

PERSONAL HEALTH BUDGETS: Including people with learning disabilities

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February 2014

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Summary and key messages

This guide has been developed from work with three sites and a network of individuals and organisations who are supporting the roll out of personal health budgets to people with learning disabilities. There are a number of case studies and examples from the sites and network included in the report, which reflect the situation at the point of publication. Alongside this report, there are six stories about people with learning disabilities on the personal health budgets website including two films. See www.personalhealthbudgets.england.nhs.uk/About/Stories

The guide is organised around the personal health budget 'markers of progress' that require specific consideration to ensure success for people with learning disabilities and their families. For further information see: www.personalhealthbudgets.england.nhs.uk/Topics/MarkersOfProgress/

The markers of progress have been designed to fit with Making it Real. www.thinklocalactpersonal.org.uk/Browse/mir/

This work adds to the evidence that a truly personalised approach has big benefits for people with learning disabilities and their families, especially those with the most complex needs. Personal health budgets are a valuable means to this end.

There is also the potential to make much better use of public money, bridge the gaps between NHS and council services for children and adults, promote change in the provider market, and develop the role of the voluntary sector.

Personal health budgets (or joint health and social care budgets) could and should be offered routinely to:

- Young disabled people who are moving towards adult life
- People being moved from unsuitable placements as part of the Winterbourne View action plan
- Other people with learning disabilities or autism who have high support needs and are not well served by conventional service approaches.



The key messages from the network of individuals and organisations who contributed to this guide are:

- The introduction of personal health budgets offers local leaders a great opportunity to work together with disabled people, their families and local services, ensuring that systems and processes are designed to support individuals rather than individuals being ‘fitted in’: “your care, your way, your say”.
- Guidance on NHS Continuing Healthcare and on personal health budgets emphasises a ‘can do’ approach to improving choice and control and to positive management of risks. The bar should not be set higher for personal health budget holders. The plan and budget should be about the whole person and the support they need to lead a full and active life, not just health needs or health care.
- Best practice in support planning is for this to be separate from assessments for eligibility and for budget holders to have a choice of assistance, including organisations external to CCGs and councils (e.g. led by people with lived experience). Support planning needs to be informed by clear clinical advice. People should get the same opportunities and access to specialist support regardless of which organisation (children’s services, adult services, NHS or local government) is responsible for funding their care.

It is important to work across health and social care and with organisations providing care and support to ensure that a wide range of support options are available. Individual service funds (ISFs) offer a way for some people who do not want to take on direct management of their personal budget to still get increased choice and control via a chosen provider.

Introduction

Why offer personal health budgets to people with learning disabilities?

By April 2014, people eligible for NHS Continuing Healthcare (NHS CHC) will have the 'right to ask' for a personal health budget. From October 2014 they will have the 'right to have' a personal health budget (subject only to clinical or financial grounds that are deemed to make a personal health budget unviable). The NHS can also offer personal health budgets (including direct payments) to people with long term health conditions or those with mental health problems. Personal health budgets are aimed mainly at people with significant health needs, providing a potential win-win opportunity for the NHS to address health inequalities and improve health outcomes for those who are not well served by conventional (often high cost) services.

This report focuses on people with learning disabilities who have complex health needs or behaviour that is viewed as challenging (including those who have autism).

People with learning disabilities who are eligible for NHS CHC are likely (compared to other NHS CHC recipients) to have more complex support packages and to require such support for decades, e.g. over 50 years for a young person entering adulthood. People with learning disabilities experience significant health inequalities, which the NHS has a duty to address, and significant social disadvantages. Personal health budgets can help the development of innovative support packages for young people in transition to adult life and individuals who may otherwise end up in high cost, poor quality services like Winterbourne View. The Winterbourne View stocktake¹ highlights the following area (amongst others) for development locally:

"increase the understanding and application of personalisation for all individuals, notwithstanding the complexity of their situation".

¹ Local Government Association and NHS England (2013) Winterbourne View joint improvement programme. Stocktake of progress report. September 2013

Thus personal health budgets should be considered for all people identified in relation to the Winterbourne View programme. Early learning from the personal health budget pilot sites and the implementation of personal budgets in social care showed that self-directed support could lead to better outcomes for marginalised groups and people with complex needs, including people with learning disabilities. The evaluation report for the personal health budget pilot² showed that:

“Separating personal health budgets into high-value (i.e. a budget of more than £1,000 per year) and low-value, it was the former that showed a significant positive impact on care-related quality of life (ASCOT) and psychological wellbeing (GHQ?12)”.

GOOD PRACTICE EXAMPLE

Jason³ lived in a long stay in-patient unit for 22 years. When he first moved out, some of the staff transferred to a support agency to provide his care. This did not work very well: the system was institutional and inflexible. Jason’s sister asked about a personal health budget, as she had heard about the impact a personal health budget had had on a patient in the national pilot.

Over the next few months things changed considerably for Jason. His sister became his appointee. With help from an independent support agency she was able to recruit a whole staff team and give the team leader more autonomy in developing a care plan that allowed both flexibility and creativity. Jason is now fully involved in his own care planning. He has moved from his original rented home with all its restrictions to a self-contained bungalow on a farm where he is

surrounded by animals (a similar environment to that in which he grew up). His sister has purchased a car on his behalf and the staff can take him out regularly.

Since moving to his new home there have been no incidents of self-harm, and there has been a significant reduction in the frequency and duration of Jason’s seizures. His sister and staff believe this is down to a more flexible structure and enabling Jason to use up his surplus energy by going for walks. Jason’s challenging behaviour has ceased and there is no need for 2:1 or 3:1 staffing. He is now part of the local community and is a frequent visitor to the local pub and social events in the village, supported by one of his team of local workers.

Jason continues to have his problems, but his sister reports that his life now has meaning and not just containment and survival.

² Forder et al (2012) Evaluation of the personal health budget pilot programme www.pssru.ac.uk

³ An amalgamation of three stories from Dorset, to protect confidentiality

Specific considerations

Implementing personal health budgets requires a change in commissioning practice to planning for one person at a time, ensuring there are appropriate supports and services in place for people to choose. This may include, for example, a pool of individuals willing to be employed as personal assistants and registered providers that can offer personalised support. Alongside this, commissioners will need to sustain access to a range of specialist expertise to underpin and complement individually arranged packages of support. As Clinical Commissioning Groups (CCGs) roll out the availability of personal health budgets, they will need to take account of some specific considerations to ensure that people with learning disabilities are included and well supported. These are detailed in this guide; in summary, they include:

- Understanding, and committing to, implementation of personal health budgets for people with learning disabilities as part of the wider personal health budget programme, including ensuring that links with local stakeholders, involvement of potential beneficiaries and provision of information and advice are inclusive of people with learning disabilities, their family carers and the range of organisations that support them.
- Taking account of the wide range of health and social care support that may be required to promote independence and enable a person with learning disabilities to lead a full life, including skilled support to plan and a positive approach to managing risk.
- Developing a variety of ways for people who lack capacity to manage a budget themselves to benefit from the flexibility of personal health budgets and to contribute to regular review of outcomes achieved.

Currently many NHS CHC teams do not have much experience of working with people with learning disabilities and there are often poor links between these teams and specialist learning disability services. Many learning disability practitioners also have a low awareness of how NHS CHC can work and the potential of personal health budgets for this group. Successful roll-out will require increased confidence in joint working: both co-production with people with learning disabilities and their families and joint working between teams with different kinds of expertise.⁴

⁴ Useful 'frequently asked questions' and 'jargon busters' can be found at:
National framework for NHS continuing healthcare and NHS funded nursing care: Annex A (p.120)
www.gov.uk/government/publications/national-framework-for-nhs-continuing-healthcare-and-nhs-funded-nursing-care
www.personalhealthbudgets.england.nhs.uk/About/healthCareProfessionals/faqs/
Think Local Act Personal social care jargon buster: www.thinklocalactpersonal.org.uk/Latest/Resource/?cid=9555
inControl personalisation glossary: www.in-control.org.uk/support/support-for-individuals,-family-members-carers/glossary.aspx?page=0

About this guide

This guide was commissioned by Think Local Act Personal as part of the personal health budget toolkit, to supplement the generic tools. It is intended to be used alongside the personal health budget 'markers of progress'⁵ to help CCGs and their partners ensure that roll-out takes account of the specific considerations needed to include people with learning disabilities and their families. It retains the numbering from the full set of personal health budget 'markers of progress' to make it easier to cross-reference, but focuses on those markers where local experience suggests that such specific consideration is most needed.

These markers have been designed to fit with Making it Real, which sets out what people who use services and carers expect to see and experience if support services are truly personalised. CCGs can declare a commitment to Making it Real and use the personal health budget markers of progress as a way to understand their local progress. For more information on Making it Real www.thinklocalactpersonal.org.uk/Browse/mir/

⁵ www.personalhealthbudgets.england.nhs.uk/Topics/MarkersOfProgress/



Marker 1: We have strong local leadership – people really want to change the culture

Why is this important to people with learning disabilities and their families?

Strong local governance structures for the implementation of personal health budgets for people with learning disabilities (as part of the 'usual business' of personal health budgets and linked to other structures such as Health and Wellbeing Boards and Clinical Commissioning Group Boards) help ensure that the programme is robust and owned by the wider health and social care community. People with learning disabilities experience significant health inequalities, the determinants of which sit mainly outside health services, therefore wider ownership and understanding of the issues faced by people with learning disabilities is important, and the programme should include a clear remit to ensure equal access and reduce health inequalities. Local authorities have a wealth of experience regarding personalisation that should be drawn on to improve chances of success.

Governance arrangements should include people from a wide range of groups, and ensure the voices of people with learning disabilities and family carers are heard, retaining a focus on issues that matter to people who use services and their families. Failure to support people well can entail significant costs, not just for the individual concerned, but all partners. 'Out of Sight'⁶ includes a number of examples of service failures resulting in costly placements in assessment and treatment units, often far from home. For example, Jo became unsettled after there were changes to his supported living arrangements, which were not resolved despite repeated requests from the family. Eventually there was an incident that led to Jo being sectioned and sent to a unit 130 miles away from his family home.

Working together is crucial to ensure good support for people with complex needs, but can be challenging when the partners have differing priorities, targets or approaches. Practitioners cannot resolve such differences alone – commitment to shared aims is needed from local leaders. Leadership can also be important to resolve 'boundary' difficulties such as:

6 Mencap and the Challenging Behaviour Foundation (2012). *Out of Sight*. www.mencap.org.uk/campaigns/take-action/out-sight/out-sight-report



- Concerns about information sharing between different teams or organisations, particularly in relation to people who lack capacity to consent to sharing their personal information. The recent 'Caldicott 2' report⁷ was helpful in setting out clearly the dangers of failing to share information appropriately, within agreed protocols
- Collaboration problems, such as some services (for example, day services) refusing access to personal assistants (PAs)
- The continued right of access to health services that are not included in the personal health budget.

What we have learnt so far

What is going well locally

- **Hull and Somerset:** having a persuasive champion such as the lead commissioner or assistant director of nursing.
- **Somerset:** having a project board that included relatives, and a representative from the local authority.

⁷ Caldicott, F. (Chair) (2013) *Information: To share or not to share? The Information Governance Review*. London: Department of Health

- **Kent:** teaming up with social services where there is a track record of implementing direct payments.
- **Kent:** being in a partnership that can drive up quality and achieve savings (Kent is part of SE 7, seven councils that have committed to working together under a Memorandum of Understanding).

Issues and challenges

- Services have experienced considerable upheaval due to health service re-organisation including changes in personnel, resulting in loss of expertise in some areas. New arrangements have sometimes resulted in a lack of clarity regarding roles and responsibilities, and relationships need to be re-established.
- The championship of personal health budgets for people with learning disabilities often sits with a small group of people, making the programme vulnerable to changes in personnel.
- A joined up approach between health and social care is vital for people with joint funding, both to maximise benefits and to avoid decisions in one area having unintended consequences in another. For example, in one authority the council will only fund support at home up to a certain level; above that the person has to go into residential care. They lose their home and, very often, their skills. If the person subsequently becomes eligible for NHS CHC and would have liked to have a personal health budget for support at home, the CCG is constrained by the effects of the previous council decisions.

Short examples of good practice

- Somerset share an example of how personal health budgets are making a difference at every meeting of their project board, and Hull frequently share success stories.
- Kent and Hull recommend starting with a relatively small cohort in order to build confidence.

Practical tools/resources

- **National collaboration for integrated care and support**
Framework document and guide to person centred perspectives on integration:
www.england.nhs.uk/2013/05/14/c-care/
- **Association for Supported Living (2011)**
'There is an Alternative' Report with good practice examples of alternatives to inpatient care:
www.challengingbehaviour.org.uk/strategy-group/resources-and-links/other-resources.html

Marker 2: We work together with people and families

Why is this important to people with learning disabilities and their families?

Co-production, involving people with learning disabilities and their families at the heart of planning personal health budgets, helps keep services focused on what matters to people who use them and their families. Peer networks and support can enable people to play a leadership role in the development of personal health budgets locally and can also encourage others, such as those who may not be so aware of personal health budgets, to become engaged. This means that specific attention is needed to including people with learning disabilities and family carers in planning (such as personal health budget steering groups or boards) and peer networks. People who lack capacity to make decisions about their support and/or their budget must still be included in whatever ways work for them.

Two groups who are likely to need specific consideration as personal health budgets are rolled out are people with profound intellectual and multiple disabilities and people who display behaviour that challenges. Family carers can be sceptical about new ways of providing support unless they can see and hear examples from families 'like ours'. This means it is particularly important to be able to connect people who may be eligible for personal health budgets, and their families, with a wide variety of personal health budget holders.

It is also important to involve and listen to both people with learning disabilities and family carers: both have valuable expertise, yet their perspectives may not be identical.

What we have learnt so far

What is going well locally

- **Kent:** working with a group of parent carers to develop an integrated pathway throughout children's services into adulthood.
- **Manchester:** supporting peer networks of family carers, including an Asian families peer network.

- **Nottingham City:** the peer network “tell it like it is”.
- **West Sussex:** supporting three family carers to tell their stories provided powerful learning for local managers.

Issues and challenges

- People with learning disabilities and their families are not always in touch with local support groups, and local learning disability groups are not always well connected with mainstream public involvement networks. People with learning disabilities who are used to speaking up in meetings such as partnership boards may need extra help to involve and/or represent the perspectives of people with higher support needs.
- Family carers of people who may be eligible for personal health budgets are often spending so much time and energy on care-giving that they have no capacity to participate in meetings – and they may not be confident computer users.
- Involving people with a range of needs, including people who lack capacity to manage a personal health budget and family carers who are tired, requires a variety of methods. This may include, for example, email, text, social network media and individual contacts in addition to conventional meetings. Many areas have so far done more to involve family carers than people with learning disabilities who might be recipients of personal health budgets.

Short examples of good practice

- Dorset gave an example of working sensitively with an older family carer (aged 84) to develop a range of options for their relative: “If you liberate people to talk to you (rather than filling in forms), you get different information and can come up with different answers”.
- Family carers from West Sussex said, “Information from other families is powerful”. Peer mentoring is being explored as a way of connecting families who already have some experience with those who are just starting out, to share ‘things you wish you had known’. Some families already do this informally, for example via private Facebook groups.

Practical tools/resources

- **Involve Me Practical Guide**
How to involve people with profound and multiple learning disabilities (PMLD) in decision-making and consultation: www.mencap.org.uk/involveMe

- **Partners in Policymaking**

A range of courses aimed at helping disabled people, family carers and staff to work together respectfully: www.in-control.org.uk/what-we-do/partners-in-policymaking.aspx

- **Personal Health Budgets guide: Ensuring equal access**

Advice on a range of equalities considerations, with practical examples and a 'thinking tool': www.personalhealthbudgets.england.nhs.uk/Topics/Toolkit/MakingPHBshappen/EqualAccess/

- **Co-production in social care: What it is and how to do it.** SCIE Guide 51, October 2013

Co-production is a key concept in the development of public services. It has the potential to make an important contribution to all of the big challenges that face social care services. This is a guide to what co-production is and how to develop co-productive approaches to working with people who use services and carers. It is aimed at managers and commissioners, frontline practitioners and people who use services and carers. www.scie.org.uk/publications/guides/guide51/

Case study: West Sussex

Where

The West Sussex area comprises three Clinical Commissioning Groups: Coastal West Sussex, Crawley and Horsham and Mid Sussex.

Who is involved

Work on personal health budgets for people with learning disabilities eligible for NHS CHC is being led by 'Independent Lives' (formerly The Independent Living Association (ILA)) in partnership with the NHS CHC team (part of the Joint Commissioning Unit across health and social care and across CCGs). Independent Lives is a Centre for Independent Living and a community hub. The Independent Lives Personal Health Budget Lead works particularly closely with the learning disability leads in the NHS CHC team.

What West Sussex have done

West Sussex were a 'wider' pilot site for personal health budgets (i.e. not subject to in-depth evaluation), including the option of offering direct payments. Independent Lives has already supported 14 young adults with learning disabilities through the personal health budget

process, working closely with the NHS CHC team. This combination of skills and perspectives is highly valued by the families involved. Independent Lives is contracted to provide assistance with support planning: they do a lot of work with families, recognising them as experts, and are now trialling 'one page profiles' as part of the support planning process. Families feel this provides a good balance with the detailed clinical information required to plan with people with learning disabilities with complex health needs and severe learning disabilities, and people who display challenging behaviour. Personal health budgets have helped the families to take a lead in designing support and employing people who know and understand the person, so that they can stay in their local community. Independent Lives is gathering a range of useful information and local contacts to stimulate ideas about what is possible.

What West Sussex are planning to do next

Key actions for West Sussex are now to:

- Establish a range of peer networks of people using personal health budgets to support each other and to influence both commissioners and support providers. This might include a variety of ways for people to meet, both in person and through email and social media groups and webinars. A mentoring scheme has now been set up for families who already have a personal health budget to mentor new referrals and the feedback is really positive. A webinar meeting is being planned for families to discuss their experiences around postural care.
- Enhance access for people with learning disabilities and families to information (about planning, options, local 'offers').
- Continue to explore innovative ways of using personal health budgets, e.g. pooling resources, integrating health and social care funding.
- Link learning from personal health budget implementation with both 'Support and Aspiration' developments for young people and the personalisation strategy for adults.
- Align processes further between health and social care so that people have a common experience however their support is funded. Linked to this, clarify that people eligible for NHS CHC or a personal health budget are still able to use other NHS services.

Marker 3: We work with all the important people to get the message across

Why is this important for people with learning disabilities and their families?

Implementing and embedding personal health budgets for people with learning disabilities will require engagement with a wide range of services, in addition to people themselves and their families. For example, services working with an adult who has profound intellectual and multiple disabilities might include:

- Advocacy
- Family carer support organisation
- Social care services (e.g. providing support at home and to participate in social and leisure activities)
- Community learning disability team (health and social care professionals)
- Primary care
- NHS CHC team
- A range of community and hospital based health services (e.g. neurology, diabetes care, wheelchair service).

Some health services will be less familiar with person centred approaches to support for people with learning disabilities. Some of the learning disability services will be less familiar with how health services work. It will be important for disabled people and families to get consistent information about what is possible from the services they know. Service providers will also need to understand, anticipate and respond to the changes in demand that may result from personal health budgets, so ways of sharing this intelligence are important as commissioners learn more about what people want.

Practitioners and support staff will need training on personal health budgets for two reasons:

- So that they understand how personal health budgets work and their potential, and can explain this to people with learning disabilities and family carers
- So that they understand the implications for their own practice and how they may need to work differently.

Commissioners will need to ensure that personal health budget holders continue to have access to the range of specialist services that may be required to back up the direct supports that budget holders purchase, such as community learning disability team, specialist behavioural support, continence advice and equipment services. Commissioners will need to ensure such services understand their responsibilities to personal health budget holders and the implications for their practice.

Brokerage and other support services with generic experience in supporting personal budget/personal health budget holders may have training needs in relation to working with people with learning disabilities and their families.

There are significant differences (in both health and social care), between services for children and young people and those for adults. Yet continuity of care is vital for people with high health care needs. Education Health and Care Plans, as proposed in the Children and Families Bill, hold promise for improved integration of support and improved continuity into adult life; at the time of writing the approach is still being developed. Strong connections are needed between services for children and young people and those for adults to ensure that:

- Preparation for adulthood starts early, and young people and their families are well informed about options for support in adult life
- Transitions (which may happen at different ages for different services) are managed smoothly
- Services for adults are well informed about young people approaching adulthood and the types of support they may want and need.

GOOD PRACTICE EXAMPLE: TRANSITION IN HEALTH CARE

The story of how Mitchell got a personal health budget in his teens has been told before by his mum, Jo. Now that Mitchell is 21, the story can be updated.

Alongside the process for deciding about funding, Mitchell's family needed to negotiate new relationships with a range of health services, as many services for adults are different from those for children and young people.

Few young people with Mitchell's complexity of need had made the transition to adult services in their local area, so Jo and the commissioner agreed to set up a multi-disciplinary 'transition health' group to think through all the issues. This group included

the NHS commissioner, NHS Continuing Healthcare Co-ordinator, paediatrician, transition social worker, community nurse and hospital learning disability liaison nurse. These people brought a range of useful expertise; there were no 'off the shelf' services that suited Mitchell and they were good at helping with problem solving. Visits to the hospital helped build relationships; one of the senior nurses came to one of Mitchell's meetings and the consultant was also invited. A personal care pathway was agreed for Mitchell, which includes advance management plans ("if this, then that"), and the key consultant wrote letters to specify what should happen if he were not available.

What we have learnt so far

What is going well locally

- **Kent:** running multi-agency workshops for CCG clinical leads, and having face to face meetings with them; presenting to Public Health.
- **Hull:** working with clinicians and social workers to explain personalisation and personal health budgets as a 'tool'.
- **Nottingham City:** the CCG and the council are working together (for example, on a joint brokerage service), so messages are consistent.
- **Somerset:** the assistant director of nursing was a key person in getting personal health budgets going.
- **Somerset:** offering experiential training – getting staff to think about what is important to them and then apply this thinking to disabled people. 'Stories are very powerful'.
- **Manchester:** offering 'Getting the conversations right' training. The overall purpose of the training is to help staff consider the process and conversations that support individuals and their carers in making decisions about personal health care and personal health budgets through:
 - understanding the rationale, overall process and potential benefits of personal health budgets
 - reflecting on their own approach/philosophy of care and how this fits with a 'personalised' approach
 - understanding the consultation skills and the consultation framework that support personalised conversations.

Issues and challenges

- Some primary care services (including GPs, dentistry and optometry) may have been used to more institutional styles of service for people with learning disabilities (e.g. most people attending a day centre) and may find it difficult to understand and adapt to the personalised model of support.
- Young people and their families are not always getting accurate information from children's services about the options as they move into adulthood. For example, NHS CHC for adults (18+) works differently from continuing care for children and young people. Different health and social care services change at different ages; young people who already have a personal health budget or those who may take one up as an adult need clear messages about what to expect.
- People with learning disabilities who are eligible for a personal health budget may have a range of support needs that require collaboration between a variety of services (including, for example, social care, mental health, forensic and criminal justice agencies). Devising a successful support plan may require sign-up from all these agencies, including a common approach to managing risk. Councillors may also need to understand and support such approaches.

Short examples of good practice

- Somerset's project board includes GPs and representatives from brokerage organisations and care homes.
- Dorset worked closely with the learning disability specialist teams, so they contribute to support planning and service design and offer training tailored to the individual.
- Hull's work with clinicians and social workers to explain personalisation and personal health budgets has taken time, but now "people start talking about [personal health budgets] without us" and practitioners have started to approach the personal health budget team with ideas about how to support someone differently to achieve the desired outcomes. Hull suggest that the best way of learning is by doing, as "Every one is different – we have had to learn as we go".

Practical tools/resources

- **Preparing for Adulthood programme and resources**
This programme provides knowledge and support to local authorities and their partners, including families and young people, to ensure that disabled young people achieve better life chances as they move into adulthood. See: www.preparingforadulthood.org.uk/
- **Communication and people with the most complex needs**
Information about what works and why this is essential: www.mencap.org.uk/all-about-learning-disability/information-professionals/communication

Case study: Manchester

Where

The Manchester project covers the three Manchester CCGs (North, Central and South).

Who is involved

The personal health budget project team is hosted by the city-wide commissioning, quality and safeguarding team. There is a peer network of family carers and a team of service auditors from Manchester People First. The chair of Manchester's Partnership Board sits on the Health and Wellbeing Board.

What Manchester have done

Manchester were an in-depth evaluation site for personal health budgets and are currently one of nine 'Going further, faster' sites that have committed to rolling out beyond national policy requirements. Manchester have taken part in work to offer personal health budgets to people with learning disabilities.

Manchester have worked hard to raise awareness of personal health budgets. They already have 70 personal health budgets in place, so they have plenty of experience. They provide training on personalised care planning and personal health budgets called 'Getting the conversations right'.

What Manchester are planning to do next

Manchester are now working to implement personal health budgets to people identified as needing to move following the Winterbourne View report. There are 29 people in total, some of whom are funded through NHS Continuing Health Care and some of whom are jointly funded.

Manchester are developing an external brokerage market and have provided accredited training for their external brokerage organisations, so they can achieve a common standard.

Information on personal health budgets is mainly in paper format, so the Manchester team are developing an app which can be used on an iPad. The app will be voice activated, and include video clips. A local community-based company are developing it.

Manchester have access to the multi-disciplinary learning disability team as well as an outreach team for people with mental health problems and learning disabilities to help them with the people identified through the Winterbourne View work. They aim to work with two people initially, and learn from this to inform the rest of the work. There is more to do on understanding and managing risks with these individuals, developing the market, and aligning systems between health and social care, but they have a wealth of learning to draw on, including work with children's services on bringing budgets together as part of the Right to Control and SEND pathfinder projects.

Marker 5: We provide clear information about personal health budgets

Why is this important for people with learning disabilities and their families?

Evaluation of the personal health budget pilots confirmed the importance for potential budget-holders of both clear information about personal health budgets in general (what is it, how does it work?) and opportunities for discussion about their own specific circumstances. Unless there is good information and confident exploration of the pros and cons for individuals, people may not understand the potential of personal health budgets and take-up will be low. People with learning disabilities need information in a variety of formats, including easy read, to aid understanding.

There is good evidence of an increasing number of people with learning disabilities who are caring for others (e.g. older parents or disabled partners)⁸ who may themselves be eligible for personal health budgets. The person with learning disabilities may therefore need accessible information about personal health budgets in order to help them in their caring role.

Ways of getting information to people with learning disabilities and their families may also need specific consideration, as they are often not well connected into the usual NHS patient and public involvement forums and channels. Many people still do not have ready access to information via the internet. Dissemination of information via advocacy and carer support organisations and specialist learning disability services is likely to reach a larger proportion of adults who might be eligible for a personal health budget. As noted under Marker 3, information also needs to reach young people who are approaching adulthood and their families.

What we have learnt so far

What is going well locally

- **Manchester:** developing an accessible app for use on an iPad to help a person with learning disabilities to be involved in planning their support.

⁸ www.fpld.org.uk/our-work/family-friends-community/mutual-caring/



- **Nottingham City:** Mencap are leading work to produce an information DVD for people with learning disabilities about personalisation processes in the City.

Issues and challenges

- It can be difficult to give budget holders all the information they might need, without overwhelming them. For example, new employers in Hull get an information pack, but this does not cover related issues such as how flexibly a budget can be used. This will need to be developed as the numbers increase beyond the level at which the commissioner can be personally involved with each individual.

Short examples of good practice

- The Manchester app enables people to develop their own support plan (with appropriate support). The app can be voice-activated and include video clips. This will give more people a wider range of ways that they can participate in planning; it gives them more control of the process and saves time.

Practical tools/resources

- **Personal health budget easy read leaflet**
www.gov.uk/government/publications/personal-health-budgets-easy-read-leaflet
- **Making written information easier to understand for people with learning disabilities**
Guidance for people who commission or produce easy read information:
odi.dwp.gov.uk/docs/iiod/easy-read-guidance.pdf

Markers 7 & 8: We help people to stay independent, and think about people's whole lives – not just their illness or impairment and not just their treatment. We make sure personal health budgets are not just about the money

Why is this important for people with learning disabilities and their families?

Personal health budgets should cover the full range of health and social care needs, not just health care, and work particularly well with people who have greater needs. For example, highly individualised support across housing, health and social care, directed by the person with learning disabilities and/or their family, proved successful for people whose behaviour presented significant challenges, in terms of both outcomes and value for money.⁹ Likewise, individualised support for people with profound intellectual and multiple disabilities resulted in higher quality of life, prevention of some care needs and reduced demand on family carers.¹⁰

People with learning disabilities may need support with aspects of life that others take for granted, such as getting a job, getting about, managing personal finances, voting and staying in touch with friends, neighbours and family (as otherwise they are in danger of becoming isolated and vulnerable to abuse). Donna's sister said:

“Going out for a coffee or a day trip can be a huge achievement for Donna and make a big difference to her mental health.”

The NHS CHC framework¹¹ emphasises that the NHS must cover both health and social care needs for those who are eligible for NHS CHC, and personal health budget setting will therefore also need to take account of this range. The Confidential Inquiry into premature deaths of people with learning disabilities¹² found that people who died because of failures in

9 Department of Health (2007). *Services for people with learning disabilities and challenging behaviour or mental health needs (revised edition) (The 'Mansell 2' report)*

10 Mansell (2010). *Raising our sights: services for adults with profound intellectual and multiple difficulties.*

11 www.gov.uk/government/publications/national-framework-for-nhs-continuing-healthcare-and-nhs-funded-nursing-care

12 www.bris.ac.uk/icipold/

health care were less likely to have had significant other people in their lives. People with learning disabilities often have restricted social networks, and there is clear evidence that this has a negative impact on their health and wellbeing. Therefore supporting people to play an active part in their community is important both in terms of quality of life, and for reducing the health inequalities that people with learning disabilities experience.

What we have learnt so far

What is going well locally

- **West Sussex:** as a 'Support and Aspiration' pathfinder, looking at how Education Health and Care Plans can help with transition to adult life for young people with complex needs.
- **Somerset:** finding that personal health budgets were particularly beneficial for people with very complex needs who wanted to remain at home but were not happy with the standard of agency care.
- **Kent:** the pathway includes a multi-agency intensive support team, as the aim is to use assessment and support planning to understand the root causes of challenging behaviour and utilise the team to support families with early intervention and prevention strategies.
- **Kent:** learning from models used by people on direct payments such as pooling budgets with people who have similar interests/needs.
- **Somerset:** assistive technology can really help, and User Led Organisations (ULOs) locally know much more about this than health services.
- **Manchester:** a set amount is added into personal health budget calculations to allow PAs reasonable expenditure on activities.

Issues and challenges

- An inflexible approach to personal health budgets that focuses only on a person's health needs is still evident from some health professionals.
- An over-protective attitude by some health staff of 'their patients' with complex needs. While this may be motivated by good intentions, over-protection can significantly reduce people's ability to live life to the full.
- Busy professionals may prefer conventional packages of care as there is a perception that they are quicker and easier to set up. While this may be true in the short term, personalised support is more likely to meet the needs of people with learning disabilities (especially people with more complex support needs) and thus prove more robust in the longer term.
- Although people on NHS CHC and personal health budgets still have right of access to the full range of NHS services, as set out in the NHS CHC framework, some staff think they do not and some policies are unclear on this point. This must be clarified in local protocols.

- Housing can be a key component of the package, but access to advice about housing options is often missing and thus people may assume the only alternative to the family home is some form of institutional care. NHS commissioners are not always clear that the NHS does have powers to contribute to the costs of accommodation.

Short examples of good practice

- Manchester have found that brokerage can help people to think about community connecting, not just paid-for services.
- Manchester have a local community interest company that will act as tenancy guarantor.
- In Plymouth a local housing trust (linked to the Housing & Support Alliance) is bringing in new investors to increase housing options. Two people in Plymouth have gone for shared ownership.

Practical tools/resources

- **10 features of an effective process**
Alakeson, V. (2012). Personal health budgets for Continuing Health Care: the 10 features of an effective process. Wythall: In Control: www.in-control.org.uk/media/119345/10%20features%20of%20an%20effective%20process%20final.pdf
- **Preparing for Adulthood**
The site has lots of resources to support young people: www.preparingforadulthood.org.uk/
- **Health Inequalities and People with Learning Disabilities in the UK: 2012**
This publication gives detailed information about the health inequalities people with learning disabilities experience: www.improvinghealthandlives.org.uk/publications/1165/Health_Inequalities_&_People_with_Learning_Disabilities_in_the_UK:_2012
- **Joint Health and Social Care Self-Assessment Framework**
This self-assessment framework is designed to be used by local areas to assess how well they are doing at meeting the needs of people with learning disabilities: www.improvinghealthandlives.org.uk/projects/hsclsaf
- **The Inclusion Web**
The Inclusion Web can be used by services to assess how well they are doing at supporting people to be included in their local community. For further information see: www.ndti.org.uk/publications/ndti-publications/inclusion-web-resource-pack/
- **Commissioning services for people with learning disabilities who challenge services**
Good practice guidance for commissioners and providers of services for people who challenge: www.ndti.org.uk/publications/ndti-publications/commissioning-services-for-people-with-learning-disabilities-who-challenge-
- **Housing**
The Papworth Trust published a useful report on case studies about the value of timely adaptations, which can reduce needs for social care and health interventions: www.papworth.org.uk/downloads/homesolutionstoourcarecrisis_121113100850.pdf
Alicia Wood (Housing and Support Alliance) made a presentation to the Challenging Behaviour National Strategy Group (Oct 2013) on “Developing a local housing strategy”: www.challengingbehaviour.org.uk/learning-disability-files/Developing-a-local-housing-strategy.pdf

Marker 10: We treat people as equal partners and take a positive approach to risk

Why is this important for people with learning disabilities and their families?

As noted under Marker 2, it is important to recognise that both people with learning disabilities and their family carers are experts in their own lives. For example, Katy's mother, Jackie, said:

*"Although Katy cannot speak, she does have her own body language. But you can only know this language once you get to know Katy. At the day centre she would thrash her arms to indicate she wanted to go to the toilet. But this would be misinterpreted as an epileptic seizure. Katy would get so frustrated."*¹³

Sometimes an advocate may be involved as well as or instead of family, particularly if there are differences of opinion about how someone wants to be supported. Close involvement of people who know and care is especially important for people who have a learning disability and who also lack capacity to make key decisions for themselves about their support or about having a personal health budget.

Unless a balanced approach is taken to risk, people's lives may be unnecessarily restricted. 'Over-supporting' people can pose risks in itself; the concept of 'just enough' support is useful as a way of exploring the best ways of balancing choice, control and risk. Disabled people, family carers and staff from different services can have widely differing views about the nature of risks, their relative importance, and the best ways of managing them. Explicit discussion is needed to underpin co-management of risk and the bar should not be set higher for personal health budgets compared with conventional services.

It is also important to ensure that a variety of training is available for personal assistants (PAs). Some personal health budget holders will wish to organise this themselves; others will want help to decide about the kinds of training their PAs need and how to arrange this. Some personal health budget holders see advantages in using a registered home care provider that has a programme of training in place for staff; others do not.

¹³ www.personalhealthbudgets.england.nhs.uk/About/Stories

It is important for people to be able to make an informed choice. Training, support and supervision needs in relation to mental capacity and safeguarding should be considered in addition to direct care and support.

For some people with learning disabilities and complex health needs there will be particular issues in relation to interventions that might usually be carried out by a clinician. There are good examples of such tasks being delegated successfully to family carers and PAs, with appropriate training and support. Whilst progress has been made on agreeing policies and procedures in services for children, policies and practice still vary widely for adults and a better balance is required between clinical governance and safeguarding on the one hand and choice, control and positive risk management on the other.

What we have learnt so far

What is going well locally

- **Dorset:** a mainstream provider provides training to NVQ level 3. The learning disability specialist services provide training with regard to specific issues around the individual, such as working with challenging behaviour. They also train on clinical/invasive procedures and will sign these off.
- **Hull:** initially had a 'risk enablement panel' that discussed even simple pieces of equipment. Now it only meets to review exceptional cases, as managers have confidence in practitioners. A panel can be a positive forum for learning together if approached in the right way.
- **Somerset:** needs for training on clinical tasks/invasive procedures are identified as part of the assessment process and the brokerage service manage this case by case.
- **Nottingham City:** funding for some training is included in personal health budgets. A personal assistant pack is being developed that will provide links to all the training that is available, along with sources of funding such as Skills for Care.
- **Hull:** involving the ULO in the risk enablement panel helped them understand why certain provisions might be included in a support plan, so then they were able to provide the appropriate support.
- **Plymouth:** Beyond Limits worked hard with clinicians in inpatient services and the local community learning disability team (CLDT) to get agreements on support and risk management that would allow inpatients to be resettled to community support with Individual Service Funds. Whilst some inpatient services remain sceptical, the CLDT have recognised that Beyond Limits really 'stick with' people and invest in the training needed to make the support work.

Issues and challenges

- Staff anxiety about safety and loss of control can obstruct change.
- Registered homes are sometimes seen by practitioners or commissioners as the safer and easier option, compared to supported living, particularly for people who lack capacity if there are concerns regarding deprivation of liberty.
- Commissioners need to assure themselves that systems for assessing need and allocating budgets are fit for purpose in relation to people with complex support needs; some resource allocation systems may underestimate health needs.
- There is a debate about whether there should be core training for PAs or whether it is better to train on an individual basis. There is a balance to be achieved between the risk of over-regulating and creating a new profession, on the one hand, and on the other concern from the NHS about agreeing care plans (for example, with invasive procedures if they are not satisfied with arrangements for delegation).
- There have been some concerns that good PAs leave the field because there is no opportunity to develop, but increasingly there are opportunities to pursue 'core' qualifications that are usually transferable, and may also satisfy insurers. This may allay people's concerns.
- Local trainers can be valuable, but there was also concern about how one could be sure of the quality of people setting themselves up to do this.
- Health and social care need to support the availability of training and also ensure there are local assessors and peer support/supervision.
- Potential employers need support to understand the issues so they can make better informed choices.
- As well as PA skills, there are needs for skills in care planning, risk management and monitoring.



Short examples of good practice

- In Plymouth Beyond Limits organise separate 'service design' and 'working policy' days to ensure that the right people are involved in different stages of agreeing desired outcomes and then planning how to achieve these, including explicit discussion of risk and its management. They explain: "A Service Design day is the 'what' part of the planning process and the opportunity for those that know the person well to think positively about the future for them. The Working Policy Day is the 'how to' part of the planning process. This day looks at the detail of how to support the person and includes looking at when things are not going well for them."
- Dorset worked with people who were part of the local campus closure programme. Staff did not know what was possible. Dorset would advise others that there has to be a willingness to step into the unknown and take risks.

Practical tools/resources

- **Invasive procedures**

Garrard, B., Lambe, L. and Hogg, J. (2010). Invasive procedures: minimising risks and maximising rights. Improving practice in the delivery of invasive procedures for people with profound and multiple learning disabilities. Project report and recommendations. Dundee: University of Dundee.

Examples are given of a range of practical approaches to managing invasive procedures so as to enable person-centred support

- **Local authority support for people who employ personal assistants (PAs)**

The latest report into what local authorities across England are doing to support more than 100,000 people who employ personal assistants is now available. The research has been carried out by the Association of Directors of Adult Social Services, Learn to Care and Skills for Care. This is the second year the research has been undertaken and highlights the need for a long-term commitment both to enable individual employers to be good employers, supported by local authorities and other organisations, and also to help the 243,000 personal assistants (PAs) as employees through independent information, advice, guidance and peer support. See: www.skillsforcare.org.uk/paframework/

- **Individual service design**

Beyond Limits in Plymouth agreed to share their service design briefing. The documents are available at: www.beyondlimits-uk.org/p/how-we-work.html

Although written about older people, this guide contains relevant sections on managing risk: www.thinklocalactpersonal.org.uk/Browse/Co-production/Equalities/Olderpeople/?parent=8596&child=7085

- **Personal Assistant (PA) Framework and apprenticeship**

Although designed for social care, the Framework has many features that are relevant to all PAs: www.skillsforcare.org.uk/paframework/

The Skills for Care apprenticeship programme is also relevant to PAs: www.skillsforcare.org.uk/apprenticeships/

Marker 12: We provide advice and support to help people plan

Why is this important for people with learning disabilities and their families?

The quality of support people get to develop their plans is really important – those who assist with support planning need to be able to help people think creatively, link with a wide range of community resources, and focus on outcomes. Health practitioners need to contribute their perspectives as part of this, bringing skills in health promotion, prevention and management of health problems, and positive management of risk. Commissioners need to be aware that support planning with a person with learning disabilities can take longer than with some other groups, to maximise their involvement and to cover the complex mix of support needs that many people experience. Best practice in support planning is for this to be separate from assessments for eligibility and for people to have a choice of assistance, including from organisations external to CCGs and councils (e.g. led by people with lived experience).

Involving families and other supporters is a key skill. Providing them with real examples of what other people have done, and connecting them with other families, can help them understand and believe what is possible. Providing a continuum of choice and control with regard to managing the budget is also important. Family carers of people with learning disabilities play a particularly important role in facilitating involvement in assessment and support planning, and giving information.

As well as including family carers in support planning where possible, it is also important to consider family carer needs when planning. Research into carers and personalisation¹⁴ showed that family carers were not always informed of their own rights to an assessment and, as it was common practice to plan how a personal budget would be used at the same time as the assessment, there was no opportunity for any separate carer assessment to influence the personal budget or support plan.

Another important consideration is helping family carers to plan ahead for a time when they may be less able to provide care themselves or when they die. A mother said:

“I don’t trust anyone else to look after him like I do. I don’t want to think about the future, but if I die I want everything arranged as well as possible”.

14 NIHR School for Social Care Research (2013). *Carers and Personalisation*

What we have learnt so far

What is going well locally

- **West Sussex:** strong collaboration between the independent support planning organisation and the learning disability nurses in the NHS CHC team is seen by family carers as very positive and successful. "They made a huge difference."
- **Nottingham City:** Mencap are producing a DVD on the support planning process to help inform and prepare people with learning disabilities and family carers.
- **Nottingham City:** the CCG and the council are collaborating to offer a joint brokerage hub, with two health practitioner posts joining the existing hub (one to work with adults and one with children).
- **Hull:** have a simple and more complex support plan template. The ULO will provide as much support as necessary.
- **Hull:** a long term conditions matron was seconded as a 'care navigator' and helped a great deal with support planning with people who required more complex packages of support.
- **Dorset:** have engaged with the community learning disability teams around support planning to ensure there is a range of skills available to inform the process.
- **Dorset:** have an independent support agency rather than brokerage. The personal health budgets team work with the family and individual to put a broad brush support plan in place that gives an indicative budget. The support agency then flesh this out.

Issues and challenges

- Assistive technology is still under-used by people with learning disabilities in many areas, but has potential to give people more choices over their support and more control. It can also help people to feel more confident about taking managed risks.
- There are questions about the 'boundary' between support to plan and delivery of continuing support. For example, someone with learning disabilities who has had very limited chances in life may need to try a variety of activities in order to figure out what they enjoy. This kind of supported exploration is likely to be needed to contribute to the development of a support plan. Arguably it should not matter how this is arranged, as long as it is explicit.

Short examples of good practice

- In West Sussex and Kent family carers found that using 'one page profiles' and 'Planning in Health' tools was really helpful to give a rounded picture of their relatives. These tools could be used to generate brief bullet-point summaries of key issues for support workers.
- Manchester allocate an indicative budget for brokerage. Typically this will be 35 hours for a person with learning disabilities, rather than 15, in recognition of the time required to plan with people and to understand and plan for complex needs and risk.

Practical tools/resources

- **Support planning**

Cooper, O. and Warren, S. (2010). All Together NOW. Collectively figuring how to develop alternatives to just paid support. London: Paradigm, DELI Group. North West Joint Improvement Programme

Planning tools, including one page profiles and Planning in Health:

www.helensandersonassociates.co.uk

- **Features of an effective process**

Alakeson, V. (2012) Personal health budgets for Continuing Health Care: the 10 features of an effective process. Wythall: In Control: www.in-control.org.uk/media/119345/10%20features%20of%20an%20effective%20process%20final.pdf

- **Planning ahead with families**

Foundation for People with Learning Disabilities 'Thinking ahead' guide:

www.learningdisabilities.org.uk/publications/thinking-ahead-a-planning-guide-for-families

- **Outcomes**

The Health Equalities Framework is an outcomes framework based on the determinants of health inequalities: www.ndti.org.uk/publications/other-publications/the-health-equality-framework-and-commissioning-guide1

- **Information, advice and brokerage**

Think Local Act Personal collected case studies from local authorities and others through a call for practice in Spring 2013. The case studies have been categorised into the key themes of website, prevention, brokerage/ peer support, assisted signposting, self-funders/ financial advice, printed guides, remodelling services and carers: www.thinklocalactpersonal.org.uk/Browse/Informationandadvice/Informationandadvicecasestudies/

Case study: Nottingham City

Where

Nottingham City CCG covers the same area as Nottingham City Council.

Who is involved

A project manager based in the CCG commissioning team has continued to lead development work following completion of the personal health budget pilot. There is a peer network that includes family carers of people with learning disabilities: they 'tell it like it is' to inform personal health budget implementation. Development is supported by a project board; there are close working relationships with the City Council and the NHS CHC team.

What Nottingham City have done

Nottingham City were an 'in depth' pilot site for personal health budgets, including the option of offering direct payments, and are one of nine 'Going Further, Faster' sites. A major element of this work includes developing integrated systems and processes for joint budgets for people who access both health and social care services (for example, a joint brokerage hub and online directory of services). A 'Practitioner Information and Operational Procedure Document' was approved by the CCG's Quality Improvement Committee in July 2013 and sets out the vision for development as well as step-by-step guidance on process. Personal health budgets are being rolled out to anyone who is eligible for NHS CHC or has joint funding. 10 people with learning disabilities now have a personal health budget; most of these are younger people who have recently moved into adulthood.

What Nottingham City are planning to do next

Nottingham City have commissioned an information DVD for people with learning disabilities about personalisation processes in the City. Two health posts are being added to the brokerage hub (one to work with children and one with adults) and this will increase both the availability of health expertise to contribute to support planning and the capacity to work with children and young people. Peoplehub are offering training to enhance creative thinking about support planning. A personal assistant pack is being developed that will provide links to all the training that is available, along with sources of funding such as Skills for Care. Better information about the types of support and opportunities people want will be shared with providers to help develop the market.

Discussion with families and practitioners highlighted that there is more to do to:

- Improve transition from children's services to adult life
- Ensure that information is shared appropriately, gaining consent where possible and using Best Interests decisions, so that everyone involved in supporting a person and their family knows the key information required to be able to support the person well
- Build confidence and capacity in planning support with and for people who lack capacity to consent to key decisions, so that safeguarding is balanced with choice and control. Conventional types of support can be easier to arrange and feel 'safer', but experience with personal health budgets so far shows the value of personalised alternatives
- Increase the involvement of people with learning disabilities and family carers in the peer networking activity.

Options for agreeing desired outcomes and monitoring change over time are being explored (for example, the Learning Disability Star, the Health Equalities Framework).

Marker 13: People can take their personal health budget in different ways, depending on what suits them: direct payments, third party budgets and notional budgets

Why is this important for people with learning disabilities and their families?

People need to have choices about how to take their personal health budgets, or they may be put off using them. For example, a father from Norfolk said:

"... red tape could put some people off ... we're able to concentrate strongly on [our daughter's] care without having to do all the admin".¹⁵

Choice may include 'starting small', for example with a third party budget for the bulk of support and a small direct payment for something specific. This would avoid the need for the person or a representative taking on the legal responsibilities of being an employer.

Individual service funds (ISFs) offer a way for some people who do not want to take on direct management of their personal budget to still get increased choice and control via a chosen provider that both holds the budget and arrange direct support. For further information see: www.in-control.org.uk/media/128547/inc14877-sfreportsinglepages-web.pdf

As confidence grows, the person might then decide to take a bigger proportion of their personal health budget as a direct payment.

¹⁵ HomeCareDirect (2013) *The O'Sullivans – Making a success of a personal health budget in Norfolk*.
www.homecaredirect.co.uk/professionals/the-osullivans-making-a-success-of-a-personal-health-budget-in-norfolk/



Those managing a personal health budget (whether the person themselves or family carers on the person's behalf) differ in the amount of support they want with all the different aspects of managing a budget, employing staff, and so on. The options available¹⁶ are:

- A notional budget
- A third party budget (including individual service funds)
- A direct payment.

If a person has a direct payment, the NHS is not procuring a service so there is no requirement to use the standard NHS contract or local framework agreements. It is up to the person to choose the support arrangements. This also applies to third party budgets. The person should still be able to choose the provider that works best for them. If the person has a notional budget, the NHS arranges care as normal and the usual procedures apply. A direct payment can be managed using the following options:

- A bank account
- A managed account
- A prepaid card.

For people who have a learning disability and who lack capacity, the direct payment can be made to a representative, usually a family member. Katy's mother, Jackie, said:

"A personal health budget has given us control over who cares for Katy, how and when. I manage the carers myself ... Because I did not want to be involved

¹⁶ www.personalhealthbudgets.england.nhs.uk/Topics/Toolkit/HowPHBswork/Options/

in the legal and payroll side of employing carers we decided to have assistance from a charity called Enham. They took responsibility for the legal and tax affairs, payroll and insurance.”¹⁷

The best support services are able to flex their ‘offer’ according to individual needs and preferences. For example, a family carer who has had a lot of experience with managing a personal budget for social care for their son or daughter may need only minimal support with a personal health budget initially, but may want this to increase as they get older and more frail themselves. More significant change may be required at such a time; for example, many parents would say that they do not want their non-disabled children to feel obliged to take on full responsibility for managing a personal budget for their brother or sister, though they might well feel able to take on some aspects in addition to being an important member of their relative’s circle.

There is much that can be learned from the implementation of personal budgets within local authorities, with regard to both what to adopt and what to avoid, as there are significant variations in performance. For example, see the Think Local Act Personal review of personal budgets for older people: www.thinklocalactpersonal.org.uk/News/PersonalisationNewsItem/?cid=9426

There is a risk that people who have a learning disability and who also lack capacity to manage a personal health budget themselves will be left out, particularly if they do not have active family members involved. Third party budgets can be of particular value for this group; for example, individual service funds (ISFs) improve choice and control, and have been found to be beneficial for people who were (or were at risk of becoming) inpatients in assessment and treatment units. Mental Capacity Act principles apply to choice of budget management options just as they do to designing support – good practice involves listening to and involving the person and those who know and care about them, supporting decision making, and making best interests decisions where necessary.

What we have learnt so far

What is going well locally

- **Kent:** have a ‘Kent card’ (a card loaded with money that people can use).
- **Somerset:** the brokerage service can support people with managing their budget.
- **Nottingham City:** people can pool their budgets (or part of them) to achieve something together that neither could afford alone.
- **Nottingham City:** people who have both a personal budget and a personal health budget can have these ‘joined up’ through the brokerage organisation.
- **Dorset:** some family carers are getting together to form a third party organisation.

¹⁷ www.personalhealthbudgets.england.nhs.uk/About/Stories

Issues and challenges

- Maintaining flexibility and creativity once personal health budgets become more common and a commissioner can no longer be so directly involved in each individual plan.
- Developing a market of third party organisations to allow choice and meet local demand, and ensuring that budgets include a realistic allowance for such organisations' essential central costs, such as training and supervision.
- Some areas have encountered difficulties in working effectively with the Court of Protection and Court-appointed Deputies to ensure that people who lack capacity to manage a personal health budget are not left out. This can be a particular issue for people who do not have actively involved family carers or others who can represent their interests.

Short examples of good practice

- Hull suggest that in 'scaling up' there should be a distinction between essential requirements on individual budget holders and discretionary advice. For example, a CCG could set a requirement that all employers must have employer's liability insurance, but could decide for themselves whether or not to seek CRB (now Disclosure and Barring Service) checks.
- Hull: the User Led Organisation, personal health budget team and local credit union work together and tailor their support regarding budget management to meet individual needs.
- Dorset: the support agency can manage the payroll and work with a direct payment support service that that can act as a banker and accountancy service, removing many complications from personal health budget packages.

Practical tools/resources

- **Independent user trusts and other third party options**
This guide to independent user trusts sets out core principles, steps to setting up and considerations around governance.
Fitzgerald, J. (2011) Personal Health Budgets and Independent User Trusts. Blackburn: Mitchell James Ltd.): www.in-control.org.uk/what-we-do/health-programme/latest-publications/personal-health-budgets-and-independent-user-trusts.aspx
Department of Health (2012) Transforming care: A national response to Winterbourne View Hospital. Department of Health review – final report. London: Department of health: www.gov.uk/government/publications/winterbourne-view-hospital-department-of-health-review-and-response
- **Gives examples of using individual service funds (ISFs)**
Tomlinson, C.I. and Livesley, M. (2013) Individual Service Funds for Homecare. Wythall: In Control: www.in-control.org.uk/publications/reports-and-discussion-papers/individual-service-funds-for-homecare.aspx
Gives further examples of using ISFs for home care; a benchmarking tool is attached to help providers improve their capacity to offer this option.

Marker 16: We check with the person and family to see how well things are going

Why is this important for people with learning disabilities and their families?

People with learning disabilities and families using personal health budgets are the best source of information on their effectiveness, and timely reviews (focused on outcomes) can maximise effectiveness and cost effectiveness. People should also have a range of ways of asking for advice or change in between formal review dates; developing relapse or contingency plans is one way of formalising this. The abuse at Winterbourne View showed what can happen when the voices of people using services and family carers are not heard.



Gathering information on outcomes and sharing learning about what works (and what does not), is also important for future service development and strategic buy-in. For example, the national collaboration for integrated care and support emphasises the importance of strategic support and scrutiny from Health and Wellbeing Boards, but they will need good information about the impact of personal health budgets in order to support their roll-out. Any system for collecting information should focus on outcomes.

What we have learnt so far

What is going well locally

- **Manchester:** People First have service auditors who check the quality of local services.
- **West Sussex:** the support planning contract with Independent Lives includes a fee for keeping in touch.

Issues and challenges

- Getting better information on outcomes that can be shared with people with learning disabilities and their families as well as commissioners and Health and Wellbeing Boards.
- Finding a way of collecting and collating intelligence about the needs and aspirations of people with learning disabilities and their families, thus informing Joint Strategic Needs Assessments, Health and Wellbeing Strategies and market development.

Practical tools/resources

- **Outcomes**

The Health Equalities Framework offers an outcomes framework that enables people with learning disabilities, family carers, support staff and health professionals to discuss risks to health inequalities, priorities for action and evidence of progress.

www.ndti.org.uk/publications/other-publications/the-health-equality-framework-and-commissioning-guide1

Conclusion

Implementing personal health budgets for people with learning disabilities can improve the quality of support, and thus the quality of life, for individuals and their families. They can be a valuable means to an end. People with the most complex needs, including people who challenge services and are at risk of ending up in in-patient services, may benefit the most. For some, implementation can also result in cost savings. However, it is important that personal health budgets are implemented in partnership with people with learning disabilities and their families, with the focus on full and active lives and ensuring that people have more choice and control over their lives. The 'markers for success' included in this document are designed to assist local areas with the implementation of personal health budgets for people with learning disabilities, drawing on a range of expertise in ways that promote positive outcomes. The 'markers' are supported by information and examples from sites that are already implementing personal health budgets for people with learning disabilities. We hope that you find them useful.

Acknowledgements

We would like to thank Manchester, Nottingham City and West Sussex for their help with the development of this document. These three sites were already implementing personal health budgets for people with learning disabilities; we supported their development with a workshop in each site and we drew on their learning to inform our work. More information about the sites can be found in the three case studies contained in the document.

In addition to work with the sites, we conducted telephone interviews with the following people, and would like to thank them for their time and helpful contributions to this document:

Bernadette Simpson, *independent consultant and author of the 'training and developing frontline staff' guides for the personal health budget toolkit*

Sam Sly, *Beyond Limits, Plymouth*

Martin Cunnington, *Kent and Medway Commissioning Support Unit*

Leigh Holton, *North East Lincolnshire*

Roger Webb and Ray Heal, *NHS Dorset Clinical Commissioning Group*

Liz Little, *Somerset personal health budgets pilot.*

We also talked to members of the National Forum and the National Valuing Families Forum.

We would also like to thank the NHS England personal health budgets delivery team and the members of the Personal Health Budgets for People with Learning Disabilities Network, for the information they provided to support this project and for their help with the development of this document. Network members are listed below:

Helen Akehurst, *NHS Anglia CSU, CHC Learning Disability Nurse*

Martin Ayres, *NHS Gloucestershire CCG, Senior Commissioning Manager (Learning Disabilities)*

Katherine Beard, *West Sussex Independent Living Association, Senior Personal Health Budgets advisor*

Martin Cattermole, *Personal health budgets advisor, NHS England*

Jackie Downing, *Guys & St Thomas' Community Services, Community Nursing, Development Manager, Adults with Learning Disabilities*

Matthew Fairhurst, *NHS Manchester/Manchester City Council, Support Broker*

Claire Geary, *Arden CSU, Learning Disability Nurse Assessor*

Mathew Griffiths, *Southwark Clinical Commissioning Group, Continuing Care Development Officer*

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Susan Harvey, *NEW Devon CCG, quality assurance Nurse Consultant*

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Helen Hemming, *NHS Manchester Central CCG, Personal Health Budgets Project Manager*

Adam Huszcza, *NHS Coastal West Sussex CCG, Business Development Manager*

Charlotte Infield, *CHCP Hull, Finance Administrator*

David Johnstone, *Personal Health Budget holder, Worcestershire*

Gemma Newbery, *NHS Nottingham City, Personal Health Budgets Pilot Project Manager*

Gary Parvin, *NHS Manchester Central CCG, commissioner*

Terri Phipps, *Southwark NHS, Continuing Care Broker*

Viv Soave, *Personal Health Budget holder, Worcestershire*

Andrew Tyson, *In Control, Consultant*

Roger Webb, *NHS Dorset CCG, Project Manager Personal Health Budgets*

Christine Witcher, *AgeUK Oxfordshire, Support Broker Manager*

Peter Witney, *Anglia CSU, Project Manager*

Tony Wolke, *Kernow CCG, Continuing Care Co-ordinator*

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Think Local Act Personal is a sector-wide commitment to moving forward with personalisation and community-based support, endorsed by organisations comprising representatives from across the social care sector including local government, health, private, independent and community organisations. For a full list of partners visit www.thinklocalactpersonal.org.uk