



**The challenges  
for commissioners**

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Report 2015

# The challenges for commissioners



## An Introduction

**The purpose is to develop knowledge and practice which assists the introduction of personal health budgets for children and young people with long term conditions.**

**The paper focuses upon the issues faced by the commissioners of personal health budgets (PHBs).**

### Who helped

#### The work comprised:

- A short desk-top review of issues and practice, drawing on intelligence from informal networks, from designated delivery partners and from published documentation.
- An "invitation only" seminar held in London on 2nd February 2015, which sought to build on and develop the above; and in particular to gather information about challenges and to identify good practice exemplars.
- Further follow up and consultation on-line and with named individuals.

**We would like to thank in particular those individuals who attended the London seminar as well as those who sent us written information.**

#### The seminar attendees were as follows:

Clare Lazarus and Andrew Tyson, In Control project consultants

Sue Bottomley, Leeds CCG and NHSE and overall project lead for In Control

Bernadette Simpson, project consultant working on equipment and Personal Assistants

Elizabeth Brandill-Pepper, Joint Children's Commissioner, Royal Borough of Kingston

Joan Lightfoot, Royal Borough of Greenwich

Bridget Cameron, Greenwich CCG

Julie Drake, Joint Commissioner, Children's Lead, Leicestershire County Council

Maria Smith, Leicestershire CCG

Paula Vyze, Assessment and Commissioning Manager, Nottinghamshire County Council

Corine Koppenol-Lyndon, Children's PHB Consultant/Manager and Specialist Advisor (Children), CQC

Alison Markwell, Designated Clinical Officer for SEND, Central London, West London, Hammersmith & Fulham, Hounslow & Ealing CCGs

# Long-term health condition

There are over 15 million people living with a long-term condition in England.

This includes both physical and mental health conditions such as arthritis, asthma, COPD, depression, dementia, diabetes and many more. These are conditions which cannot at present be cured but can be managed or improved through person-centred approaches that deliver the right care for that individual no matter what their condition(s) to ensure that they are involved in managing their condition(s), receive the care they need to live and die well, and that both they and their carers feel supported to maintain a good quality of life.

(Information from Personalised Care and Support Planning Handbook: The Journey to Person-Centred Care, Core Information, published by NHS England and the Coalition for Collaborative Care, 2015).

## Guidance and regulations

These are currently evolving rapidly. At the time of writing the key documents are The National Health Service Direct Payments (2010), and the amended regulations (2013). See also the supporting Guidance on Direct Payments for Healthcare, understanding the regulations and the Right to Have a Personal Health Budget guidance (2014).

For latest news and changes go to NHS England personal health budgets.

Remember, as PHBs which were not in the form of a direct payment were legal before the pilot, much of the new regulation and guidance applies specifically to direct payments as no other legislation needed changing. However, the policy intention is for the good practice to apply to all PHBs.

### There are three ways for people to receive and manage their personal health budget:

- a direct payment;
- a notional budget;
- a third party budget

Note also social care, health and SEN have different direct payment regulations.

# The role of Clinical Commissioning Groups

**Clinical Commissioning Groups (CCGs) are the bodies charged by the Secretary of State with leading the introduction of PHBs across England.**

There are 211 CCGs and they each have their own governance, management and delivery arrangements; all have a population with a unique history, culture, demographic and socio-economic make-up and with different assets and needs; and they have a variety of local experiences of personalisation in education, health and in social care to date. This makes for a complex picture.

NHS commissioners face many demanding calls for action; and although we may argue that the personalisation agenda and the extension of PHBs to children and young people with long term conditions is of the greatest importance, this work has to compete for attention with a raft of other pressing issues.

### With this in mind, this paper builds on our discussions to:

- Set out opportunities
- Note challenges
- Propose simple actions that localities might take
- Provides a list of useful links and resources

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# Opportunities

**Seminar participants identified a number of opportunities in extending the existing PHB arrangements to a wider group of children and young people. These changes are part of the broader direction of travel for the NHS towards person centred care and increased levels of choice, which were articulated most recently in the Five Year Forward View and the NHS Mandate documents.**

**In both this and in the section which follows on challenges, we reproduce the words of the people consulted with minimal commentary. No value judgements are attached to these statements.**

- The new joint commissioning duties specified in the Children and Families Act provide a real opportunity to join support up around the child or young person and their family. CCGs are key partners in terms of responsibility for delivering the reforms at the strategic and individual child level.
- The Children and Families Act accompanying SEND Code of Practice 0-25 reaffirms and gives further detail on the Government's commitment to joint commissioning and extending choice and control through the use of personal budgets.
- Healthwatch provides an opportunity for families and their representatives to ask searching questions and seek redress. A few places (eg Barnsley) are experimenting with a "junior healthwatch" focused on children and family supports.
- There are some examples now of service specifications being written which include reference to personal health budgets, personalisation and co-production: this provides an important signal and an opportunity to flag the significance and reach of the policy.
- Parents/carers are being upskilled as are children and young people to understand and make use of personal budgets. In addition families are increasingly being networked to ensure they are supported by their peers. Some parents now have experience of personal budgets in social care, which is potentially help as they move over to personal health budgets.
- The Local Government Association's Making it Personal Virtual Group on the Knowledge Hub provides a vehicle for connection and networking.
- Think Local Act Personal's new children and young people's personalisation network will also build a network; and will promote good practice and help members address common issues and problems.
- The Council for Disabled Children is developing a support/learning network for Designated Medical Officers in relation to long-term conditions: this should assist this important group to promote the messages more widely.
- We should "use the language that others use" when communicating with them: for example, when talking to schools use the language of learning, attainment and achievement. This helps to break down barriers and build trust.
- The development of co-produced local offers with detailed local information for families and others about the resources available in local areas for all children and young people with SEND aged 0-25.

- There are a large number of other initiatives taking place, some local, some national, which whilst they may not directly focus on personal health budgets for children and young people with long-term health conditions, do help to provide conditions for a changed culture. Often it is then up to local commissioners, providers and families working together to make the most of these things in their locality.

### Examples include:

- The best of the work in the Winterbourne View programme, which seeks to bring people back home and design person centred supports for them in their home community.
- The best of the work in adult services, particularly where people have been enabled to have genuine choice and full control through imaginative support solutions.
- Work in schools; not least the work of school councils in empowering and inspiring young people to speak out.
- New simple and structured conversations with providers; focused on levels of need (high/medium/low). The tri-borough has a three pronged approach focussed on: workforce cost/activity cost/unit cost.
- Drive to introduce new models of care within the NHS to move services closer to people in the community and give them more choice and control. eg Integrated Personal Commissioning Demonstrator Programme.

# Challenges

**Participants at the seminar identified a number of challenges they face. We have grouped the challenges under a series of headings and concluded each with a suggested way forward for commissioners.**

## Culture: How the NHS does things

**Seminar participants began by discussing the challenges providing by the prevailing NHS culture.**

- The introduction of PHBs is much more a change in thinking and approach than it is a change in process and procedure. To date this hasn't always been appreciated within the NHS and this means that the opportunity for real life-changing adjustments for families, which foster creativity and build in the contribution of family, friends and community is missed.
- Sometimes the NHS is better at "doing for" than "doing with." Real co-production with children, young people and families is at the heart of the new culture and moving towards this presents some real challenges for clinicians and managers.
- A difficulty with the service culture, particularly in some hospitals where consultants are "gods to families." It was noted that the NHS is very diverse and the culture is more problematic in some places than others.
- Cultural change becomes more difficult when leaders and key staff move on; much of the progress with personalisation to date has been "personality driven" – ways need to be found to move beyond this and embed a personalised approach in business-as-usual.
- NHS culture can be risk-averse, sometimes in ways that fetter the choice and control promoted by personalisation and personal health budgets. Culture change invariably provokes anxiety and we need the means to manage and address this anxiety, and to build the resilience to see the change through to its conclusion.
- A danger that we simply "transfer over" the model used in adult social care services without considering what is needed to make it work for the families of children and young people with long term conditions.
- The specialist/tertiary care sector is sometimes not in tune with NHS England and local CCG policy and practice and it can be difficult to reach or influence.

Very often, parents take their lead from the specialist service they rely on, as they have the clinical knowledge and expertise to look after their sick child. This means that specialist/tertiary services can become unduly influential in ways which do not always promote personalisation and personal health budgets.

- Royal Colleges are also highly influential bodies within the NHS; they need more information about the benefits and challenges of personalisation and personal health budgets so they are able to promote them with their members in a realistic manner.
- Change needs to be across the whole system: procurement, legal and finance colleagues all require an understanding of what the new approach is driving at, and need to understand that their job today is to help families, supported by clinicians, to find solutions on their own terms and which work for them.
- There are also cultural challenges in terms of integration with social care, and these can be even more complicated where boundaries are not co-terminus and several organisations are involved.

## A way forward:

At this stage in the process commissioners need to adopt the mantle of transformational leaders. In their public statements, in their interventions with providers and in their work with clinicians and managers, they must make it clear that the National Health Service is moving to a genuinely personalised culture across all its operations; and that to succeed in this all staff are required to embrace new thinking and change the ways we do things round here.

Personal health budgets bring with them the potential to tap a well of creativity provided by ordinary citizens, citizens who are motivated by the desire for a good life for themselves and for their families. This resource has disappeared from view over the years - and the overarching challenge for system leaders today is to bring it back to the centre of our thinking and planning.

# Challenges

## (Continued)

### Resources

Seminar participants were very mindful that Personal Health Budgets do not represent “new money” and will have to be delivered within existing resources. With this caveat in mind they listed three specific challenges:

- A concern that services are properly resourced for this work and that there is a poor understanding of the infrastructure needed both within the NHS and in the communities served (the voluntary and community sector, user led and peer support organisations) - and the financial resources required to provide this infrastructure.
- In some CCGs it is difficult to identify a lead for children and young people, with capacity to focus on this work.
- A concern that personal budget allocations may be insufficient: “small people must not mean small budget.” This may be more a problem for children’s services in the round, than for personal health budgets as such: but personal health budgets may be responsible for surfacing the issue.



### A way forward:

Commissioners must now be honest and realistic with staff and the public about the resource constraints they face to implement these changes; but they are also required to be very robust in their budget-setting negotiations – policy imperatives will not be delivered without providing both adequate community infrastructure to support the introduction of personal health budgets, and adequate resources for the budgets themselves.

**“Small budgets for small people” is not acceptable.**

### Processes

Seminar participants provided a list of specific process issues that challenge them.

- The NHS is now “primary care led” but primary care services tend to exclude the most disabled children because their needs are so special.
- The nature of medical systems and clinical pathways can pose difficulties: it is a real issue that many children and young people with complex care needs require that those needs are met through the support of a number of different clinical specialists; a personalised approach can help to bridge these specialist areas, but to allow this to happen successfully processes and pathways need to flex.
- The NHS tends to measure activity rather than outcomes; NHS payment systems are sometimes in reality more “payment by activity” than “by results.” Personalisation and personal health budgets are premised on the requirement that we develop clear, measurable outcomes.
- The NHS has an obligation to assure itself that support arrangements are safe and that they deliver high quality services. The systems and procedures the health service uses to prevent harm and assure quality can sometimes work against creative solutions, and can push families towards what is safe and familiar.
- There are a number of technical challenges in relation to the disaggregation of budgets generally and at the level of the individual child and family. There are real difficulties sometimes in establishing unit costs, which can make it more difficult to allocate monies in the form of personal health budgets in ways that are demonstrably fair and transparent.
- There is a lack of consensus about the best available tools for analysing cost: there is a real need for consistency across the country.
- here is quite often a lack of confidence in some of the “generic” public statements about commissioning activity. Many existing Joint Strategic Needs Assessments and Market Position Statements are seen as unhelpful and insufficiently reflect the needs of children and families where there are issues of special educational need, disability or a long term health condition.
- At the move to adulthood, the issues raised by localism and cash-limited budgets become even more acute, with challenges about thresholds/eligibility for both NHS Continuing Health Care and adult social care coming to the fore.
- There are a number of specific challenges posed by the new requirements of the Children and Families Act which will impact on this group of children and young people. One issue of particular concern is the 20 week timeframe for completion of the assessment and planning process.
- There is a lack of consensus and understanding about the role of Designated Medical Officers (DMOs) in the new arrangements.
- There are particular problems for those children and young people who have mental health issues and who may be users of Child and Adolescent Mental Health Services (CAMHS): personal health budgets provide great opportunities for this cohort of children and young people – but there are also significant challenges which probably require further detailed attention.
- To work well, personal health budgets need to be regularly monitored and reviewed in the right way (“what is working and not working”; “what needs to change and how”); and the families using them need on-going clinical and professional support. This poses a major challenge for the NHS at a time of austerity.

### A way forward:

Personal Health Budgets give rise to many process issues, some of which are new, others of which had previously been buried. Commissioners need to be relentless in seeking solutions to these issues, sometimes themselves, but frequently by asking questions and holding to account colleagues with specialist responsibilities. Personal budgets in health and in social care should represent a better, more human way for ordinary families to get the care and support they need: to succeed in this we require processes which are simple, easily-understood and easily-navigated by all concerned. The NHS locally now needs to develop a clear offer of support to those families with a child with long term health conditions. The new energy driving integration and alignment across health, social care and SEN represents a real opportunity here; and regardless of some disappointing practice to date, Joint Strategic Needs Assessments and Market Position Statements continue to offer powerful levers that commissioners might apply to good effect, for the benefit of these groups of children.

# Challenges

## (Continued)

### Some broader challenges

Finally, seminar participants listed some of the broader challenges in the NHS' operating environment.

- Our highly media-conscious culture brings its own risks as well as opportunities: risks of unhelpful exposure if things are seen to go wrong. CCGs need to take a measured view of this set of risks and to prepare clear policy positions for contact with the media and the public.
- "Professional parents" can present particular challenges. This is where families undertake extensive research and become fixated on a particular solution for their child's problems.
- The Children and Families Act and related SEND Code of Practice 0-25 leaves some issues open to local interpretation for example how private speech and language therapy assessments sit alongside clinical pathways. The "commissioning" task is poorly understood by the wider world: this means that the potential contribution of commissioners in introducing these changes is also in danger of being poorly understood, and their impact less than it might be.
- For personalisation to work well there needs to be a reservoir of accessible community resources which are accessible to families, are easy to use and are detailed in the Local Offer. The picture today is very variable in this regard across communities. Where there are short-falls, CCGs should work with their local authority colleagues to promote welcoming and accessible communities for all.
- There needs to be real political understanding and leadership of personalisation, personal health budgets and the processes to support these at all levels, local, regional and national. Politicians should be briefed and should be in a position to advocate for these changes with local NHS managers and clinicians. Politicians should be in a position to deal with issues and difficulties for families – their constituents - as they arise, and to do so in an informed and positive manner.

### A way forward:

Commissioners now need to work on these issues in ways that are both strategic and tactical. In many instances they will need to take a personal leadership role in building a local alliance for change. Family or user-led organisations and colleagues from the local voluntary and community sector are often invaluable allies in this process: other system leaders, both within and without the local NHS may also have important roles to play. A clearly articulated vision, locally agreed and owned, with delivery responsibilities allocated to the key partners will go a long way towards embedding the changes in practice which are now called for.

## Specific action for localities

**We propose a number of possible actions for localities; in some they should work alongside colleagues with a regional or national remit.**

**Which actions are taken and how these are pursued will depend on local contingencies and circumstances. In most cases, we would propose a local strategy, with several key foci.**

- 1. Give people a recipe and answer the questions:**
  - a. How and in what way will families of children with long term conditions have the right to ask for a PHB?
  - b. Explain the right to have a PHB. Do people understand the difference?
  - c. What are the criteria where there is evidence that they could benefit? - clarify what the term benefit means here, and in whose view (from discussion on NHS England PHB website)
- 2. Develop a national list of parent/carers happy to speak about their experience (link with work Charlotte Infield is doing in relation to Markers of Progress and parent/carers)**
- 3. Link with the Integrated Personal Commissioning programme – two of the potential 10 sites focus on children and young people (the South West being one, to add second when we know)**
- 4. Major on the "health duties" specified by the joint commissioning section of the Children and Families Act - highlight the "musts" in the Code of Practice.**
- 5. Promote the NHS Mandate and the responsible commissioner guidance.**
- 6. Link to the recent direct payments for healthcare guidance and amended regulations 2014 which clarified terminology and extended the opportunity to employ people who live in the same household (subject to CCG agreement).**
- 7. Link the PHB process to the Education Health and Care Plan pathway as set out in the Code of Practice wherever possible.**
- 8. Include examples – see DVD PHBs – three years on: Stories from the pilot programme and <http://www.personalhealthbudgets.england.nhs.uk/Topics/Toolkit/HowPHBswork/Stories/>**
- 9. NSPCC & In Control publication on safeguarding.**

# Interesting practice

**These are some of the examples of interesting or helpful practice we have heard about. Not all concern PHBs for children and young people with long term conditions as such; but they do all concern practice which may be helpful to the commissioning process for this group of families in different local circumstances.**

## Culture change

- Kingston – having different conversations at the individual, operational and strategic level. Providing coaching sessions between professionals and professionals and professionals and children, young people and families.
- Kingston – defining house rules at each meeting.
- Greenwich – participation groups.
- Tools to support participation e.g. Improving Access to Psychological Therapies (IAPT) For Children, Young People and Their Families.
- Leicestershire transition event including parents/carers talking about their experience.
- Working with school councils in Leicestershire – gives a broader perspective.
- North West – setting up a children and young people's peer network.
- Leeds and Kingston are anticipating that PHBS will cost less than provider services.
- Leicestershire – universal time framework that works across the three local authorities in the county.
- Leeds – co-production – focus on 0-5 pathway and health offer – involved group of parent/carers broader than normal group – used 1:1 meetings and groups. 5 priorities identified by families and other priorities identified by frontline practitioners – informed hospital and community provision – family priorities used to check delivery.
- Leeds – young people's website.
- Leeds – work on community wealth, identifying families with skills

- Greenwich – flexible packages for children and young people going in and out of hospital – focussed on personalisation not PBs
- East Sussex – strong discharge policy working with a charity 'Well charge.'
- Leeds – parents using their budgets creatively.

## Desegregating budgets

- Leeds – have worked out unit costs for continuing care – tapering the value of the contract over a period of 3 years. A Community Care Nursing contract which covers NHS Continuing Care and short break services.
- Greenwich – used the Bradford cost calculator model.
- Good work also reported in Leicestershire, Dorset and East Sussex.

## Therapies

- Tri-borough are just starting to re-commission Speech and Language Therapies – these will be included in their Personal Budget offer from April 2015.
- Greenwich - CAMHS & integrated children services are currently out to tender

## PHBs

- Greenwich has started a conversation about this – they are keen to include support for young people with challenging behaviour.
- East Sussex are piloting 11 packages; they developed a Resource Allocation System, based on the approach taken in Manchester.
- The South West collaborative on Integrated Personal Commissioning will focus on support to children and families and will establish a special interest network.
- In Bassetlaw CCG in Nottinghamshire, the Commissioning Support Unit is leading on PHBs –and are beginning work to assess how the Education, Health and Care Plan process can call on differently commissioned services to benefit families.

## Work with providers

- In Greenwich, they used the NHS Atlas to support discussions with providers.
- In Leeds the role of Designated Medical Officer was delegated to the NHS provider Trust; this has been successful.
- In Greenwich, this role is held by the community paediatrician.

## Products shared on the day/as a result of the day

- Kingston - Personal Budgets agreement; PBs guide for parents and carers; PBs guide for professionals
- Croydon's SALT specification.
- Case study examples with PHB and PB from the SE7 Pathfinder Group.
- SE7 Joint Commissioning Booklet for children and YP with SEND.
- SE7 u-tube video with SE7 Young People Advisory Group: <https://www.youtube.com/watch?v=atck5kEixGI&feature=youtu>
- Parental Journeys from Hampshire to look at etc
- Examples from Bath and North-East Somerset
- Commissioning for outcomes & co-production – a practical guide for Local Authorities (New Economics Foundation).
- NHSE e-learning



# The next steps

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## A Short list of general resources that might help

- NHSE Personal Health Budgets website <http://www.personalhealthbudgets.england.nhs.uk/>
- Peoplehub website <http://www.peoplehub.org.uk/>
- In Control website <http://www.in-control.org.uk/>

## Contact details for contributors to this paper

### Sue Bottomley

[sue.bottomley@hotmail.co.uk](mailto:sue.bottomley@hotmail.co.uk)

### Bernadette Simpson

[bernadette@collaborative-solutions.co.uk](mailto:bernadette@collaborative-solutions.co.uk)

### Elizabeth Brandill-Pepper

[Elizabeth.brandill@kingston.gov.uk](mailto:Elizabeth.brandill@kingston.gov.uk)

### Joan Lightfoot

[Joan.Lightfoot@royalgreenwich.gov.uk](mailto:Joan.Lightfoot@royalgreenwich.gov.uk)

### Bridget Cameron

[bridget.cameron@rperidotassociates.co.uk](mailto:bridget.cameron@rperidotassociates.co.uk)

### Julie Drake

[julie.drake@leics.gov.uk](mailto:julie.drake@leics.gov.uk)

### Maria Smith

[maria.smith@westleicestershireccg.nhs.uk](mailto:maria.smith@westleicestershireccg.nhs.uk)

### Paula Vyze

[Paula.Vyze@nottscg.gov.uk](mailto:Paula.Vyze@nottscg.gov.uk)

### Corine Koppenol

[corinekoppenol@hotmail.com](mailto:corinekoppenol@hotmail.com)

### Alison Markwell

[alisonmarkwell@nhs.net](mailto:alisonmarkwell@nhs.net)

### Andrew Tyson

[andrew.tyson@in-control.org.uk](mailto:andrew.tyson@in-control.org.uk)

### Claire Lazarus

[clairelazarus@btinternet.com](mailto:clairelazarus@btinternet.com)







**Telephone: 01564 821 650**

**Email: [admin@in-control.org.uk](mailto:admin@in-control.org.uk)**

Andrew Tyson and  
Claire Lazarus, In Control

2015

Carillon House, Chapel Lane

Wythall, West Midlands

B47 6JX