Personal Health Budgets 2018
What every voluntary, community and social enterprise needs to know.
Foreword

Personal health budgets are being offered to people to help them take charge of their healthcare and choose new kinds of support that are the best fit with their lives. The voluntary, community and social enterprise (VCSE) sector could and should play a big part in making that change happen, both by helping people to access and use personal health budgets, and also through providing new kinds of support to choose from and purchase. VCSE organisations need to understand and prepare for the changes and opportunities which personal health budgets will bring. By VCSE organisations being part of designing and delivering those changes in local areas, many more people will be able to use their personal health budget as a route to healthcare which genuinely helps them to transform the experience of living with a long term condition.
Who is this report for?

- Voluntary, community and social enterprise sector (VCSE) organisations
- Health professionals and commissioners

There are already nearly 18,000 people using personal health budgets and this number is expected to grow rapidly. The NHS wants 100,000 people to benefit from personal health budgets by 2021.

In many areas, we know there is more that can be done to improve people’s understanding, access and ability to manage a personal health budget and more that can be done to develop innovative support services on which to spend a personal health budget.

The voluntary, community and social enterprise sector could use its unique ethos, reach and skillset to help many more people benefit from personal health budgets. VCSE organisations can do this in ways which are sustainably funded, drawing on their learning from engaging successfully with personal budgets in social care.

Health professionals and commissioners who work well with local VCSE organisations on personal health budgets will increase choice and achieve outcomes for a larger and wider group of people.

This guide shares some of the ways that voluntary, community and social enterprise sector (VCSE) organisations offer support for people who have a personal health budget and their families. It includes a series of case studies and recommendations for voluntary sector organisations and their partners.
What are personal health budgets and why are they important?

Personal health budgets are an important route towards personalised health and care for many people. They can enable people to make new choices, take more control and share responsibility for their own health and wellbeing.

Adults eligible for NHS Continuing Healthcare (CHC), or who have a fluctuating condition which means they are sometimes eligible, and children who receive continuing care can take control of the money allocated to their care. This is a personal health budget. They can ask:

- The NHS to manage that money for them - called a notional budget
- Or, with the exception of some individuals they can take that personal health budget in cash, which they manage and spend themselves on their support - called a direct payment
- A third option is to ask another organisation to manage the budget - called a Third Party Budget.

NHS organisations are able to offer personal health budgets to some groups of people with health needs and to ensure that people and their families can get the information they need to be able to decide whether to take a personal health budget, and to use it well.

People need information, advice and brokerage support to access a personal health budget and use it well, and the voluntary sector can play a vital role in helping people to understand, access and make good use of personal health budgets.

Personal health budgets are one, vital part of a deeper shift towards a new range of health and care services which:

- See good lives, wellbeing and resilience as their ultimate goal
- Think about the whole-person, whole-family and whole-community
- Offer more choices and rights, but which are also clearer about how people can share responsibility for their own health and care

These wider shifts are set out in the NHS England Personalised Health and Care framework and Integrated Personal Commissioning operating model. The Joint VCSE Review made recommendations for how VCSE organisations and their local partners can develop effective, personalised and sustainable health and care responses.
Most people using healthcare do not know about personal health budgets, or do not fully understand them. Each regional and local area needs a comprehensive information strategy which reaches groups and communities who might otherwise be overlooked, with accessible, well-tailored information.

**NHS AND VCSE ORGANISATIONS WORKING TOGETHER**

VCSE organisations which have a track record of reaching local communities may be able to reach groups or communities which local NHS organisations have struggled to reach consistently. VCSE organisations are often particularly good at involving people (including those from often overlooked groups) in co-designing accessible information and may wish to use peer approaches, or develop a coproduction network. This information-giving work may not be directly funded by personal health budgets, but investment in it is a crucial part of increasing the numbers of people who use personal health budgets and their impact.

**INVOLVING THE RIGHT PEOPLE IN CREATIVE CARE PLANNING**

Some people and families can make creative choices with little help. But to ensure that all groups and communities have access to new choices, each area needs to take a strategic approach to identifying and reaching those groups who need support and offering them Information, Advice and Guidance (IAG) services, many of which are delivered by the VCSE sector. This can include peer-support from people with lived experience of personal health budgets.

**WHAT DOES A GOOD LIFE LOOK LIKE?**

A personal health budget is effective when it starts with a creative care plan, which has the input of medical professionals and people from outside the NHS. Even where an individual requires very complex medical care to stay safe and well, the starting point for a great care plan is not “Which service does this person need?” but, “What does a good life look like to me, and how can I and the people who support me work towards it?” The input of VCSE organisations can ensure that care plans stay person-focused, imaginative and that they draw on all of the resources available in the local community.

**CONNECTING WITH THE RIGHT SUPPORT ORGANISATION TO MAKE DECISIONS**

VCSE organisations can be well-placed to offer individual support with choosing, managing and reviewing support services, including managing money and staff or contracts with support providers. There are online systems which organisations or individuals can use to keep track of money and to pay organisations or staff. Many people would benefit from more personal support at key times such as choosing a form of support, reviews of their support package and when there is a change or problem. Organisations which provide brokerage services need to have good links with different kinds of support provider and have the opportunity to use what they learn about what people want and choose to improve services. Brokerage services can offer individuals support with setting up a trust to manage their budget.

Independent organisations offering third party budgets will help the personal health budget holder to identify what they want and are able to afford with their budget, and will help them to make and review their choices.

For instance, the organisation might help the individual choose a team of personal assistants (PAs) which are employed by the organisation, rather than directly by the individual. Where that organisation is also providing the support itself, that kind of Third Party Budget may be Individual Service Fund (ISF). ISFs are already an established way for VCSE social care provider organisations to support people to make more active choices and take more control over social care personal budgets. Similar principles and practices (outlined in guidance from Think Local, Act Personal and others) can be applied to ISFs in health as are used in social care. ISFs involve the least structural change, which can make them more achievable but are more vulnerable to a window-dressing approach which does not result in real change.
So it is vital that VCSE support providers involve people who use services and their families from the start in a design process which explores how they can make genuinely different choices and take real control over their services and lives.

**ADVOCACY GROUPS CAN HELP NAVIGATE THE SYSTEM**

Some people find that too many rules and processes are put around how they access, plan and use their personal health budget. Great support from statutory organisations and from local advocacy organisations can tackle this and also have a positive impact on the wider culture of local health and care systems. This can be achieved in part through advocacy and voice organisations supporting local people to tell local system leaders their views about the kinds of service they value, or would value if they were available. VCSE organisations which bring people together who have the same condition or community background can help actual and potential personal health budget holders to share learning with each other and to explore pooling some of their resources. This can enable people to purchase more cost-effective support, or exercise more commissioning power.

This means that an effective personal health budget programme must be woven in to a wider programme of community building and connecting work, much of which will be delivered by local charities and community groups. Some groups of people will even benefit from involvement in starting up new small community enterprises and user-led organisations.
What do VCSE organisations and their partners need to think about?

In order to provide effective and sustainable support to personal health budget holders, there are some challenges for VCSE organisations to overcome, with help from NHS and other local partners.

MOVING FROM A TRADITIONAL FUNDING MODEL

Some existing organisations, particularly those which work on a small scale with a particular group or local community, can struggle to move from a traditional funding model such as a grant, to more variable funding through personal health budgets. Procurement processes which are designed for larger organisations may inadvertently exclude very small organisations or start-ups which have no track record, but those may be exactly the kind of innovators which the local marketplace needs to create real choice.

VCSE support providers will need to adapt their offers to the expectations of personal health budget holders and to become part of local systems used to enable those individuals and families to contact and choose from support providers, such as e-marketplaces, pre-paid cards and framework agreements. VCSE organisations will need to model personal health budget income and expenditure, which can be less predictable than traditional grant or contract income.

An example:

One Centre for Independent Living (CIL) reports setting up a personal health budget support service with its own resources, in liaison with the local clinical commissioning group (CCG,) which was valued by a small number of personal health budgets. But the service proved financially unviable due to the small numbers involved, in an area with low personal health budget take up. The CIL felt that CCG investment and deeper understanding of the role and value of the VCSE sector would have helped their service and also increased personal health budget take up.

Whilst many CILs can draw on the expertise they have already developed through supporting social care users with direct payments, some have not sufficiently understood the added complexity of working with people with very complex medical needs. VCSE organisations are likely to need expert advice on this and new partnerships with health organisations.
Recommendations for VCSE organisations:

VCSE organisations should ensure their support and advice teams understand what personal health budgets are and how they can benefit people, drawing on both national guidance and the local strategy and infrastructure.

VCSE advice and support offers should draw on asset-based thinking and on learning from Self Directed Support programmes in social care, whilst also recognising the added complexities for some people with very complex medical needs. For some, the initial goal may focus on managing pain or symptoms, or achieving a better level of health more consistently. Stable, effective care can then provide a platform on which to pursue ordinary living goals.

VCSE INFORMATION, ADVICE AND GUIDANCE ORGANISATIONS SHOULD:

- Measure and demonstrate their success in helping people to make creative and effective choices, including people from overlooked or under-served groups and communities.
- Build links with provider organisations in order to understand what can be delivered via personal health budgets and also to inform the design of support services.
- (If bringing people together around shared needs, identities or goals, including specific conditions) explore how people eligible for personal health budgets can connect with each other, share learning and pool resources.
- (If providing care and support services) market their support to personal health budget holders (both those with managed budgets and those with direct payments) and develop ways for individuals to purchase their services directly.
- Consider how people with lived experience can be involved and employed in IAG and brokerage roles.

Local infrastructure organisations should offer support to VCSE provider organisations with modelling unit costs and return on investment, and with planning and managing risks.

VCSE support providers should develop Third Party Budget approaches (drawing on learning from the social care ISF model), which give people more choice and control of their support and their lives.
Recommendations for commissioners

Commissioners should gather information from personal health budget holders and the VCSE organisations working with them, including:

- What personal health budget holders are choosing and why
- Personal health budgets holders’ experiences of the support they choose
- Forms of support which personal health budget holders would like to choose but which are not available, and views on how existing services could be adapted and improved.

Commissioners should:

- Work with the VCSE sector to identify those groups which would benefit most from new choices and increased control and those groups which are most likely to miss out without support to make choices, so that experiences and outcomes for those groups and communities can be tracked and plans made to increase reach to them.
- Build a diverse local market place of VCSE organisations offering information, advice, brokerage and support. Health organisations should co-design assessment, planning and review processes with people with lived experience of personal health budgets, via VCSE partners and user-led organisations which can reach and engage with them.
- Invest in start-ups, innovators and very small social enterprises to broaden choice for people using personal health budgets. Commissioners should invest in VCSE infrastructure organisations which can support small, specialist and community-specific organisations to promote equality of access to personal health budgets for poorly-reached local groups and communities.
- Work with VCSE organisations to develop and resource brokerage approaches which combine the use of technology, creative planning and clinical expertise.

Local health and care systems will need to continue to provide grant and contract based funding to some small and specialist support organisations to ensure they can move successfully to the new system and that they can manage peaks and troughs in demand.

There are also some kinds of VCSE organisations, such as some information providers, which are essential to ensure equality of access to personal health budgets, but which cannot be funded through personal health budgets themselves. Again, these may require more traditional funding. It is important that local people who use healthcare and their families are involved in identifying organisations which they value and in making local planning and investment decisions.

Some VCSE organisations have found that engaging with people who have taken direct payments has been easier than offering support to people with notional budgets, where rigid NHS procurement processes may still be applied. Commissioners should work with local people and providers to develop procurement processes which enable choice and innovation. Healthy local marketplaces of support provision will include organisations of all sizes, including very small organisations, which may require specialist support from a micro-enterprise support agency (such as Community.
NHS ORGANISATIONS AND THEIR PARTNERS SHOULD:

- Engage with non-traditional providers and innovators which can offer personalised care, or could develop offers with CCG support, (such as Community Catalysts.)

- Co-design e-marketplaces and other purchasing systems with people who use services and their families, local VCSE organisations and providers, ensuring that a balance is struck between managing any risks, ensuring choice and the need to build a more diverse marketplace of providers.

System leaders should avoid a narrow focus on the number of people using personal health budgets, judging the success of their personal health budget programme also on:

- The diversity of their provider market, including evidence of innovation and start-ups

- The outcomes and experiences of people using personal health budgets and their families, including people who experience health inequalities

- Evidence that the personal health budget programme is increasing coproduction of health and care services and systems, boosting citizen voice and improving relationships with the VCSE sector

- Evidence of increased social action and added Social Value.
Examples and learning from local areas.

Helping people to make choices and use a personal health budget.

**USING A PERSONAL HEALTH BUDGET TO MOVE INTO ADULTHOOD - Cheshire**

Cheshire Centre for Independent Living help people who control their own care or health budgets to manage their resources, make choices and live well. Ms Black is a 20 year old lady with profound and multiple learning difficulties and complex physical health needs. She loved school and had received great care from children’s services, but they were very anxious about the lack of coordinated planning as Ms Black reached adulthood. CCIL established with the CHC team that young people’s services could be extended to age 25 and also a 12 month extended transition with the school so that Ms Black could continue with hydrotherapy and other effective therapies. The CIL gathered costs and evidence from several agencies and professionals to establish a step down plan for when school ended and stimulation. The family now have a clear plan of care providers and meaningful community engagement.

**VALUING THE WHOLE PERSON - London**

Age UK Islington’s personal health budget support planning and coordination service is being developed within the support they offer to all groups. They use a structured approach and work towards a consistent set of outcomes, with a strong focus on prevention, self-care, social prescribing and wellbeing to provide health navigation, community enablement and support. Age UK Islington’s personal health budget support planning and coordination service is being developed within the support they offer to all groups. They use a structured approach and work towards a consistent set of outcomes, with a strong focus on prevention, self-care, social prescribing and wellbeing to provide health navigation, community enablement and support.

**CREATIVE SUPPORT FOR BUSY LIVES - Sussex**

Sussex-based charity Independent Lives has a clinical nurse training service called “Your Training Your Way”. They deliver bespoke training to a personal health budget holder’s PAs to undertake care and clinical tasks such as enteral feeding, tracheostomy, catheterisation and gastronomy care in a person centred way. One budget holder said, “The nurse team have been so responsive in finding options that work for us and that will fit into a busy schedule.” This approach enables Natasha’s PAs to accompany her to personal health budget funded activities and live a busy life: enjoying rebound therapy, music and drama at a local college, hydrotherapy, ICT, yoga, cookery and sensory art. Natasha’s Mum, Glenys now works for Independent Lives as a personal health budget adviser drawing on her lived experience to which gives people confidence in her: “Knowing that I also manage my own personal health budget for my daughter who has complex needs in her: “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”.

**MUTUAL SUPPORT - Essex**

Husband and wife Jonathan and Debs started up a user-led peer support project called Sociability which helps people with mental ill health to ‘recover’ through mutual support to design their care and use a personal health budget where needed. Sociability is built from their own experiences of using health services. Jonathan says, “Like everyone else with mental health needs I have resources and assets, I’m not just a diagnosis or a collection of problems. I have skills I can share, and I want to share them.”

**BUILDING INFORMAL NETWORKS - Sheffield**

Age UK Sheffield Independent Living Co-ordination Services take a whole-person approach to helping people who could use a personal health budget to navigate services but also to build into care plans support for carers and family and help to build long-lasting informal support networks. The service uses a ‘guided conversation’ approach to understand both their needs and aspirations. So for one individual, alongside formal care and support services, advice on tackling her debt, benefits income and lack of central heating or hot water were vital steps towards living well, as was being able to afford a pet dog who has become a big part of her getting exercise and being outside in the community. For another individual who has dementia and cancer, redirecting some of her limited resources towards transport solutions meant being able to access activities and the family caravan with support, which gives her family breaks to enable them to sustain care at home.

A coaching approach can help people using the service or their families to search for solutions which feel like the best fit to them, alongside the research carried out by the service itself.

Finalising the support plan can be as much an emotional as a practical process, as people adjust to their new role within a more self-directed system.

**Examples and learning from local areas.**

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1. Don’t focus on the condition. People value a personalised approach and understanding of their lives and goals more than an in-depth medical knowledge of their condition. For instance, getting transport sorted might feel just as important as physiotherapy.

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VCSE organisations delivering care and support to personal health budget holders

FLEXIBLE SUPPORT - Somerset

Keir uses a wheelchair and very limited movement from the neck down requiring support with all aspects of daily living. He and his partner Janet live in Somerset, and for nine years have used their personal health budget for a combination of agencies, employed PAs and local self-employed community micro-providers. Keir explained “We didn’t want all our eggs in one basket; we wanted some flexibility and choice.” The family use agencies in the mornings for Keir’s early starts, PAs during the day and Louise, a micro-provider who offers physiotherapy, reflexology and support for the whole family. Louise finds self-employment enables her to manage her own time and terms of her service, working with local families. Both parties value the close relationship they have built up and the flexibility this gives them as circumstances change. One Community Catalysts coordinator supports Louise and 250 such micro-providers who each have highly tailored support offers.

DIVERSE SERVICES TO HELP PEOPLE OUT OF HOSPITAL AND LEAVE INSTITUTIONALISED CARE - Newham

Newham Shared Lives Scheme developed what had previously been a social care service into a new form of support for people recovering from stroke, who were otherwise at risk of remaining in the medical system, due to barriers to returning home such as inaccessible accommodation or inappropriate housing. CQC-regulated Shared Lives schemes recruit and carefully approve people to become Shared Lives carers, then match them with an adult who needs support. The adult moves in with their chosen Shared Lives carer to live as part of the household, or visits them regularly for short breaks. Shared Lives schemes have also developed mental health support which keeps people out of hospital and have helped people with learning disabilities from the Transforming Care group to leave institutionalised care and live in an ordinary family home and community. All of these groups can purchase Shared Lives using a personal health budget. Shared Lives Plus is working with NHS England and seven CCGs to scale up Shared Lives as a new form of health service.

MAKING THE MOST OF FUNDING FOR ADDED SOCIAL VALUE - Warrington

In Warrington the CCG works with a number of VCSE organisations to provide information and brokerage support to develop a support plan. Some of these organisations can also provide support with payroll and training staff to people who go on to use a personal health budget, as well as offering some support, activities or equipment themselves. For instance, local charity, Warrington Disability Partnership offers information, guidance and payroll, as well as having a mobility equipment showroom and a wheelchair user group. St Rocco’s Hospice is a first port of call for people approaching end of life and their families who are looking for information and support about their care and treatment, including personal health budgets options. Alongside block-contracted bed provision, it also offers personal health budget-purchased hospice at home support and complementary therapies. Building on existing, well-trusted organisations and relationships enables the CCG’s VCSE partners to do more with modest infrastructure funding and the CCG to get added social value for the money it and individuals spend.

Personal health budgets can help to redesign local health systems

DEVELOPING NEW PATHWAYS ACROSS HEALTH, SOCIAL CARE AND EDUCATION

In Control were invited to work with one family after being sent a detailed letter of complaint about the huge range of services involved in their care of their pre-school child who has significant and complex health and disability conditions. These included housing, acute health, long term health, a provider agency, education and social care. The family were finding the list of people to negotiate, liaise and comply with exhausting and experienced contradictions, date clashes and role confusion, despite Mum giving up work to care and co-ordinate full time. In Control liaised with all the agencies and helped the family define the main issues. The family was able to resolve the acute health care issues, access and use a personal health budget, and coordinate a sustainable approach from professionals in primary and a wide range of secondary health services, children’s services, education and housing. Learning from the situation, In Control reflect back to the agencies the experience of this family and others, supporting the CCG to develop a new personal health budget pathway including co-designed protocols and policies.

CCG PARTNERSHIP WITH HOSPICE AND VOLUNTARY SECTOR – THINKING DIFFERENTLY

A partnership between Southern Derbyshire Clinical Commissioning Group, Treetops Hospice Care and Erewash Building Community Resilience brought together the CCG’s oversight, administration and audit process with the Hospice’s ability to identify people who could benefit and support them to plan creatively as well as person-centred care and support planning for support staff from Erewash Community Resilience. They have found that wider use of the new approach to support planning helps everyone think differently, even if it does not directly lead to a personal health budget. Systems have been streamlined (including virtual personal health budget panels rather than waiting for face to face meetings), staff across the system have been “given permission to think and act differently” and attitudes such as “this is the way we have always done it” have been challenged constructively. This has been time consuming but “success breeds success.”
Support and further guidance

1. THE KEY PEOPLE IN YOUR AREA
The key people to talk to in your area about how to develop your offer to personal health budgets and the relevant local partners are:

- Local VCSE infrastructure organisations, such as a Council for Voluntary Services (CVS)
- User-led and self-advocacy organisations and forums
- Social enterprise support organisations
- Condition specific organisations
- Family carer support organisations

Each area’s CCG should have a designated lead for personal health budgets. The local HealthWatch and Health and Wellbeing Board may also be a source of information and support.

2. LINKS TO THE IPC PROGRAMME RESOURCES AND REGIONAL NETWORK
There is a wide range of resources on personalised care and commissioning here: [www.england.nhs.uk/pc]

Further guidance on personal health budgets here: [www.england.nhs.uk/personal-health-budgets]

3. KEY ORGANISATIONS AND WHAT THEY OFFER
Think Local, Act Personal: a wide range of tools and guidance on making personalisation real, including a model for coproduction: [www.thinklocalact/personal.org.uk]

The Coalition for Collaborative Care brings together people with long-term conditions, and health, social care and voluntary organisations to develop personalised care: [www.coalitionforcollaborativecare.org.uk]

Community Catalysts: support to develop community enterprises and more diverse local marketplaces of provider organisations: [www.CommunityCatalysts.co.uk]

In Control: research, resources and help for families with personalisation and self-directed support: [www.in-control.org.uk]

People Hub: an organisation of people and families who use personal health budgets: [www.peoplehub.org.uk]


Volunteering Matters: guidance on developing volunteering within health and care services and promoting active citizenship for people who use services: [www.volunteermatters.org.uk]

Skills for Care: online guidance to support personal health budget holders to employ their own care and support staff. They also have funding available to train individuals to be employers and develop the skills of the staff they employ: [www.skillsforcare.org.uk/epahub]

4. LINKS TO OTHER RESOURCES AND GUIDANCE
Chapter Two of the Five Year Forward View
The Delivery Plan
The Joint VCSE Review Final Report and Recommendations
High Impact Actions from the People and Communities Board