

**Together for Short Lives special educational needs and disability (SEND) project**



**Personal budgets workshop  
17 March 2016**

**Report of our findings from the event**

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**Introduction**

As part of our Department for Education-funded project to engage children's palliative care in the SEND reforms in England, Together for Short Lives hosted a personal budgets workshop on 17 March 2016. This was the third of our personal budgets workshops, with the previous events taking place in November 2014 and November 2013. The event - held in London - sought to improve the extent to which delegates' understood:

- what personal budgets for children and young people aged 0 – 25 are
- how to commission using personal budgets for children with life-shortening conditions
- how to better support families and prepare for personal budgets
- the England-wide public policy framework for personal budgets
- different approaches being taken to personal budgets by commissioners, children's palliative care providers and families
- the potential implications of personal budgets for commissioners, children's palliative care providers and families - including opportunities and threats.

The morning session of the workshop consisted of presentations from:

- Steven Pruner, Personal Health Budgets Regional Lead at NHS England
- Leah Booth, a young person who uses a personal budget
- representatives from Together for Short Lives' External Relations team

Shaylea William (Operational Lead, Children and Young People's Complex and Continuing Care Team, NHS Nene, Corby and Milton Keynes Clinical Commissioning Groups) also participated in a question and answer session.

The afternoon session included an opportunity for delegates to discuss in groups what they had learnt during the morning sessions – and consider and what actions organisations and individuals can take to continue to adapt to greater use of personal budgets.

Delegates included commissioners and providers from health, education, social care, local authorities and children's palliative care providers. All the presentations from the event are available on our SEND online hub at [www.togetherforshortlives.org.uk/sendresources](http://www.togetherforshortlives.org.uk/sendresources)

## **Executive summary**

- Commissioners and service providers are taking a proactive approach to personal budgets, attending courses and training sessions to share best practice.
- In some areas, commissioners have robust systems and panels in place to holistically assess the needs of each individual and to conduct financial risk assessments.
- There remain wide regional disparities in the number of personal budgets in place and knowledge of personal budgets among commissioners.
- Engaging with commissioners can be difficult for service providers as their catchment area can include multiple CCGs and local authorities. This problem is compounded by high staff turnover at local authorities, which means that service providers have to regularly liaise with new commissioners.
- Young people and their families need additional help with the administrative burden of managing their own personal budget. This includes areas such as human resources and payroll services.
- Families want more non-clinical assistance in areas such as maintaining their home. They need commissioners to recognise that this type of support enables them to take care of their own children.
- Commissioners, service providers and service users all need better information and support regarding personal budgets. This should set out what each party can and can't do using a personal budget and where they can access additional support or advice.

## **Recommendations**

1. The Department for Education should continue to provide workshops and training sessions for professionals and service providers to share best practice and learn from other areas.
2. The government should fund a designated website or staffed phone line to enable young people, their families, service providers and commissioners to access up to date and accurate information around personal budgets and to signpost them towards further support if necessary.
3. Commissioners should broaden their offer of support to those with a personal budget, using expertise from within local authorities to offer further support in areas such as human resources and payroll.
4. Children's palliative care providers should continue to proactively communicate with one another through their existing networks to share best practice when engaging with commissioners and demonstrating their value.
5. Together for Short Lives should continue to support children's palliative care providers and commissioners to share best practice – using online networks such as a designated LinkedIn group and their regular newsletters.

## **What our delegates told us**

The afternoon session of the workshops was a discussion session during which we asked delegates to consider four questions about personal budgets in their local area:

1. What have you been doing to prepare for personal budgets?
2. What is happening in your local area? How are you overcoming challenges?
3. What are families and commissioners asking for in your local area? How are you responding?
4. What else do you need? From Together for Short Lives, the NHS or local or national government?

A summary of the key themes emerging from their responses is set out below. Please note that this is not an exhaustive list of all the comments made during the events.

### **What have you been doing to prepare for personal budgets?**

- Offering personal health budgets when someone is eligible for continuing care.
- Attending events alongside fellow professionals to find out what approaches are working and how they have overcome challenges in their area.
- Robust support planning. Many delegates spoke of the importance of a full and holistic assessment of needs and desired outcomes at the beginning of the personal budget process so that they can be tailored to meet the outcomes that the user wants. This includes establishing clear desired health outcomes from the offset.
- Robust risk assessments that address how well the family will be able to manage their spending over the allotted period and how commissioners will make sure the child is safe if this money is misspent or spent too quickly. Some areas reported having panels that assess how money is spent and look at the risks involved in agreeing their personal budget.
- Children's palliative care providers reported engaging with local commissioners from the outset of personal budgets, while commissioners reported similar conversations with both families and providers.
- Supporting children and their parents to have greater choice over their care by preparing and then using an Any Qualified Provider list.

### **What is happening in your local area? How are you overcoming challenges?**

- Regional disparities: in some areas, commissioners had received lots of enquiries regarding personal budgets and had many of these in place. In other areas, however, there had been very little take-up at all.
- Challenge in making sure that all personal assistants have baseline care training and certificates. A commissioner said they are seeking to overcome this by finding a regional solution.

- There is a challenge for children's palliative care providers in defining their 'local area'. Many serve a wide geographical area that includes several CCGs and local authorities. This issue is exacerbated in areas with denser populations such as London, where hospices reported working with 'up to 17 CCGs' – each with their own processes.
- Staff retention:
  - Several delegates said that high staff turnover in social care is resulting in a loss of knowledge and expertise.
  - Restructuring of departments within local authorities has compounded this problem as experienced staff change departments or role and their expertise is lost.

**What are families and commissioners asking for in your local area? How are you responding?**

- Families are asking for help with the administrative burden of a personal budget. To address this, a CCG reported that they pay for brokerage services to do the administrative work that families are required to do.
- Families are asking for action now as they do not have time to wait – their lives are short. Several delegates relayed the frustration that many young people and families feel regarding the length of time it can take to set up a personal budget.
- Families are asking for non-clinical assistance in areas such as cleaning the house, gardening or other simple tasks. It was noted that it can be difficult for commissioners to realise that parents are the best carers for their own children, but only if they themselves receive support.
- Commissioners are seeking value for money through personal budgets.

**What else do you need? From Together for Short Lives, the NHS or local or national government?**

- Workforce training: commissioners agreed that best practice sharing is currently poor and that there is a highly variable level of understanding of the benefits of personal budgets among commissioners.
- Better data on demographics projections so that local areas can plan further ahead. Delegates highlighted the large number of babies and young children with very complex needs.
- Better information and support in the form of a booklet, website or staffed phone line. This would not just be for users, but for staff, providers, personal assistants. It should set out what you can and can't do with a personal budget and provide information on available support.
- Further training for users and those delivering services. For those with a personal budget, they need support so that they can manage their own care staff. This should include support and training for service users in areas such as:
  - equality and diversity

- conducting interviews
  - human resources - for example, developing job descriptions and writing contracts
  - conducting risk and safety assessments
  - payroll
- Professionals working directly with families need clearer information on the pros and cons of personal budgets so they can inform families with confidence.

### **For more information**

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