



National Development Team for Inclusion

 think local
act personal

TOP TIPS
FOR DEVELOPING
PERSONAL HEALTH
BUDGETS FOR CHILDREN
AND YOUNG PEOPLE WITH
COMPLEX NEEDS



Top Tips for Developing Personal Health Budgets

These top tips are based on work that the National Development Team for Inclusion (NDTi) undertook for Think Local Act Personal and NHS England with Plymouth, Hampshire and Derbyshire. They have identified a number of crucial 'building blocks' that are essential for the successful development of Personal Health Budgets for children and young people:

Leadership

- **Gaining ownership and leadership from Clinical Commissioning Groups and Local Authorities** regarding the implementation of Personal Health Budgets is an important first step. There is a danger that Personal Health Budgets are seen as a 'fringe' activity and not as part of the core strategy to achieving better outcomes and value for money. This agenda needs to have explicit and high profile support from senior decision makers if all parts of the system are to engage in the changed practice and behaviour that Personal Health Budgets require. This covers not just support/action around the process of Personal Health Budgets, but also a commitment to giving children, young people and families more choice and control, so that they have better lives embedded in their local communities.
- It is important that there is a **dedicated post held by an individual of sufficient seniority** who has a strategic overview of this agenda **and** is directly engaged with the work. Engaging with families, and practitioners, and getting whole system ownership is time consuming and cannot be led as an 'add-on' to substantial other responsibilities.
- Most of the sites in this initiative faced organisational change and turbulence during this work, with key people leaving or being moved to other work. This resulted in a loss of knowledge and commitment to Personal Health Budgets. Whilst recognising these are challenging times in the NHS and local government, **strategies to ensure consistency of leadership** with any new initiative are an important factor in success.

Understanding Personal Health Budgets as Whole System Change

- Progress is more likely when there is an understanding from key players that work on pilot initiative through programmes like Integrated Personal Commissioning is being used to **understand and prepare for significant and fundamental changes** to how the health and social care system operated for children, young people and their families. Where introducing Personal Health Budgets was seen as a discrete project, without consideration of the whole system implications or a clear intention to carry on beyond the life of the initial few families, buy-in from key players was difficult and limited progress was made.
- A specific aspect of this is the **cross-agency willingness to adapt organisational policies and processes** in order to enable person-centred practice to be implemented. For example, having a shared NHS and council policy and pathway for joint funded budgets.

Understanding and Commitment from Key Players

- Working in new ways requires **people to be willing to change how they do things and try something different**. This is particularly important in relation to families (see below) and health and social care professionals.
- **Securing the active participation of professional staff**, particularly in relation to training and other activities designed to introduce person-centred support planning is an essential building block for change – a factor previously identified by the In Control project, Me, My Family, My Home, My Friends and My Life.¹ The previous points about leadership clearly have a major impact on achieving this.

Families at the Centre

- Families have a crucial role to play as part of the process of change (In Control 2016). Thus, their **early engagement and the delivery of good information for families** was found to be essential. It takes time to engage with families, explain Personal Health Budgets and the potential benefits and gain support and commitment for them. Families therefore need to be involved from the outset.
- Developing **peer support networks** of families who have experience of personal health budgets and a good understanding of what is possible would be a positive step to address this.

¹ In Control (2016) Me, My Family, My Home, My Friends and My Life: www.in-control.org.uk/what-we-do/community-of-change/children-and-young-people/our-work/me,-my-family,-my-home,-my-friends,-and-my-life.aspx

- An important building block is **investing in and listening to families**. Family expectations are often constrained by their experiences of what has been available and possible in the past. Therefore, clear images of possibility, along with basic information about what Personal Health Budgets are, what they can achieve and how to access them are needed.
- **Keeping families and children/young people central** so that good practice regarding support planning and overall Personal Health Budget implementation is not lost as pilot initiatives move to being mainstreamed and the number of Personal Health Budgets increases.



CASE STUDY

The importance of Personal Health Budget advisors with lived experience...

“Having a Personal Health Budget can transform people’s lives! However many people can be very daunted at first and worry they will be taking on too much; but with the right support, guidance and conversations built around their needs, the experience can be very positive.”

– Glenys Newman, Personal Health Budget advisor at Independent Lives a Charity in West Sussex

Glenys works for Independent Lives and is one of three Personal Health Budget advisors with lived experience. She first heard about Personal Health Budgets in 2012 just before her daughter Natasha, who has complex health needs and learning disabilities turned 18. After it was confirmed that Natasha was eligible for NHS Continuing Healthcare Funding, an advisor from Independent Lives visited to explain how a Personal Health Budget could work. After deciding they wished to proceed with a Personal Health Budget to enable them to have more control over the support they received with Natasha’s care, the advisor worked with the family to write a person-centred support plan and draft a budget detailing how the funds would be spent. The Personal Health Budget also funded a personal assistant to go into school with Natasha during her final term so as to become familiar with all her support needs, learning how she communicates and how to best support her during activities such as hydrotherapy or riding her trike.

The budget was revised the following year when Natasha left school to provide increased support. This has enabled her to continue living at home which was what both Natasha and her family wanted. Whilst Glenys was being supported by the Personal Health Budget advisor from Independent Lives it was suggested that she might like to apply to a vacant advisor post, as her lived experience was extremely valuable for the role.

After being Natasha's main carer for 19 years and feeling unable to commit to work, Glenys was keen to be able to share her experiences to assist others through the process, having experienced first hand just how invaluable having that support was. Through the flexibility of managing Natasha's Personal Health Budget Glenys was able to tailor the support so that she was able to apply for the role and return to work part-time.

Independent Lives sees that at the heart of Personal Health Budgets are good, person-centred conversations with their customers, helping capturing what is important for and to them to remain healthy. Glenys role is to guide the customer through these conversations which are then captured in a support plan. This can be written together with the individual and their family, the Personal Health Budget advisor and health care professional.

Glenys shared her thoughts on working as an advisor:

"When I first visit customers they often have very little understanding of what a Personal Health Budget is and how it can be used to deliver their care in a more person-centred way.

They appreciate the continuity of having a named advisor who will remain available to them for support for as long as they are in receipt of a Personal Health Budget direct payment. Many customers choose to employ their own PAs and are often daunted by the prospect of becoming employers.

I am able to assist them by equipping them with the necessary tools to become effective employers, confident in managing their staff and meeting the legal obligations of being an employer.

I manage to put people at ease and for them, knowing that I also manage my own Personal Health Budget for my daughter who has complex needs can be reassuring as I have first-hand experience of the challenges they can face."

Clarity around Support Planning

- Support planning is best delivered by people who understand how to do this in a person-centred way. This is often outside the statutory sector. It is important to **agree where support planning sits** and be clear about the role of the voluntary sector in this.
- **Ensure local health and social care professionals are fully engaged in the support planning process**, and that barriers between families and professionals are pulled down. In Control (2016) found that families generally liked good practitioners because they knew they were there for them. Valuing and supporting staff through these changes is important.

Linking into Wider Service Systems

- Support planning for young people has to be **connected to the Education, Health and Care Planning process**, with clear agreement about how Personal Health Budget planning maps onto education health and care plans.
- Personal Health Budgets and support planning will lead to needing different service options (otherwise there is limited point in doing it). It is therefore important to **tie learning from support planning into market development**, so that deficits such as a lack of personal assistants can be addressed and children and young people can access a range of creative community resources.

Developing Staff Skills

- A different approach from staff is essential if Personal Health Budgets and real person-centred support planning are to be a reality. Therefore **on the job training to implement support planning and embed such skills in the wider workforce** is important. Staff need to understand how to build a shared understanding of an individual, what is needed and what is possible. An absence of plans and actions to train staff in these things contributed to there being insufficient local capacity for support planning.

The Third Sector and Community

- Personal Health Budgets, like personal social care budgets, will lead to use of a range of non-traditional support options. Some of these are most likely to come from outside the traditional service sector. Thus, it is important to **develop relationships and invest in knowledgeable voluntary and third sector organisations** locally. They have important links with families and communities, bring different perspectives and add to overall capacity. As noted by In Control (2016), although the system largely means education, health and social care, it is important to pay attention to community, housing and the rest of civic society.



CASE STUDY

The importance of Personal Health Budget advisors with lived experience...

This young person (K) now has a PHB, and there has been very positive feedback from the family about the whole process. This is a description of what happened with them during this project.

K and her family were referred to the PHB Project Team by Umbrella, a local charity supporting children and young adults with disabilities. Umbrella had received funding from NHS England to promote Personal Health Budgets with their service user group and as part of this they referred families into this work.

At the time of referral, K was 23-years-old. She has dermatitis, curvature of the spine, severe learning disabilities, behaviour that challenges and autism. These greatly affect her life in a variety of ways and she needs very specific support in order to enable her to have a good quality of life.

K lives with a Shared Lives Carer (a council supported service). As part of her Social Care support, K was provided with a place to live and access to activities outside the house, including attendance at services provided by Umbrella.

As part of the Support for Life Planning Process the following information was provided by one of K's healthcare workers (A Speech and Language Therapist):

"K has faced a lot of change and loss in her life, including the death of her mother. Trying to cope with the experiences she has had would be difficult for many people but far more so for K as she does not have the skills and resources of people without learning disabilities.

K's autism means she struggles to make sense of the world and her severe communication difficulties means she cannot identify, let alone share or talk through her feelings and so they can become overwhelming at times. She can also become extremely anxious. Some of this can be alleviated with appropriate communication to ensure K knows what is going to happen. However, some of the anxiety arises because there are too many demands being placed on her in terms of constant varied stimuli. For most people this is not a problem as they can filter out that which is not the main point of focus. This is not possible for K.

Approximately 70% of people with autism will have a sensory perceptual impairment. This has been described as being characterised by turbulent, fluctuating, inconsistent and unreliable perception where individuals struggle to make connections with their environments. K's presentation and behaviour suggests that she has this impairment. Unconsciously the person with such difficulties will seek the sensory stimulation to raise their arousal levels when they are under-responsive to certain sensory modalities, and react negatively to those which cause over-arousal. This can be seen in K with her need for tactile stimuli and her distress when there is too much auditory stimuli.

A lot of K's distress and agitation is caused by internal stresses (e.g. emotions, over-arousal) or because she is in an environment that is too stimulating and demanding for her. In both these cases K can be best supported by being moved to an environment that regulates the sensory stimuli in the way K needs, to calm and organise her nervous system and brain processing. This environment can be created with the use of sensory equipment."

Having collated observations of K by her Shared Lives carer, the Learning Disability Assessment and Treatment Service, and the Specialist Speech and Language Therapist, as well as her reactions when trying out sensory equipment in a day service for people with autism, it was possible to determine K's sensory needs. Her ideal sensory environment would be one in which sounds would be soothing and consistent, such as nature sounds (water, birds etc.) or soft music. K responds positively to certain visual stimuli such as colour-changing fibre optic lights, bubble tubes and projections of images onto a wall / ceiling. She also needs tactile stimuli. "Dangly" objects provide K with the tactile feedback she seeks on an almost constant basis. However, when she is distressed she requires greater stimuli. This can be provided by such things as a weighted blanket and being immersed in water of a consistently warm temperature. There had been questions as to whether equipment such as a hot tub would be necessary at home. It had been seen that K is significantly calmed by being in hydrotherapy pools; however, these can only be planned visits. K would benefit a great deal from being able to access this type of sensory input when she needs it most, at times of distress and agitation.

Personal Health Budget Use and Impact

The Support Planning process took place over a period of several months, and included a meeting of K's professional network, and three, one to one meetings between K, her Shared Lives Carer and the PHB Commissioning Manager for Southern Derbyshire Clinical Commissioning Group.

As the Shared Lives Carers' understanding of person-centred care and Personal Health Budgets was developed, it was agreed that access to ambient water temperatures, via a hydra pool, had helped K to relax and avoid anxiety. Whilst K accessed a Hydra-pool once a week for half an hour, it was recognised she often experienced anxiety and break outs at unplanned times, usually within the home. A PHB was used to purchase an inflatable hot tub.

There are plans to use the remaining funds from the PHB to purchase a Sensory Lamp for the small sensory room the Shared Lives Carer has created within the small terrace house in which K lives with Family A.

K and her Shared Lives Carer have recently attended a Community Support Delivery Group Meeting, where her Carer has talked about the positive impact on K's health and wellbeing as a result in her accessing a PHB. This has included K no longer taking medication linked to her condition. K's review will take place with her key healthcare worker (in K's case her Speech and Language Therapist) where K's identified health outcomes will be reviewed against the Support Plan, which was put in place as part of the PHB application process.



Think Local Act Personal

Think Local Act Personal (TLAP) is a national strategic partnership of more than 50 organisations committed to supporting the continued implementation of personalisation and community-based health, care and support.

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