



Personal health budgets and young people with complex needs

An Introduction

The purpose of the document is to help commissioners and professionals develop effective strategies for implementing Personal Health Budgets (PHB's) for young people aged 14-25 with complex needs¹

The paper draws information from the following sources:

- A short desktop review of issues and practice.
- An invitation only expert seminar held in London on the 21st March 2015 that sought to identify challenges facing commissioners and practitioners supporting young people aged 14-25 and identify good practice exemplars.
- Three Preparing for Adulthood workshops run by NDTi for NHS England in June 2015.
- Wider learning across the country including the DfE Preparing for Adulthood programme.

A force field analysis (http://psychology.wikia.com/wiki/Force_field_analysis) technique has been used to identify challenges that are obstructing the introduction of PHBs for young people and factors that are facilitating progress in this area. The paper makes suggestions for how leaders can develop strategies to minimize the impact of obstacles and strengthen the forces for change.

These recommendations are encapsulated in seven top tips leaders can use to increase the number of young people with complex needs using PHB to live full lives.



¹ Note - In this paper young people with complex needs refers to young people who are eligible for Continuing HealthCare (CHC) and those with long term Conditions (LTCs).

The term long term conditions is used to describe young people who have conditions which cannot be cured but can be managed or improved through person centred approaches and flexible support but who are not eligible for CHC.

Personal health budgets and young people with complex needs

Evidence from stories of people who use PHB suggests they offer young people the following benefits:

- Greater choice and control over their lives and support
- Flexibility to design creative, individual support packages that deliver aspirations for an ordinary life (often of living locally near friends and families where they are tenants in their own home),
- Capacity to develop consistent support across school, home and community through the use of personal personal assistants.



The following links provide useful information about the difference PHBs can make to the lives and support of young people with complex needs.

<http://www.peoplehub.org.uk/mitchells-story/>

<http://www.peoplehub.org.uk/thomas-story/>

<http://www.sendpathfinder.co.uk/personal-budget-information> (Wigan example in v 3 and 6)

A number of areas around the country are exploring how PHBs can help young people with learning disabilities and challenging behavior receive effective support early on and avoid unnecessary admission to Assessment and Treatment Units (for example Think Local Act Personal PHBs and young people project, Plymouth). Other sites are exploring how PHBs can help young people with life limiting conditions live full lives and achieve their aspirations.²

However despite positive feedback from people who use PHB and their families, information from local areas suggests the number of young people with complex needs who use them is low. Most of the young people with PHBs are those who are either eligible for Continuing Care (under 18) or NHS Continuing Health Care (if over 18). There are currently few examples of young people who have complex needs (as set out in the NHS Forward View into action: Planning for 2015 /16) who do not receive Continuing Care or NHS Continuing Health Care using PHBs.

This paper sets out practical first steps commissioners and practitioners can take to enable young people with complex needs realise the potential of PHBs to achieve better outcomes.

Policy context

There are a number of policies and national strategies, which can help to promote the use of PHB for young people with complex needs.

Children and Families Act 2014

The Children and Families Act 2014 seeks to deliver cultural as well as organisational change. The first section, Section 13, makes it clear that local authorities, in carrying out their functions under the Act must have regard to the importance of children and young people, their parents and carers, participating as fully as possible in decisions about their support and local strategic decision making.

Four key elements of the reforms include,

- Local Offer
- Joint Commissioning
- Coordinated assessment and Education, Health and Care plans,
- Personal Budgets

The SEND reforms make a number of requirements of health professionals and commissioners including the introduction of a new Designated Medical Officer (DMO) / Designated Clinical Offer. DfE and DH have produced information on the SEND reforms and Code of Practice for health professionals.³

One of the key themes of the SEND reforms is Preparation for Adulthood. In addition to ensuring a smooth transition to adult services the Children and Families Act 2014 requires everyone working with young people aged 14-25 to work together to support them to prepare for adulthood with four key outcomes (employment, independent

living, community participation and health and wellbeing). This requirement is applied to all aspects of the reforms including personal budgets.

In order to achieve this ambition health professionals will need skills in raising aspirations for life, ensuring young people are at the heart decision-making and partnership working.

For more information on preparing for adulthood see www.preparingforadulthood.org.uk

Care Act 2014

The Care Act introduces a number of requirements to improve young people's outcomes and experience of moving into adulthood.⁴

Young people and families can request a care and support assessment before they are 18 to identify whether they are eligible for Adult Social Care and if so what their indicative budget would be. The local authority needs to carry out the assessment if there is significant benefit to do so and it would help prepare the young person for adulthood.

The Act talks about the importance of aligning plans and support. It is expected that the transition plan (if under 18) or care and support plan (if over 18 years) form the social care element of the EHC plans whilst young people are in education. The Act provides the opportunity to align support plans for personal budgets from health and social care.

² www.togetherforshortlives.org.uk/news/2512_personal_health_budgets_easy_to_read_leaflet_published

³ www.gov.uk/government/uploads/system/uploads/attachment_data/file/357645/Health_professionals_guide_to_the_SEND_code_of_practice_-_Sept14.pdf

⁴ www.skillsforcare.org.uk/Standards/Care-Act/Learning-and-development/Transition-into-adulthood.aspx

Policy context

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Personal Health Budgets

The NHS Five Year Forward View strengthens the claim that more people with long-term conditions should be able to benefit from the flexibility offered by personal health budgets. The Five Year Forward View also advocates person centred, asset-based approach to assessment, planning and support.

Young people who are under 18 (and eligible for Continuing Care) or over 18 (and eligible for NHS Continuing Healthcare) have had a right to have a personal health budget since October 2014. As a result of the Forward View into action: Planning for 2015 /16, clinical commissioning groups (CCGs) have starting to look at expanding their local personal health budget offer to others who could benefit.

Expectations of CCGs were outlined in 'Forward View into action: Planning for 2015/16. The planning guidance specifically mentions children and young people. CCGs should consider exploring how PHBs could benefit a wider group of people who,

- Are receiving NHS Continuing Healthcare or Children's Continuing Care, who already have a right to have a personal health budget;
- Have high levels of need but are not NHS Continuing Healthcare, but who have health needs which would be suitable;
- Have Education, Health and Care plans, and who could benefit from a joint budget including money from the NHS;
- Have learning disabilities or autism and high support needs (in line with Sir Stephen Bubb's report⁵),
- Who make ongoing use of mental health services,
- With long-term conditions for whom current services don't work, so end up accessing acute services more and
- Those who need high cost, longer-term rehabilitation e.g. people with an acquired brain injury, spinal injury or mental health recovery.

Most of the children and young people who have complex needs will have EHC plans whilst they are in education but not all. It is important that CCGs consider both groups when they are developing PHB strategies.

NICE guidelines

In September 2014 NICE published draft guidelines on transition to adulthood.⁶ The final NICE guidelines on transition from children to adult health and care are due February 2016.

Continuing Care review

The Framework for Children and Young People's Continuing Care is currently out for consultation (ends 23rd October 2015).

The framework has been refreshed to take account of recent changes to legislation across education health and social care.

Barriers and challenges that obstruct the development of PHB for young people and should be managed

- **Lack of demand due to poor Information, Advice and Support** – Young people and families rarely receive accessible information about preparing for adulthood, how adult services work and how PHBs might be able to help now and in the future. This isn't part of the school curriculum or their conversations with professionals. As a result myths about personal budgets flourish and families do not request PHBs.
- **Lack of shared vision of improving life chances of young people with complex needs and the role of PHB** – One of the biggest problems facing disabled young people growing up is that practitioners across health, education and social care tend to view 'transition' as a transfer to adult services rather working together to help young people live ordinary lives now and in the future. This means that potential of using PHB to increase young people's life outcomes is often overlooked.
- **Different assessment and eligibility criteria across children and adult health, education and social care services** – Designing personalised support packages that help young people with complex needs achieve ordinary lives generally requires long term multi agency planning.
- **Lack of knowledge** – Whilst many practitioners and commissioners can see the potential of using PHB to help young people with long-term conditions achieve better outcomes they are unsure how to draw down funding for young people who are not eligible for CC/CHC and what alternative support options may be available.
- **Lack of keyworkers to help navigate the system** – All research on transition highlights the importance of having someone who plays a key-working role. Where there are keyworkers they are often not confident about how to navigate the health systems and the role PHB can play.
- **Person centered support planning for young people aged 14-25** – The Children and Families Act, the Care Act and the NHS Five Year Forward all advocate a person centered, asset based and outcome focused approach. This means moving away from the dominant deficit, medical model to one that focuses on what is important to individuals as well as for them and builds on strengths and self-determination. Professionals are at very different stages in their understanding and skills in person-centered practice, writing outcomes and creative support planning which are key components of good PHB practice.

⁵ www.england.nhs.uk/wp-content/uploads/2014/11/transforming-commissioning-services.pdf

⁶ www.nice.org.uk/guidance/indevelopment/GID-SCWAVE0714/consultation/transition-from-childrens-to-adults-services-draft-guideline-consultation.

Policy context

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- **The voice of young people is often over shadowed by that of parents and professionals**
 - Young people's experiences and views need to be central to developing their own plans and wider PHB strategies. Greater support is needed in relation to Mental Capacity Act 2005, supported decision-making and commissioning strategies such as Working Together for Change⁷ to ensure the voice of young people who don't use words to speak informs individual and strategic planning.
- **Perception of risk** – Health professionals often express a lack of confidence over clinical risk and signing off health tasks for PHBs.



- **Block contracts** – In many places the PHBs are one off examples that are set up in response to individual situations or a crisis. Scaling up PHBs will require money that is currently tied up in block contracts to available to be used more flexibly. There is often concern that dismantling some block contracts (such as therapies) could lead to small amounts of resource being available (thus reducing choice and capacity) and could destabilize universally provided health care services. Integrated Personalized Commissioning (IPC) and Individualised Service Funds (ISF) may offer a way of addressing this if they include sufficient numbers of young people with long-term conditions.
- **Timing** – The option to extend PHBs to a wider group of people with complex needs was introduced in April 2015. This initiative is therefore a new opportunity and will take time to embed.

- **Impetus** – whilst there is a right to have a personal budget for CC and CCH funding the option to extend PHBs to a wider group is not a right to have. This could affect the drive behind its implementation.

Forces that support the development of PHBs for young people that should be used and increased

- **Dissatisfaction with the status quo** – Using concerns that the system doesn't deliver good outcomes or value for money (from young people, families, practitioners and commissioners) to lever change.
- **Co-production** – Working with young people and families who have the most to gain from these changes. For example, NE Herts peer network for personal health budgets.
- **Getting on with it** – Many young people with long-term conditions will have complex support packages and may be eligible to funding from education, health and social care. Whilst they are the perfect candidates for Integrated Personalized Commissioning it is often easier for one part of the system to get started and then bring in other agencies than wait for full, inter-agency agreement.
- **Children and Families Act** – The SEND reforms require education health and care to develop joined up approaches to all elements of the reforms. In a number of areas this is leading to a shared training, understanding and implementation of personalisation, personal budgets and preparing for adulthood.
- **Passports, annual health checks and health action plan** – all help young people to have a smoother transition to adult services. For example Southampton's Ready Steady Go model⁹ promotes person-centered support, self-management and requires children and adult health services to work together. Leicester City has dedicated staff that encourage GPs to offer annual health checks and health action plans from Year 9 for young people with learning disabilities. However only a few of these initiatives actively encouraged PHB's which suggests that even when transition is going well PHBs are not necessarily at the heart of it. PHBs should be built into exiting good practice.
- **Strong leadership** – Particularly where leaders provide permission to think outside the box.
- **Aligning eligibility and funding**
 - Some areas are beginning to carry out indicative NHS Continuing Health Care assessments from 16 to enable the development of personalised support packages. In Greenwich young people can request an indicative NHS CCH assessment at the same time they request their Transition Assessments under the Care Act. Wiltshire and Portsmouth have developed transition pathways as part of their work on the Local Offer, which explain what each agency will do from 14-25 years.

⁷ www.thinklocalactpersonal.org.uk/_library/Resources/Personalisation/Personalisation_advice/WTFC_Final.pdf

⁸ www.preparingforadulthood.org.uk/resources/all-resources/factsheet-the-children-and-families-act-and-the-care-act

⁹ www.uhs.nhs.uk/OurServices/Childhealth/TransitiontoadultcareReadySteadyGo/Transitiontoadultcare.aspxinto

Policy context

Continued

- **Planning for life outcomes from Year 9** – The SEND Code of Practice requires all annual reviews from Year 9 onwards to focus on the four PfA outcomes and plan the successful transfer to adult health and social care. Some areas are using this review to trigger key information advice and support, indicative assessments and budgets. These areas are using innovative approaches to identify how to engage scarce health professionals in this process such as group planning¹⁰
- **Ensuring key navigators are in place, understand the potential of PHB and can signpost families and young people** – Young people's transition outcomes are greatly enhanced if they have a keyworker and if their GPs know about them from age 14.¹¹

Keyworkers, GPs and navigators such as schools and colleges need to understand the potential of PHBs and how to signpost people. People Hub has a useful stories and materials on their website to raise awareness <http://www.peoplehub.org.uk>
- **Ensuring there is a clear focus on the needs of young people and young adults** – Due to current demographics the design of adult services can be dominated by the needs of older people. Ensuring PHB strategies are informed by the views and experiences of young people aged 14-25 is key to ensuring that this initiative works for all.



Conclusion and top tips

As the paper highlights despite personal stories demonstrating how PHB's can help people with complex needs achieve ordinary life outcomes the numbers of young people using them is low.

There are a number of factors that are resisting a steady increase in numbers. Firstly the culture of health, education and social care has historically defined the problem of transition to adulthood as a transfer from one service to another. Growing up with choice and control over your life and support and achieving ordinary life chances is at the heart of personalisation but is counter cultural to service land. Whilst the SEND Preparing for Adulthood agenda helps to redefine the definition of transition the cultural challenges cannot be underestimated.

Secondly trying to implement anything during transition to adulthood is notoriously challenging, as it requires joined up vision and working across children and adult education, health and social care services.

Thirdly PHB for young people are often a smaller part of the bigger reform agendas which can make it difficult for it to get the focus it needs to address the factors resisting its implementation.

Therefore maximizing the number of young people using PHB to achieve better outcomes and experience of becoming adults will require commissioners and managers to produce more evidence of how PHBs can address challenges in the system and create more demand from young people and their families.

This could be achieved in the following ways,

- Utilizing the opportunities presented with the SEND and Care Act reforms. Whilst PHBs are not a key feature of the reforms it can and should be attached to many of the reform activities, especially preparing for adulthood requirements.

For example the PHB offer can be built into EHC assessment, planning processes and review processes, personal budgets offer, the Local Offer and joint commissioning duties.

- Focusing on young people whose packages are expensive but who are at risk of achieving poor outcomes, for example,
 - Young people with learning disabilities (and who have challenging behavior)
 - Young people with mental health needs
 - Young people with palliative care needs or life limiting conditions
 - Young people leaving residential care
- Using pilots to increase the numbers of young people and families with positive stories and drawing out how the system needs to change to help this happen for more young people.
- Supporting young people and family leadership and ensuring their voices are heard in strategic decision making and commissioning.

Finally achieving change nationally will require a significant awareness campaign that enables commissioners and practitioners to see how PHB can help them address pressure in the system and implement statutory requirements. Local support is required to enable people to utilize the potential of personal budgets especially for young people with long-term conditions.

This includes how to draw down funding and scaling up PHB for young people.

¹⁰ www.preparingforadulthood.org.uk/media/385588/getting_to_scale_quickly.pdf

¹¹ www.cqc.org.uk/sites/default/files/CQC_Transition%20Report.pdf

Conclusion and top tips

Continued

Seven top tips for commissioners and practitioners to get started

- Improve information; advice and support to young people and their families that shows how PHB can help disabled people with complex needs achieve Independent Living. This needs to be triggered by the Year 9 transition review as set out in the SEND Code of Practice. Families and young people need opportunities to meet other people who have used PHB and develop accessible materials, stories and videos.
- Develop the workforce so that staff understand the potential of PHB and how to use them. Schools, colleges, health, social care, SEN, GPs all involved with EHC plans need a basic understanding of PHBs, what they offer, how they work and how to signpost.
- Use the statutory SEND Local Offer, as an opportunity to co produce health and wellbeing pathways for disabled young people with complex needs aged 14-25. Work with young people, families and senior decision makers across health, education and social care to carry out a gap analysis of current provision, develop a transition pathway that includes PHBs in the offer and identifies commissioning priorities. Make sure that the SEND Local Offer includes accessible information (including video clips) on PHBs and how to access them.¹²
- Plan ahead. The Children and Families Act 2014 and the Care Act 2014 both promote early intervention. LAs and CCGs should use information from EHC plans of 14+ year olds to predict future demand and develop personalized post 16 pathways. Make full use of the personal budget and the joint commissioning duties in the SEND reforms. Consider working with other CCGs and LAs in regions for young people whose conditions are low incidence but have poor outcomes for high cost.
- Integrate the work on the SEND Local Offer with the local PHB offer NHSE has asked CCGs to develop.¹³
- Explore how to move from block contracts to more flexible ways of personalizing support. This includes the potential of Individual Service Funds.
- Invest in family and young people leadership. The strongest drive for PHB is likely to come from families who have had a good experience of PHB and those frustrated by the status quo. Find opportunities for them to influence decision makers and commissioning strategies.
- Work small and think big. Transforming local systems cannot be achieved over night. Identify small cohorts of young people who would benefit from PHBs and use these to support young people to achieve better outcomes and experience of growing into adulthood. Use the learning from these pilots to identify what needs to change in the local system across education, health and social care.

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¹² www.preparingforadulthood.org.uk/resources/all-resources/developing-the-preparation-for-adulthood-section-of-the-local-offer

¹³ www.england.nhs.uk/healthbudgets/understanding/rollout/

Appendix

Appendix 1

Implications for NHS England national programmes

- More work needs to be done to understand why adult health services don't carry out NHS CHC assessments and provide indicative allocations before a young person is 17½ years. Steps should be taken to strengthen accountability for early intervention.
- Ensure that there is a clear focus in the Integrated Personalised Commissioning (IPC) demonstrator sites on children and young people with complex needs. This includes that there are sufficient number of children and young people in the cohorts. There also needs to be a range of resources and materials for young people, families and professionals and commissioners on IPC and how to get started.
- The Transforming Care and IPC programme provide an opportunity to see how personal budgets (including PHBs) can support young people with learning disabilities and challenging behavior move into adulthood with better life outcomes and avoid admission to Assessment and Treatment Units.
- Develop a range of materials on how young people with complex needs have used PHB to achieve better life outcomes. This needs to include what helped local areas to deliver this and how they overcame challenges. Information needs to be in a range of formats including short video clips that local areas could use for their SEND Local Offer.

Appendix 2

Interesting practice

Improving health pathways and passports

Bedfordshire has a health facilitation service that supports GPs to provide annual health checks and Health Action Plans for young people with learning disabilities aged 14 and over.

Alder Hey's Children's NHS Trust has developed a number of transition pathways for children with long-term conditions. They have established transition roles and clinics to promote better working between children and adult services.

Southampton has developed a Ready Steady Go programme for all young people over 11 years old who have a long-term condition. It is a programme that has been designed to help young people (and their families) gain knowledge and skills to help them manage their condition and navigate the transfer from children to adult health services.

The programme encourages children and adult services work together to improve young people's experience of moving into adult services.

<http://www.uhs.nhs.uk/OurServices/Childhealth/TransitiontoadultcareReadySteadyGo/Transitiontoadultcare.aspx>

Portsmouth have developed a graphic for their Local Offer that describes the local health transition pathway for young people with SEN and disabled young people. It explains what happens when by which professional.

Appendix

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Personal budgets

Wigan has used personal budgets to help young people with SEN and complex health needs to have consistent support across home, school and school transport.

Plymouth, Hampshire and Derbyshire are all part of the Think Local Act Personal PHB pilot. They are each working with at least five young people with complex needs to develop person-centred transition plans and use personal budgets (including PHB's) to develop flexible support to achieve better life outcomes. Learning from the pilot is being used to inform their implementation of the SEND reforms, Care Act, PHBs. Two of the sites Integrated Personalised Commissioning.

Me My Family My Home

This project is run by In Control and is funded by the DFE SEND Prospectus Programme. It is working with demonstration sites to use person centred approaches and personal budgets to help children and young people with complex support needs and/or complicated home lives have better outcomes.

Market development

Hertfordshire has two posts in health transition teams. They have a long history of developing local post 16 options and support for young people with complex needs. Hertfordshire is using information from EHC plans from Year 9 to forecast demand and develop the market. They have joint panels and jointly fund packages across health, education and social care.

Using health improvement tools

Leicester City has used CQUINS to develop good practice in health and transition to adulthood. They have also developed a protocol and workforce development for health professionals working with young people from 14-25. This includes the preparing for adulthood outcomes, helping families understand what is available post 25 and how to increase independent living.

They have a strong history of investing in person-centred planning and training across health, education and social care and use these approaches to deliver annual reviews for EHC plans that include health and wellbeing as one of the 4 PfA outcomes.

Resources and useful organisations

NHSE Personal Health Budgets
www.personalhealthbudgets.England.nhs.uk/

Peoplehub
www.peoplehub.org.uk/

In Control
www.in-control.org.uk

National Development Team for inclusion
www.ndti.org.uk

Council for Disabled Children
www.councilfordisabledchildren.org.uk/what-we-do/supporting-the-send-reforms

Making it personal publications on personalisation for children and young people
www.kids.org.uk/mip2

Improving health and lives learning disabilities observatory (IHAL)

www.improvinghealthandlives.org.uk

Preparing for adulthood programme
www.preparingforadulthood.org.uk

From the Pond into the Sea. Children's transition to adult health services. CQC. June 2014 http://www.cqc.org.uk/sites/default/files/CQC_Transition%20Report.pdf ISFs

SEND Pathfinder personal budget information pack www.sendpathfinder.co.uk/personal-budget-information

Personal Health Budgets and young people with life limiting conditions
www.togetherforshortlives.org.uk/news/2512_personal_health_budgets_easy_to_read_leaflet_published

SEND Code of Practice guidance for health professionals

www.gov.uk/government/uploads/system/uploads/attachment_data/file/357645/Health_professionals_guide_to_the_SEND_code_of_practice_- Sept14.pdf

Personalisation and commissioning
www.thinklocalactpersonal.org.uk/_library/Resources/Personalisation/Personalisation_advice/WTFC_Final.pdf





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