

Response ID ANON-KY1S-C2QQ-Y

Submitted to **A consultation on extending legal rights to have for personal health budgets and integrated personal budgets**

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Section 1- introduction to consultation

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Organisation:

Together for Short Lives

Executive Summary

Purpose of the consultation

Answering this consultation

The following section contains background on personal health budgets, integrated personal budgets, and additional funding streams that could potentially be incorporated into an integrated personal budget. Would you like to read this section, or would you like to skip straight to the questions?

No, I would like to skip straight to the questions

Section 3- Extending individual's rights to have

People with ongoing social care needs, who also make regular and ongoing use of relevant NHS services

Q1a. Do you agree that people who are eligible for both a personal budget and a personal health budget should have the right to an integrated personal budget?

Yes I agree in principle, but..

If you selected 'Yes, I agree in principle, but...' or 'No, and my rationale for this is...', please outline your reasoning in the free text box below::

Together for Short Lives believes that all 49,000 babies, children and young people in England with life-limiting or life-threatening conditions should have the right to an integrated assessment, plan and personal budget - if they would like one. We welcome the fact that the Department of Health and Social Care aspires to increase the percentage of people identified as likely to be in their last year of life, so that their end of life care can be improved through personalisation according to their needs and preferences. However, this will not include all children with life-limiting conditions, because not all are in their last year of life - and it is extremely challenging to predict when they are. We are keen that Integrated Personal Commissioning and/or personal health budgets are not the only means by which the government seeks to improve the choice and control which people of all ages have over their palliative and end of life care; for choice to be realised, the NHS and local authorities have an important role to play in commissioning care across a range of settings, include hospitals, hospices and in the community. Government and NHS England have an important role to play in reminding commissioners of their responsibilities in doing so - and in holding them to greater account.

Personal budgets can provide greater choice and control for young people and families of children with life-limiting conditions. However, there are a series of barriers which we ask NHS England to work with us to overcome to offer them greater choice and control:

1. It is particularly important to address the regional disparity in the knowledge of personal budgets amongst commissioners:

o Commissioners must recognise that parents often have the best understanding of their children's needs – but require support to meet their needs.

o It is key that those commissioning personal budgets understand how vital non-clinical assistance can be, allowing for sufficient provision within children's personal budgets.

2. High staff turnover within clinical commissioning groups can lead to a frequent loss of knowledge and expertise.

3. The regional disparity in care provision also must be overcome for the increased use of personal budgets to be effective - currently there is a great regional disparity in care commissioning (www.togetherforshortlives.org.uk/commissioning2017):

o Fewer than a third of CCGs have implemented the NICE guidelines on 'End of life care for infants, children and young people with life-limiting conditions: planning and management'

o 63% of CCGs commission the provision of community paediatricians

o The commissioning of out of hours community nursing, community paediatricians and equipment services is also subject to this postcode lottery, with 67%, 29%

and 52% of CCGs commissioning these respectively

o Almost half of CCGs are taking no action to implement the government's end of life care commitment

4. Families and young people often feel frustration at the length of time it takes for personal budgets to be set up.

Together for Short Lives asks government and NHS England to work with us to overcome these barriers through working to take the following action:

1. Facilitate workshops and training sessions involving commissioners, care providers and other related professionals to share best practice and to foster an understanding of complex care needs amongst those commissioning personal budgets.
2. Fund a helpline or website to provide up-to-date information relating to personal budgets for carers, professionals and commissioners to further equalise the knowledge disparity.
3. Mitigate the postcode lottery of care by through stronger oversight - communicating commissioning responsibilities to CCGs and local authorities, as well as ensuring NICE guidance on end of life care for children and young people are implemented nationwide.
4. Bridge the accountability gap by developing a mechanism to monitor how CCGs and local authorities are supporting children's palliative care.
5. Better promote local offers and make resource allocation systems available to families of those receiving personal budgets, so they are aware of the support which is available to them.
6. Reduce the length of time it takes for personal budgets to be set up.
7. Help build supportive networks for families, which can provide support and hold authorities to account.

There are also distinct challenges presented to the voluntary care sector (VCS) which will need to be mitigated for the increased usage of personal budgets to be beneficial:

- VCS providers have little experience in marketing their services – therefore it will be important for guidance and assistance to be made available.
- VCS providers and commissioners must have a close relationship to ensure accurate estimates of the cost of services.
- It is often difficult for the VCS provider to determine their 'local area', resulting in interaction with multiple CCGs, who all have distinct processes, so a degree of regional standardisation utilising STPs may be beneficial.

A further fundamental challenge to the success of personal budgets stems from the currently unsustainable, regionally inconsistent nature of statutory funding for voluntary sector children's palliative care services. On average, the overall amount of statutory funding for charities providing children's palliative care is falling year on year (22% in 2015/16 compared to 23% in 2014/15 and 27% in 2013/14). Statutory funding must not be neglected in favour of promoting the more market-based personal budget approach. Should statutory funding decrease, these charities could become even less sustainable, putting lifeline services for families at risk and undermining the choices that they are able to make about how and where their children receive palliative care. Regardless of the number of children and families who decide to use a personal budget to fund the palliative care they need, it is vital that NHS and local authority commissioners continue to provide statutory funding to services in hospital, the community and in children's hospices.

We ask that the government provides funding to NHS England to increase the Children's Hospice Grant to £25 million. This would help to make children's hospices more financially sustainable. Leaving vital, complex services at the mercy of these growing market forces could leave inadequate, uneven provision across England, resulting in those with personal budgets without choice and thus unable to reap the benefits of expanding personal budget eligibility.

Q1b. Do you agree that any right to an integrated personal budget, should include a right to have a direct payment, if appropriate?

Yes I agree in principle, but..

If you selected 'Yes, I agree in principle, but...' or 'No, and my rationale for this is...', please outline your reasoning in the free text box below::

Together for Short Lives believes that all 49,000 babies, children and young people in England with life-limiting or life-threatening conditions should have the right to receive their personal budget by direct payment if this is what they would like.

Direct payments can provide greater choice and control for parents. However, it is important to provide these families with additional support to relieve the administrative burden which comes with direct payment. It is also vital that young people and their families understand what their responsibilities are as part of receiving direct payments, as many have found it unclear, resulting in them having to make up their own rules up to a point. We would welcome the opportunity to work in partnership with the government and NHS England to mitigate these challenges. Help from local authorities and/or CCGs with payroll management and other HR responsibilities would greatly assist in freeing families from the administrative load which comes with receiving direct payments. Training in administrative matters is something which those receiving direct payments believe would be beneficial. If this was in conjunction with training for commissioners, it would be an excellent opportunity to foster understanding between commissioners and those receiving care. Furthermore, providing information through the previously-mentioned government-funded helpline/website would also greatly help those who have no experience managing these administrative matters.

It is equally important that for those receiving personal budgets through direct payments to understand how to separate business and care relationships. VCS providers have found that negotiations over the purchasing of care services has strained the care relationship with families, especially when they become protracted. We would welcome working in partnership with NHS England and the government to develop workshops to provide guidance and understanding for both sides.

People eligible for Section 117 aftercare services, and people of all ages with ongoing mental health needs who make regular and ongoing use of community based NHS mental health services

Q2. Do you agree that a person eligible for Section 117 after-care services under the Mental Health Act 1983 should have a legal right to a personal health budget / integrated personal budget?

Not Answered

If you selected 'Yes, I agree in principle, but...' or 'No, and my rationale for this is...', please outline your reasoning in the free text box below::

Q3a. Do you believe that a person of any age under the care of community-based mental health services for a significant period of time should have a legal right to a personal health budget / integrated personal budget?

Not Answered

If you selected 'Yes, I agree in principle, but...' or 'No, and my rationale for this is...', please outline your reasoning in the free text box below::

Q3b. What do you feel would constitute a reasonable definition of 'a significant period of time'?

Please provide your answer in the text box below::

Q3c. Do you agree that any right to a personal health budget for mental health, should include a right to have a direct payment, if appropriate?

Not Answered

If you selected 'Yes, I agree in principle, but...' or 'No, and my rationale for this is...', please outline your reasoning in the free text box below::

People leaving the armed forces, who are eligible for ongoing NHS services

Q4a. Do you agree that people leaving the armed forces who have a requirement for ongoing care through NHS services, (with some exclusions including primary care and pharmaceuticals), should have the right to personal health budgets where appropriate?

Not Answered

If you selected 'Yes, I agree in principle, but...' or 'No, and my rationale for this is...', please outline your reasoning in the free text box below::

Q4b. Do you agree that any right to a personal health budget for this group, should include a right to have a direct payment, if appropriate?

Not Answered

If you selected 'Yes, I agree in principle, but...' or 'No, and my rationale for this is...', please outline your reasoning in the free text box below::

People with a learning disability, autism or both, who are eligible for ongoing NHS care

Q5a. Do you agree that a person with a learning disability, autism or both who has an integrated package of care should have a legal right to an integrated personal budget?

Yes, I agree in principle, but..

If you selected 'Yes, I agree in principle, but...' or 'No, and my rationale for this is...', please outline your reasoning in the free text box below::

Many of the 49,000 babies, children and young people in England with life-limiting or life-threatening conditions have a learning disability. As such, we believe that they should have the right to an integrated assessment, plan and personal budget - if they would like one. However, as set out in the answer to 1a, there are several barriers to the expansion of personal budgets being effective.

Q5b. Do you believe that a person of any age with a learning disability, autism or both with ongoing eligible health needs should have a legal right to a personal health budget / integrated personal budget?

Yes I agree in principle, but..

If you selected 'Yes, I agree in principle, but...' or 'No, and my rationale for this is...', please outline your reasoning in the free text box below::

Yes, as we have discussed in the answer to 5a, we welcome the expansion of personal budgets to those with learning disabilities should the barriers laid out in 1a be mitigated.

Q5c. Do you agree that any right to a personal health budget/integrated personal budget, for this group should be a right to have a direct payment, if appropriate?

Yes, I agree in principle, but..

If you selected 'Yes, I agree in principle, but...' or 'No, and my rationale for this is...', please outline your reasoning in the free text box below::

The shortcomings discussed in 1b are equally prevalent in this case, thus they must be overcome in order to make direct payments a success.

People who access wheelchair services whose posture and mobility needs impact their wider health and social care needs

Q6a. Do you agree that people who access wheelchair services whose posture and mobility needs impact their wider health and social care needs should have the right to a personal health budget or integrated personal budget?

Yes, I agree in principle, but..

If you selected 'Yes, I agree in principle, but...' or 'No, and my rationale for this is...', please outline your reasoning in the free text box below::

In addition to the barriers set out in 1a, it is important to make specialist mobility equipment more readily available. Children's needs evolve rapidly and can quickly outgrow their wheelchairs, so a long wait for equipment can have a particularly negative impact. Many children are incorrectly deemed ineligible for the equipment they need by the NHS, thus must approach charities with waiting lists of over a year, severely diminishing their quality of life. While personal budgets should mitigate this somewhat, it is important commissioners budget enough for the required equipment and that this equipment is available. Again, there is a large regional disparity in assessment and availability which must be addressed by NHS England holding wheelchair services across the country to account, equalising the provision of mobility equipment.

Q6b. Do you agree that any right to a personal wheelchair budget should be a right to have a direct payment, if appropriate?

Yes I agree in principle, but..

If you selected 'Yes, I agree in principle, but...' or 'No, and my rationale for this is...', please outline your reasoning in the free text box below::

Should the previously-mentioned issues around relieving the administrative burden placed on those receiving direct payment be mitigated, as discussed in 1b, it would be beneficial. Especially as children in wheelchairs and their families often have negative experiences within the NHS due to feeling ignored. The SEN Pathfinder showed direct payments to have the potential to overcome this, as it found those receiving direct payment felt more understood and listened to.

Q7. Are there any other groups that you believe would benefit from having a 'right to have' a personal health budget and/or integrated personal budget?

Please provide your answer in the text box below::

Together for Short Lives believes that all 49,000 babies, children and young people in England with life-limiting or life-threatening conditions should have the right to an integrated assessment, plan and personal budget - if they would like one. However, as we set out in our answer to question 1a there are a number of barriers which we would be open to working with NHS England and the government in order to overcome.

Incorporating additional funding streams

Q8. Are there other funding streams that you believe would be beneficial to incorporate into integrated personal budgets?

Are there other funding streams that you believe would be beneficial to incorporate into integrated personal budgets?:

We ask that NHS England works with the Department for Health and Social Care and the Department for Education to simplify the personal budgets that children with life-limiting conditions and their families may be eligible for. We note that these children may hold personal budgets relating to education, health and care (EHC) plans, which may comprise a personal health budget, education and/or social care budget. The health and social care elements could be held as an integrated personal budget.

We ask NHS England to streamline these into one, integrated system of assessing, planning and budgeting the care and support that disabled children and young people need across education, health and care. We welcome the proposal that welfare payments and housing support could be integrated into health and social care personal budgets. We would welcome the opportunity to explore with NHS England how this could work for children with life-limiting conditions and their families.

Establishing a right to direct payments in NHS continuing healthcare funded home-care

Q9. Do you agree that people who are managing their NHS continuing healthcare funded home care as a personal health budget should have the right to a direct payment, if appropriate?

Not Answered

If you selected 'Yes, I agree in principle, but...' or 'No, and my rationale for this is...', please outline your reasoning in the free text box below::

As set out in 1b, there are a number of issues around the understanding of direct payment responsibilities, especially when families are receiving direct payments for the first time. In the case of home care, the separation of caring and negotiating relationships between care providers and those receiving care are of vast importance.

Equalities

Q10. Do you think any of the proposals set out in this document might have a beneficial or adverse impact on any equality issue- in particular, in relation to any of the groups who share a characteristic that is protected for the purpose of section 149 of the Equality Act 2010?

Please provide your answer in the text box below::

Before you submit your response

What is your ethnicity? Choose one option that best describes your ethnic group or background

English / Welsh / Scottish / Northern Irish / British

If other, please describe your ethnic origin:

How did you hear about this consultation?

GOV.UK or other government website

Other please specify:

We will be producing a report after the consultation closes. Let us know what we can include from the options below:

Your response, Your name (individual name), Your organisation's name

Are you happy for the Department of Health and Social Care to use your email address to send you updates about its policies?

Are you happy for the Department of Health and Social Care to use your email address to send you updates about its policies?:

Yes

Are you happy for the Department of Health and Social Care to use your email address to send you updates about other Department of Health and Social Care consultations?

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Help us improve how the department runs consultations by answering the following questions:

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