaches, including self-directed support, co-production, self-management, empowering information and community capacity building.[1] It is essential that an individual's care and support is organised to reflect that person's, and their families/carers', needs and wishes.

17. We welcome the level of ambition of the proposals and believe that the opportunities may be greatest for those with long-term conditions who use

[1] It's Still Personal, ADASS, June 2017 https://www.adass.org.uk/media/5950/its-still-personal-june-2017.pdf

integrated health and social care services already and where services could be “unbundled” to create meaningful choice.

18. **The proposals must be underpinned by a shared commitment at all levels in the NHS to putting the needs of the person at the centre of decision-making**. The commitment to personalisation is not as embedded in the NHS as it is in local government and it will take time to change this. There has to be a strong commitment from NHS system leaders to change organisational culture and behaviours, so that the needs of the person, not the organisation, are paramount. This must include the relationship between clinicians and the people they are treating. We caution against forcing the pace of the proposed extension because for the reforms to work we need a shared commitment to personalisation at all levels in the NHS.

19. In relation to children and young people, the Department for Education similarly needs to embrace cultural change and a commitment to review how it organises funding so that when relevant it can be brought within a personal health budget or integrated personal budget.

20. **Personal health budgets and integrated personal budgets are not an end in themselves – they must lead to meaningful choice for individuals that improves their outcomes**. The mere act of extending the right to a personal health budget or integrated personal budget will not automatically make a difference to a person’s wellbeing. The policy rationale must be to increase choice and outcomes through a holistic look at people’s needs with personal budgets used to divert or delay increasing need. It also needs to be underpinned by a market, information and support, where required (especially if taken as a direct payment) that enables choice and a workforce that can respond to the expected increase in take-up of personal budgets.

21. Breaking down care pathways to identify care and support that is suitable for personal budgets can be very challenging. In addition, the prevalence of block contracts in the NHS for purchasing care and support can significantly reduce people’s choice and this could affect progress. It can be challenging to remove money from block contracts without impacting on the sustainability of NHS providers and this will need to be addressed if the proposed extension is going to lead to improved outcomes. One way to tackle this is to ensure that any growth in funds is used differently and not automatically allocated to existing contracts.

22. Furthermore, in many areas there is not a diversity of providers within the voluntary and community sector to provide choice. The voluntary and community sector social care market is already very fragile. Careful consideration will need to be given to how commissioners can support providers to develop the market, so that it offers genuine choice and is able to respond to care pathways. Local government has an important role to play shaping and informing market development in support of personal budgets and personal health budgets.

23. People also need clear information, advice and support to navigate their way through the care and health system and make good quality decisions about the services and support they purchase. We need to improve how people can access feedback from service users and make informed purchasing choices.

24. Finally, we will need to ensure that the workforce is sufficiently developed so that there are the right people with the right mix of skills in the right places to support a greater take-up of personal budgets, particularly personal

assistants. The National Audit Office recently highlighted the importance of a sustainable social care workforce.[2]

25. A key next step after the consultation will be mapping the practical steps that need to be taken so that the extension of legal rights leads to a reality of increased choice and better outcomes for people.

26. **We need to aim for consistency in entitlement during the transition from children and young people to adults.** Adult services need to respect and understand that a young person might have had choice and control over a larger budget than is the case once they move to adult services. If there is a change in entitlement, then this needs to be managed through a shared framework that continues to support independence and better outcomes.

27. We also need to understand how the proposed extension links to Education, Health and Care Plans. There is a significant opportunity to integrate the Education, Health and Care Plan within a personalised care and support planning approach, bringing all the resources together around the individual.

28. **We need to recognise that people's motivations are different; not everyone wants a direct payment or the responsibility of being an employer**. A personal health budget or an integrated personal budget can be managed in one of three ways:
    a. Notional budget – the council or the NHS manages the budget and arranges the care and support.
    b. Third party budget – an independent organisation manages the budget and works with the individual, family and/or carers to ensure the right care is put in place and outcomes achieved.
    c. Direct payment – the budget holder has the money in a bank account or equivalent account and takes responsibility for purchasing care and support, and where relevant, directly employing staff.

29. In other words, in recognising that people's motivations are different, we need different solutions so that they have the level of control they want. For people who want a direct payment, it will give them the opportunity to exercise greater control and flexibility over their personal health budget or integrated personal budget, provided it is accompanied by appropriate support.

30. The budget holder should be able to choose the level of support they receive.[3] Many local authorities have already commissioned direct payment support services (DPSS) and CCGs should explore working with them to develop joint services. DPSSs are important mechanisms to help address the ongoing issue of ensuring quality of both non-regulated services and personal assistants. A further challenge is that whereas councils can recover 20 per cent VAT on services they directly commission such as employment support for people with learning disabilities, HMRC rules mean that the VAT is added if purchased by the service user via a direct payment. This can lead to resistance to services being included within a direct payment which runs contrary to the principle behind direct payments.

31. With greater control comes greater responsibility and not everybody wants a direct payment with which to arrange and purchase their own care and support. In particular, take-up of direct payments has been lower amongst older people. While this partly reflects difficulties with the process, which councils have worked hard to improve, Age UK has highlighted that some

[2] https://www.nao.org.uk/report/the-adult-social-care-workforce-in-england/
[3] https://www.england.nhs.uk/wp-content/uploads/2017/06/516_Options-for-managing-the-money_S7.pdf

older people in the later years of their life just want to access high-quality and safe care without the additional complexity of managing a personal budget or directly employing carers and assistants. Some people might prefer one of the other ways of managing a personal budget as set out in paragraph 28.

32. In addition, the sleep-ins crisis risks undermining the personalisation agenda. Direct payment recipients who paid personal assistants a flat rate for overnight care shifts, in full compliance with National Minimum Wage (NMW) legislation, now find themselves personally liable for 6-years back-pay due to a change in Government policy which requires the NMW to be paid for the duration of sleep-in shifts.

33. **The possibility of bringing other appropriate funding streams within an integrated personal budget should be explored thoroughly.** People with complex health conditions are often eligible for a range of other benefits and support, particularly for housing and employment. This can mean that people receive money from a number of different places and deal with multiple professionals and processes. Integrating other appropriate funding streams within an integrated personal budget has the potential to further align and join-up person-centred care to address health and wellbeing needs. Not all funding streams will be suitable for integration, however, and the consultation proposals are already very ambitious, so we are keen this aspect of the consultation is explored thoroughly, and phased to ensure that, when appropriate, it can be implemented effectively.

34. **Further progress of the personalisation agenda could be put at risk by the financial challenges facing adult social care**. Discussions about taking personalisation further are happening in a very difficult financial climate. The LGA estimates that local government faces an overall funding gap of over £5 billion by 2020. As of March 2018, our analysis shows that the gap for adult social care will be £2.2 billion. This includes: £900 million just to cover the unavoidable core cost pressures of demography, inflation and the National Living Wage; and an immediate and annually recurring minimum of £1.3 billion to stabilise the provider market.

35. While there is strong support for personalisation, the scale of the funding pressures combined with demographic changes, means that there will be less money to support people's choices. When asked about the impact of financial savings in the 2017 ADASS Budget Survey, 36 per cent of respondents agreed that personal budgets are getting smaller. This increased to 54 per cent when respondents were asked to anticipate the impact of savings over the next two years. ADASS is leading work to explore how a strength or asset-based approach might help to sustain progress in personalisation during austerity. In order to continue the progress of the personalisation agenda, adult social care must be sustainably funded in the long-term.

36. **There is an opportunity to build upon local government's extensive experience of personal budgets**. The 2014 Care Act makes it clear that all people eligible for council-funded social care will receive a personal budget, but local government's experience of personal budgets stretches back over 20 years. There is a huge amount of learning which we hope DHSC and NHSE will fully utilise when further developing their proposals. While significant progress has been made, with many people benefitting from greater choice and control, it has taken time, expertise and resources to unlock those benefits.

37. In addition, the Integrated Personal Commissioning Programme (IPC) is a partnership between the LGA and NHS England which over the last three years has supported areas across the country to develop a personalised

model of integrated care for adults, children and young people with high and ongoing needs. The final report from the Programme will be published in September 2018 and should inform how the DHSC and NHS England consultation is taken forward. We will also want to ensure that the three integration pilots recently announced by the Secretary of State, the IPC and this consultation are all linked together.

Annex A Case Studies

North East Lincolnshire FOCUS[4]

Agnes (not her real name) is in her 80s with dementia, she lives in her own home alone and has no local family network. She needs help with personal care, diet, medication, finances, shopping and housework. Most of all, Agnes wanted to remain in her own home.

However, Agnes was not coping very well. The support provided during this period consisted of: four 30-minute calls per day for personal care, one shopping call and one cleaning call per week, and a corporate appointee for finances.

It was decided that the support package was not working, that the risks were too great, and Agnes was placed in respite care. Analysing a number of cases where people had been admitted to respite care with similar and lesser needs, the general result was that they became permanent residents with poor outcomes, in terms of their health, and increased dependency levels.

In Agnes' case there was a determined effort to return her home, which led to:

- Agnes being allocated a Personal Budget with support from the financial appointee to enable her to use some of her own money to part fund a new care package
- Agnes supported to appoint her own team of 3 carers
- extended support hours from 8am to 1pm and from 3pm to 8pm
- Installation of the Just Checking service
- tele-care to monitor 'gaps'

Due to the more intensive involvement by a consistent staff team it was quickly realised that Agnes' night wandering was related to severe weather conditions. It was therefore agreed that the carers could put in an extra night shift, without the involvement of the case manager, in these circumstances. These are purchased by Agnes but monitored by the appointee. The outcome for Agnes was extremely positive:

- Care staff got on well with Agnes and made sure they put her needs and wishes first
- They supported Agnes to go shopping, to cook and bake making sure she had fresh cooked food every day
- Agnes used to be a keen golfer and was able to take part in sessions on the driving range, which was something she hadn't been able to do in a long time
- Agnes now enjoys gardening with her carers
- The carers have helped her establish contact with family members who had moved to New Zealand
- Agnes has a bus pass and goes out for meals and shopping trips with her carers, which is an enormous change from the isolated life she was leading that was greatly impacting on her mental and physical health

[4] https://www.adass.org.uk/media/5950/its-still-personal-june-2017.pdf

Coventry City Council – pooled personal budgets[5]

Background
Nicola, Debbie and Sam are young people who have profound levels of learning disability with complex needs and challenging behaviour. Nicola, Debbie and Sam are friends from school. They were all due to attend College but their placements were not funded.

Action
Everyone involved in the assessment and support planning process recognised that Nicola, Debbie and Sam had good friendships with one another, had similar interests and support needs and lived locally to one another. They each required a robust package of support that would meet their complex needs (with some elements of 2:1 support) but it was also identified that some elements of their support could be shared and that they had previously been supported together.

The Brokerage Team were asked to find a provider who was able to provide support to Nicola, Debbie and Sam and be willing to include some hours of shared support for them to spend time together as a small group. A suitable provider was found and currently provides 10 hours of shared support a week.

Outcome
The provider devised a varied and vibrant activity planner that reflected the individual needs of Nicola, Debbie and Sam and met their individual outcomes. The impact of pooling a personal budget has meant their friendship could continue after leaving school and that they are able to access community based activities.

[5] http://wm-adass.org.uk/case-study-pooled-personal-budgets-nicola-debbie-and-sams-story/