

Personal Budgets & Personal Health Budgets

Towards Co-production in Oxfordshire



By Keith Birnie & Jon Hyslop

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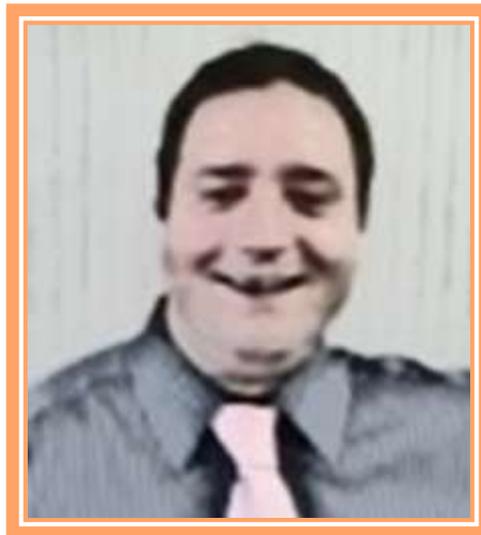
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Dedication

We'd like to dedicate this to the memory of Andy Crowe, formerly of Healthwatch Essex and ecdp (formerly Essex Coalition of Disabled People), who developed peer support among personal budget users and must have helped many thousands of people over a long career in the disabled people's movement before his untimely death in 2018.



To children of the early 1990s, Andy was known as Billy Homer in the BAFTA winning kids TV series 'Press Gang', first screened at a time when disabled people were just breaking through into the performing arts. Before going on to University, he became the first person in the UK to pass his driving test using a four-way joystick manufactured by Steering Developments Ltd.. His own studies led him to focus on assistive technology, before moving into disability rights and peer support.

Andy was an experienced Self-Directed Support Adviser, having worked for ecdp from the time before Personal Budgets became the norm in adult social care in 2008. Andy was an intelligent and empathic practitioner who understood the need to provide disabled people and their families and friends with support at the same time as helping them navigate the health and social care system.

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Acknowledgements

We gratefully acknowledge the co-operation and participation of the many organisations, individuals and groups who have generously collaborated with us to develop this vision over the past two years. It has taken a lot of trust, and we hope that this report honours the faith that people have placed in us. There are too many to name individually, but we are especially grateful to:

- All the personal budget and personal health budget users and family carers who spoke with us. Within this group we are particularly grateful to Don O'Neal, Christine Witcher and Kathy Liddell, all of whom wear multiple hats, and who put in much more than they get out!
- Adrian Chant and Rebecca Lanchbury of Oxfordshire County Council and Ellie Simcox of Oxfordshire Clinical Commissioning Group, who grasped the opportunity to pull things together across the local health and care system and commissioned this report.
- Andrew Tyson and Amanda Nally of Volunteering Matters and NDTi. Their positivity and expertise about national developments has been crucial in aligning our recommendations with innovations in other parts of the country.
- Debbi Challen and Lorraine Bairstow from Oxford Health NHS Foundation Trust, and the many local authority social care practitioners who helped us to think about how support could be co-ordinated across local authorities and the NHS.
- Stig (who drew the cover), for coping with unreasonable deadline pressure.

Summary

Oxfordshire County Council (OCC) and Oxfordshire Clinical Commissioning Group (OCCG) have asked us to work with local organisations, groups and individuals to make independent recommendations about how to improve support for personal budget (PB) and personal health budget (PHB) users. We have attempted to do this collaboratively, but the recommendations are ours alone.

In individual and group meetings, we have found that there is a great deal of knowledge and experience in Oxfordshire about how people can use personal budgets and personal health budgets to have better lives. This seems to be held by long-term PB/PHB users, carers, and people who were employed in health and social care services in the previous decade. We think the best way forwards is to build on this knowledge and experience, and make it more widely available to other people who could benefit from it.

We know that there are large and fairly stable numbers of people using personal budgets in Oxfordshire. Approximately 3,800 adults in the county use some sort of personal budget for long-term social care, around 1,400 of whom take their PB as a direct payment (see Appendix 3 for details). There are smaller but growing numbers of people using Personal Health Budgets, and using personal budgets to organise support for children with Special Educational Needs and Disabilities. In adult social care people now have to be experiencing a higher degree of hardship or disability to qualify as eligible, and many are being asked to make larger financial contributions to the cost of their own care. Care packages are frequently reduced on review, as the Council makes tough decisions against a background of reducing income and increasing need¹. In this context, we don't know how many more people will be prepared to take on the task of managing their own care and support through a PB/PHB. Our recommendation is therefore to begin by improving support for existing users.

We have found that:

- People who use PBs & PHBs have broadly consistent views about the areas in which their care and support could be improved, but don't necessarily know how this could be achieved.
- Statutory bodies, support providers, and the individuals and groups who connect personal budget users to support, have the aspiration to improve the range and quality of that support.
- The capacity to provide better support is limited by the available financial and staffing resources, which in most cases are shrinking.

We conclude that the best way to improve support is to build capacity and capability within communities, by working with organisations, groups and individuals who are already involved with PBs/PHBs, and reaching out to others who might be able to help.

We recommend that OCC and OCCG support this by:

- Creating a steering committee, linked with formal statutory structures (like the Co-production Board) and supported by one or more development workers.
- Developing a new Peer Network, supported by development workers, with a formal relationship to the steering committee.

We have five main sets of recommendations for specific pieces of development work that can be carried out over the next two years, using a community development approach. These relate to:

- Improving support for people at every stage of obtaining and managing a personal budget or personal health budget.
- Supporting people in their relationships with personal assistants.
- Improving the range and quality of support that people can pay for with personal budgets and personal health budgets.
- Helping PB/PHB users to work collaboratively with one another.
- Making the financial processes support the aims of increasing choice and control, instead of getting in the way of it.

The structure recommended should allow for new proposals to be incorporated in response to needs which emerge later on, and for pieces of work which are no longer relevant to be discontinued. Over time we imagine that some of the money used to pay for development workers will be replaced by longer-term funding arrangements to sustain successful development projects.

i. Oxfordshire County Council (2018) Service & Resource Planning 2019/20 to 2022/2: Report by the Chief Finance Officer/ Available at: <http://mycouncil.oxfordshire.gov.uk/documents/g5393/Public%20reports%20pack%20Thursday%202013-Dec-2018%2010.00%20Performance%20Scrutiny%20Committee.pdf?T=10> Retrieved on: 21/12/2018

Section1: Background, Co-production and Introduction



In July of 2017, we were contacted by the Engagement Team of Oxfordshire County Council because of a recommendation from their daytime support review.

“Personal budgets for people with eligible needs – supporting choice

We recognise that personal budgets and the choice it brings are not wholly welcome, and that for many people managing these and making informed choices is difficult. Nonetheless, it is important that people using daytime support have the opportunity to find out what is available and decide what works best for them, with the support they need to do this. We are proposing to invest an additional £100,000 per year, in supporting people to make choices. We will co-design this with people who would be eligible to use daytime support.”

They had contacted us because of a report we wrote in 2014, called ***Personal Budgets: Where Next in Oxfordshire***. The report had been commissioned by Healthwatch Oxfordshire at a time when personal budgets in the NHS (PHBs) were starting to become more common. The report made a series of recommendations about resources, support, bureaucracy and helping people to work together. The recommendations are in Appendix 4, and the full report is still available on our web site.

Also in July 2017 we were approached by Volunteering Matters, who were doing some work with NHS England trying to develop regional networks of voluntary sector organisations to support the implementation of Personal Health Budgets and Integrated Personal Commissioning (integrating Personal Budgets funded through lo-

cal authority adult social care services with Personal Health Budgets). According to NHS England, Integrated Personal Commissioning (IPC) aims to ...

“... ensure that services are tailored to people’s individual needs, building on learning from personal budgets in social care and progress with personal health budgets. Through IPC, people, carers and families with a range of long-term conditions and disabilities are supported to take a more active role in their health and wellbeing, with better information and access to support in their local community, and greater choice and control over their care.”

NHS England

*What is Integrated Personal Commissioning (IPC)?*ⁱⁱ

We have always sought to work collaboratively, and were happy to work with both organisations. We suggested that there would probably be a benefit in co-ordinating both these projects, because a lot of the people and organisations involved on one would probably be involved in the other. Volunteering Matters (VM), Oxfordshire Clinical Commissioning Group (OCCG) and Oxfordshire County Council (OCC) were also keen to reduce duplication and co-ordinate wherever possible. So from the autumn of 2017, we found ourselves part of an informal group working towards common objectives around the Council and NHS projects.

From the beginning, it was obvious that a lot of the groups, individuals and organisations who had been working on personal budgets and personal health budgets (PBs/PHBs) in 2013/14 were no longer active. Building involvement with local stakeholders therefore took time. By the spring of

2018 ourselves and VM had drafted a broad vision of what we wanted in Oxfordshire (see Appendix 2). However, this was nothing like a fully-developed commissioning strategy, and we had not shared it with enough people to frame it as a joint vision of what should happen. OCC and OCCG therefore agreed to delay the plan for improved support for PB/PHB users until the following year (April 2019). At the same time, they commissioned us to consult widely and develop this report, with the aim of informing more detailed proposals.

ii. Available at : <https://www.england.nhs.uk/ipc/what-is-integrated-personal-commissioning-ipc/> Accessed on: 27/1/2019

2. Co-production and producing this report

Our approach to developing these proposals

We acknowledge that the reason many statutory bodies are looking to community development models is to save money. OCC's daytime support review began with a target of saving £1 million, and sat within a wider context in which the Council needed to make £15.2 million savings between 2017/18 and 2019/20ⁱⁱⁱ. This year's draft budget proposes further cuts of £1.2 million this year and again next year by reviewing care packages for older people^{iv}. The £100,000 the Council proposes to spend on co-producing support for PB users is therefore in the context of a wider reduction in spending. Commissioned support for PB users in adult social care is at a much lower level than when we wrote our report in 2014, although support for NHS PHB users has grown. Our remit here is not to make recommendations about how OCC or OCCG should be making their financial decisions, but it's important to be realistic about what can be achieved with a relatively modest investment against a background of rising need and service reductions.

We believe that the limited investment that OCC proposes to make is best

spent using a community development model (see overleaf for a summary). This involves working with all stakeholders to co-produce support. Rather than starting with a grand plan to provide a comprehensive range of support for all PB/PHB users, we recommend beginning by working with people who are already using PBs/PHBs to improve their experience. This process has started with the group and individual meetings preceding this report, and the survey carried out by OCC in 2018. We recommend that it is continued in the form of a steering committee with representatives from all stakeholder groups, supported by one or more development workers whose role will also include supporting a new peer network of PB/PHB users.

Our approach in this report is to make recommendations about the best way a recurring £100,000 (perhaps with a contribution from OCCG for PHB users) can be used to grow community-based support. Like the overwhelming majority of the people we spoke to, we are opposed to the wider cuts to health and social care services, and continue to campaign against them. However in this report we have tak-

Six Components of Community Development

1. Help people to see that they have common concerns about local or other public issues, which they could benefit from addressing together, under their control.
2. Help people to work together on those issues, often by forming or developing an independent community group, supporting them to plan and take actions, and encouraging evaluation and reflection as a way of improving effectiveness.
3. Support and develop networking between communities and independent groups across the community sector and build links with voluntary sector bodies.
4. Promote values of equality, inclusiveness, participation and co-operation throughout the work.
5. Empower people and their organisations to influence and transform public policies and services and other factors affecting their lives.
6. Advise and inform public and private authorities on community perspectives and assist them to strengthen communities and work in partnership with them.

From Gilchrist, A & Taylor, M (2016)
The Short Guide to Community Development.

en a pragmatic approach to achieving the maximum benefit from the funding available by carrying out a series of linked developmental projects at the same time as building a sustainable network. This approach was agreed by participants at the planning meeting on 4/12/2018.

Co-production

In 2017 Oxfordshire County Council decided it was going to use an approach called 'co-production' to develop services in at least four service areas^v. People disagree about what co-production does and should mean^{vi},

but OCC has been collaborating with the Social Care Institute for Excellence (SCIE) on this project, and they say:

“Co-production has been broken down into the following:

- a. co-design, including planning of services*
- b. co-decision making in the allocation of resources*
- c. co-delivery of services, including the role of volunteers in providing the service*
- d. co-evaluation of the service.”*

SCIE (2015) Co-production in social care: What it is and how to do it, p.51. (our numbering)

Referring to these four elements may help to make clear the extent to which this report can be thought of as part of a process of co-production.

a: Co-design

We (Community Glue CIC) have been commissioned to write this independent report. Oxfordshire County Council and Oxfordshire Clinical Commissioning Group, which have paid us to write it, have not had a direct say in the contents, although representatives have been involved at every stage. Part of our remit was to talk to a range of key people and organisations involved in PBs locally, which we did together with colleagues from VM and the National Development Team for Inclusion (NDTi) in September and October, presenting our findings to an open meeting on 23/10/2018.

In November, we attempted to follow this up with conversations with individual PB/PHB users. This was much less successful, perhaps reflecting the difficult relationship between PB users and the local authority, which has been reducing entitlement and increasing charges over the past several years. This forced us to rely more heavily on our earlier conversations, our notes from the meetings held earlier (see Appendix 5), and a survey of personal budget users conducted between January and June 2018 (23 people responded). This is the information we used to identify the main issues, and to begin to develop solutions.

On 4/12/2018, we presented our proposals in the format presented here to the open group that had been working on PBs and PHBs since October 2017. We were able to gain detailed feedback, and in some areas refine our proposals further. A further meeting is planned in February 2019 to launch this report. From this point, we hope the group will transition into a steering committee to oversee the implementation of the recommendations in this report.

b: Allocation of resources

This report will make a series of recommendations about what is purchased with the money that OCC has earmarked for supporting PB users, but we have no control over whether our recommendations are accepted. Both OCC and OCCG have systems for stakeholder engagement in budgetary decisions, which are outside the scope of this report.

c: Co-delivery of services and volunteering

Community Glue is committed to working with the organisations, groups and individuals that are already helping to embed support for personal budget users in local communities. Our recommendation is that wherever possible, funding should be used to build this capacity, where necessary engaging with other local organisations and groups. This is consistent with a wide range of other community development approaches being introduced (or

in some cases reintroduced) both in Oxfordshire and more widely. These include the Community Circles approach ^{vii}, Local Area Co-ordination ^{viii}, the 3 Conversations Model ^{ix}, asset-based community development ^x and social prescribing ^{xi}.

An important element of our proposals is the creation of a new peer network to support PB and PHB users throughout the county. We are clear that to get the best out of volunteers, the network will need considerable input from paid staff.

d: Evaluation

Evaluation will be the responsibility of commissioners. However, if the proposals of this report are implemented, a steering group of local PB/PHB users and other stakeholders will continue to oversee developments from the work proposed here on an ongoing basis.

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- iii. Terroni, K. (2017) Daytime Support in Oxfordshire. Report by Kate Terroni, Director for Adult Service. Published 24/1/2017. Available at:https://mycouncil.oxfordshire.gov.uk/documents/s36119/CA_JAN2417R26%20-%20Daytime%20Support.pdf Retrieved on: 20/12/2018
 - iv. OCC (2018) Public Reports Pack: Performance Scrutiny Committee 13-12-2018. Available at: <http://mycouncil.oxfordshire.gov.uk/documents/g5393/Public%20reports%20pack%20Thursday%2013-Dec-2018%2010.00%20Performance%20Scrutiny%20Committee.pdf?T=10> Accessed 12/12/2018
 - v. Oxfordshire County Council (2018) Working together by co-production. Available at: <https://www.oxfordshire.gov.uk/residents/working-together> Accessed 26/12/2018
 - vi. Durose, C. Needham, C. Mangan, C. and Rees, J. (2017) Generating ‘good enough’ evidence for co-production. Evidence & Policy: A Journal of Research, Debate and Practice 13(1):135–151. doi: <https://doi.org/10.1332/174426415X14440619792955>.
 - vii. Helen Sanderson Associates (2018) Community Circles. Available at: <http://helensandersonassociates.co.uk/about/hsa-foundation/community-circles/> Accessed 26/12/2018
 - viii. Local Area Co-ordination Network (2017) Local Area Coordination in England and Wales – the core characteristics and design principles. Available at: <http://lacnetwork.org/wp-content/uploads/2018/02/Local-Area-Coordination-in-England-and-Wales-core-characteristics-2017.pdf> Accessed 26/12/2018
 - ix. Partners for Change (2017)The P4C 3 Conversations Model <http://partners4change.co.uk/> Accessed 26/12/2018
 - x. This model was developed by the ADCD institute in the USA. Their strategic partner in the UK is Nurture Development. They have a page about ABCD here <https://www.nurturedevelopment.org/asset-based-community-development/>
 - xi. Social prescribing is used to denote a range of non-clinical supports and services purchased by (or accessed through) primary care services. From 2016 the University of Westminster has hosted a social network in the UK. <https://www.westminster.ac.uk/patient-outcomes-in-health-research-group/projects/social-prescribing-networkprescribing>

3. What will happen, who will do it, and how will they do it

a. Who

We recommend that OCCG and OCC work collaboratively with existing organisations and groups, where necessary reaching out to re-engage groups that have disengaged from the development of personalised services in Oxfordshire, and developing new links with others who could potentially contribute to the process. Without being prescriptive about exactly who is in each group, we have identified four broadly distinct groups who can contribute to the process in different ways. We will refer to each of these types of group in each of the chapters that describe what we are proposing.

i. Statutory agencies

These include OCCG, OCC and Oxford Health NHS Foundation Trust. These are the organisations with a primary responsibility for designing the systems which make PBs and PHBs available, within statutory legal frameworks. They often employ people who assess who is eligible for support, and make the final decisions about what they will or will not fund through a PB/PHB. These agencies often have staff who are very skilled at working with people with specific illnesses or impairments, and may have existing contractual arrangements with organisations providing support of different types.

ii. Connectors

These are the organisations, groups and individuals that connect people who are allocated a PB/PHB with the support that they need to obtain funding and manage a support plan. At a formal level, they may be organisations such as Connection Support Direct Payment (DP) Service ^{xii} (which provides advice on every aspect of DPs including employing a PA) or Purple ^{xiii} (currently contracted to provide a managed account service to OCC PB users). At an informal level, it could be people's friends, family members (including informal carers), work colleagues, or members of disability-related organisations and social media networks where people share ideas and support one another.

iii. Providers

This group includes everyone who provides support through the use of a personal budget or personal health budget. There are two main sub-groups: those who are paid to provide support, and community supports which may cost relatively little in themselves, but which people need support to access. The first group includes PAs (whether they are employed by an agency, by a personal-budget holder or are self-employed), residential care services and the large number of charities and social enterprises providing creative,

tailored supports. The second group includes things like sport facilities, parks or allotments, clubs and societies.

iv. Peer network

There have been several attempts to create networks of PB users and support groups over the years, and we have been involved with most if not all of them. These are always challenging for a range of reasons:

- Most obviously, PB /PHB users are often unwell, have limited mobility, and informal carers are usually very busy. This makes regular attendance difficult.
- Finding a frequency, time and venue that works for everyone in a large and predominantly rural county is hard.
- Transport costs and the costs of additional PA support while attending the meeting are often prohibitive.
- People sometimes come to meetings with specific individual queries that the group is not capable of answering.
- Organisations have historically not been adequately funded to provide administrative support, and people have not always been able to confirm whether meetings were going ahead (or what was discussed at the last meeting).

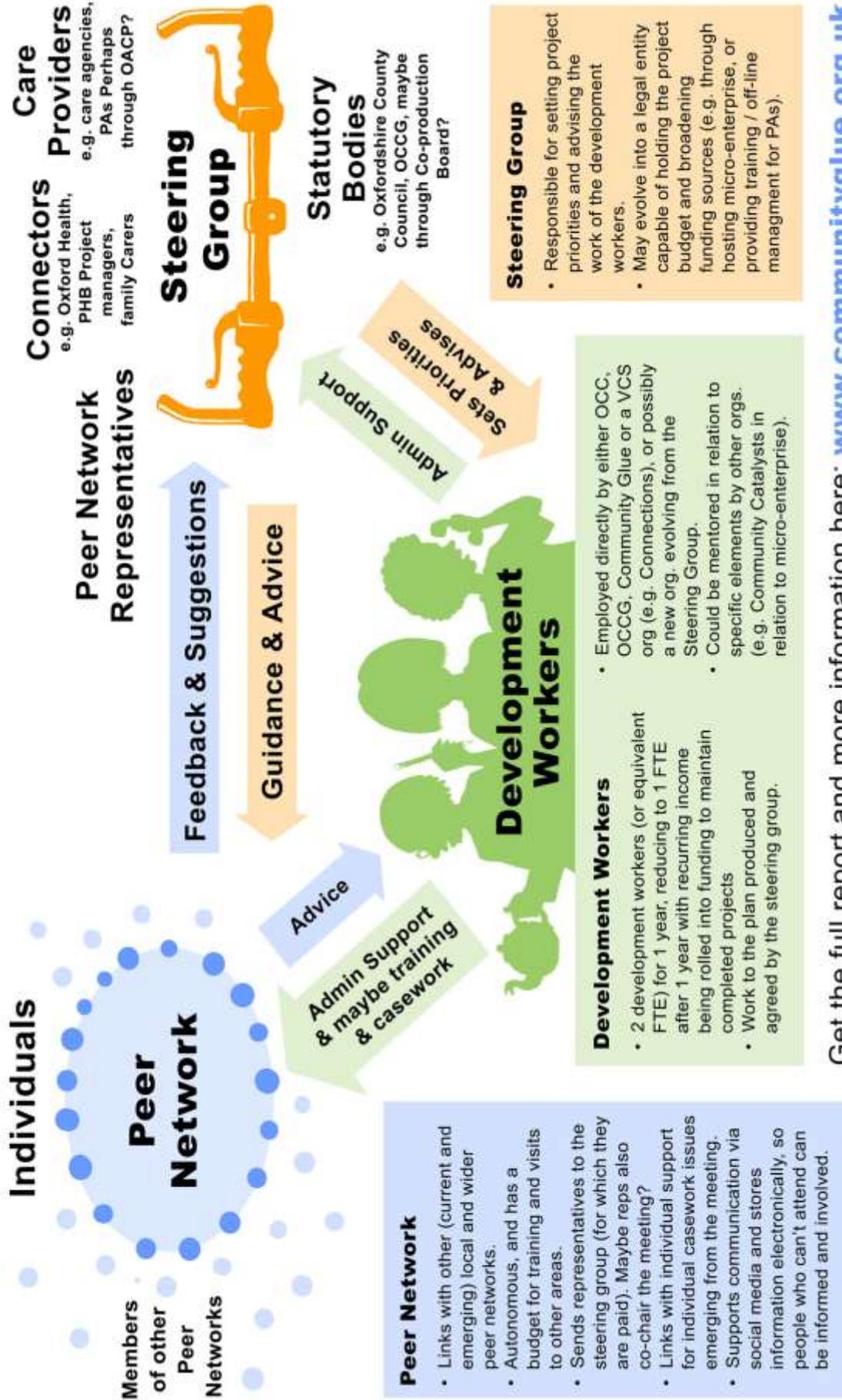
We have had links with groups in other parts of the country for nearly ten years. Our experience is that there is

no magic formula for a successful peer network. However, those groups that have had successful, long-term networks often have the following features:

- Accessible buildings with good transport links and a budget to reimburse people for the costs of their attendance.
- Guest speakers and listeners. Speakers can cover a range of topics of interest to PB/PHB users. Listeners can include managers from local statutory agencies and providers who are prepared to hear people's concerns.
- Administrative support to schedule meetings, book speakers, facilitate or chair (if necessary), and to act as a contact point.
- Links with case-work support for people with complex queries.
- Some sort of social media and phone/email support for people with queries arising between meetings, and for sharing details of what happened for people who couldn't come.

Links with statutory agencies are particularly important. Support groups need to be provided with up-to-date, reliable information about health and social care systems. For people with frustrations about the system, knowing that their concerns are being taken seriously and acted upon provides a powerful motive for engagement. For those agencies with a responsibility for providing PBs/PHBs, current service users provide an effective means of

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finding out what's working well, and what needs to be improved. For support providers, these meetings can provide up-to-the-minute intelligence about needs and gaps in the market.

b. What

We are making recommendations for developments in five main areas, which emerged consistently in discussions over the past year and a half. This is not intended to be a final list. On the contrary, we are expecting that new proposals will emerge through the steering committee and peer network, and some of our initial proposals will fail or be made irrelevant by developments in local or national social policy. This list is our starting point. Chapters 4 to 8 of this report respectively spell out these recommendations in more detail.

4. Improving support for people at every stage of obtaining and managing a personal budget or personal health budget.
5. Supporting people in their relationships with personal assistants
6. Improving the range of support available.
7. Helping PB/PHB users to work collaboratively with one another.
8. Making the money work, by providing people with better advocacy and advice around financial decision-making.

c. How

Development and Design

Appendix 2 contains a vision statement developed with local stakeholders that reflects our values. The process we are recommending is aimed at ensuring that people who use PBs/PHBs have the maximum possible choice and control over the decisions that affect their lives. In order to achieve this, we need to design a system that builds choice and control into the way that services are developed and designed, as well as the way that support is delivered. The diagram on page 9 shows how people would be involved at two levels. Firstly, a PB/PHB user will be able to attend or participate in a peer network, which should help people to share knowledge, build confidence and collaborate with one another. This peer network will also be a partner in a steering group, which will make the decisions about how (and whether) recommendations from this report and elsewhere get taken forwards. They would be supported by dedicated development workers to achieve this.

Community-based Support

In our view, support that is embedded in the same communities as PB/PHB users has a number of advantages over services provided directly by the Council or Oxford Health NHS Foundation Trust or commissioned from other providers. It is generally better trusted, can be more flexible in the

way it's delivered, is very cost-effective when delivered by volunteers, and can build confidence and knowledge about using PBs and PHBs within communities. However, support from social workers and NHS staff is still vital. As well as making the decisions about eligibility, risk management and safeguarding, staff have a wealth of experience about what has worked well in the past. We also think it is vital to involve family carers and support providers, and to begin to make connections with the other individuals, groups and organisations who can help.

New ways of working such as social prescribing and Community Circles are currently being pilot-tested in local health and social care services, and are very compatible with the community development approach we are suggesting. Strong links allow knowledge about how the system works to flow into local communities, and feedback about what is and is not working to move in the other direction. Although cost-savings may be possible, community development approaches require ongoing financial support and engagement to be sustainable. Volunteer-based networks are notoriously unstable, particularly when their members are people with serious illnesses or impairments. Recruitment, training and administrative support is essential for any long-term development, and when the aim is to build capacity within communities the time-scale is better measured in years than months.

- xii. Connection Support (2018) Direct Payment and Employment Resources. Available at: <http://www.connectionsupport.org.uk/oxfordshire/projects/direct-payment-employment-support/direct-payment-employment-resources/> Accessed on: 27/12/2018
- xiii. Purple (2018) Oxfordshire: Welcome to Purple, available at: <https://wearepurple.org.uk/direct-payment-support/our-contract-areas/oxfordshire/> Accessed on 27/12/2018

Section 2: Proposals for improving support



4. Support at each stage of the process

Many people wanted more support at each stage of the process of obtaining and managing a PB/PHB. Support from statutory sector workers was highly valued, but was often concentrated at the beginning of the process. People who knew about it found the help from support organisations such as Connections and the PHB project managers at Oxford Health NHS Trust extremely valuable, but many people did not know they could access it. Some people used the managed account service from Purple, but we heard that people often had difficulty contacting them or getting explanations when the figures didn't seem right. For people to be confident about using PBs/PHBs, they need to know they can get the right support at each stage of the process, when they need it. This will require coordinated action from the range of stakeholder groups described in Chapter 3.

When people describe problems applying for and managing a PB or

PHB, this is often heard as a need for better information. Of course people do need information, but we believe they also need help to make good use of it. This means having someone to help make sense of the information, and explain what they actually need to do with it. It also means having someone to talk to when things aren't going well (or even where they are). That is why in this section, we are recommending that support is provided by other human beings. Doing this professionally requires more money, so the approach here will focus on peer support, supplemented by experts where necessary.

a. Before applying for a personal budget

In the meetings running up to this report, we often discussed the difficulty of getting information to people at the right time. This is particularly hard when people are trying to make the

decision about whether to try to manage their own support using a PB/PHB. People came up with three sets of suggestions about where this might be achieved:

- From statutory sector workers such as GPs and Practice Nurses are already in contact with people who have progressive conditions, where they are either receiving support already or are likely to become eligible in the future.
- Through peer networks such as disabled people's organisations and social groups.
- By advertising.

During the last decade when the government was trying to promote the use of personal budgets, there was a lot of research about how peer networks could help. It was particularly useful where people who were thinking about personal budgets could meet with those who were already using them. Peer networks often helped people to get an idea of how personal budgets might help, for example by:

- Producing publicity materials
- Publicising personal budgets in the local media.
- Operating 'surgeries', and providing briefings to planning forums, user groups and conferences ^{xiv}.

Locally, we know that the peer support group for personal health budget users was very helpful in developing the materials that explained how the system worked. Similarly, leaflets about per-

sonal budgets in adult social care have worked well when they are not too technical, and written from the perspectives of users. We think this is something the peer network and development worker(s) could take forwards.

In the past it was recognised that some people would require training to manage a personal budget. Peer networks often provided this, and sometimes also trained statutory sector workers ^{xv}. We recommend that training on managing a personal budget should be available to members of the new peer network, by attending meetings, accessing online resources and participating in an online community.

b. During assessment and support planning

i. Support in eligibility assessments

To be eligible for a personal budget from public funds, people first need to be assessed for eligibility. During the past two years, many people have told us about the need for people to be supported in the assessment process. We discuss the need for advocacy support with the financial aspect of the assessment in Chapter 8, but the initial clinical assessment can also have an impact on the amount of money offered as a PB/PHB. We know that ultimately, people need to be offered a support package that meets their needs. However, we know that many people simply assume the amount

they are allocated in their ‘indicative budget’ will be the final amount available to them. In this situation, we recommend that people have access to support (for example through an advocacy service, or through the peer network).

We have heard statutory sector workers express concern that this could make clinical assessments less collaborative, and actually get in the way of finding creative solutions. However, we believe that people are more able to work collaboratively when they feel adequately supported.

ii. Self-assessment

Early on in the implementation of personal budgets, guidance from the Policy Studies Institute had suggested that self-assessment might be more consistent with the ‘independent living’ approach^{xvi}. In some areas, peer networks were involved with developing the bureaucratic systems to enable self-assessment^{xvii}. This extended to providing potential personal budget users with training and support to self-assess^{xviii}. The Care Act 2014 embedded this approach in law, and Care and Support Statutory Guidance says that assessments may come in many formats, including:

“... a supported self-assessment, which should use similar assessment materials as used in other

forms of needs or carers’ assessments, but where the person completes the assessment themselves and the local authority assures itself that it is an accurate reflection of the person’s needs (for example, by consulting with other relevant professionals and people who know the person with their consent)”

Para 6.3

We know that self-assessments are unlikely to be accepted by the NHS or by adult social care departments without verification. So we recommend that the peer network works with development worker(s) to create a shared approach that does not raise false expectations about the amount of money that might be available, and instead focuses on documenting people’s needs and their preferences for how these could best be met.

iii. Family carers

We know that many family carers are the people who manage PBs/PHBs, sometimes because they are legally entitled to manage them on other people’s behalves (for example as a ‘suitable person’ or a parent of a child under 16 years of age), and sometimes because they are part of a PB/PHB user’s network of informal support. Earlier research has shown that where peer networks were supporting people with cognitive impairments or in mental distress, informal carers were nearly always involved^{xix}.

In these situations, we recommend that the peer network offers support to carers too. Sometimes where carers are involved, it can be hard for statutory sector planners to make sure they have heard the voice of the service user. Evidence from earlier studies shows that independent support from an advocate for the service user and support from a peer network for a family carer can ensure that everyone's voice is heard^{xx}. In some areas the 'triangle of care' approach has been used successfully to make sure that everyone concerned can participate in the process as fully as possible. We recommend that the development worker(s) liaise with the peer network, connectors and statutory workers to help develop a local protocol that ensures everyone is adequately supported to participate in assessment meetings.

c. Setting up and maintaining the support plan

During the meetings we've been having over the past two years, it seemed finding and keeping PAs was the biggest practical problem people faced. In the next chapter, we discuss in detail the additional support that could be put in place to help to get the best support from PAs, so this section is mainly about recruitment. We think more can be done to support people with recruitment:

- At the beginning of the process, after the support plan has been agreed.
- In emergency situations, where the support plan breaks down at little or no notice.
- When people's needs change, and they would like their support provided in a different way.

The people we have spoken to generally describe good support from statutory sector workers at the beginning of the process. The main difficulties people face are later on, where their needs change or they encounter problems. Research in other parts of the country has found the same thing^{xxi}.

Oxfordshire Association of Care Providers operates a 'Support With Confidence' scheme, which carries out checks, provides training and allows properly qualified PAs to advertise on a dedicated web site according to the type of skills PAs have. People told us that there are not enough PAs on the list, and some people we spoke to complained that the amounts they were charging were much higher than the rates included in their PBs/PHBs. Finding a PA can be even more complicated when people need specialist support with their health, for example in relation to the operation of complicated medical equipment. We think the steering group should work collaboratively with other partners to try and increase the amount of help that's available to people here. A number of pieces of research give good exam-

ples of the diversity of approaches taken by peer networks in helping people to find and recruit PAs. Several maintained registers of PAs^{xxii}.

Co-ordinating PA Recruitment

An interesting approach has been developed by Choices and Rights Disability Coalition, based in Hull. They support people to develop job descriptions, person specifications and agree pay rates, and then circulate details to all the PAs working locally (about 800 are on their list). They will organise interviews and even sit on the panel with people, although they will only advise and won't participate in decision-making. This helps people to make lawful decisions. By offering to host interviews in their offices, they can provide some anonymity for PB and PHB users who are worried about upsetting candidates by turning them down (and then having to ask them to leave their homes). This approach has been running successfully for 9 years. Development workers could pilot-test this approach, co-ordinating with OACP.

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5. Supporting relationships with personal assistants

We know that there are some very different and deeply held views about the 'best' way to work with Personal Assistants (PAs). We have not taken a position on this issue. Our approach is to acknowledge that there are currently people using all of these approaches in Oxfordshire, and to make recommendations about how the relationships between PB/PHB users and the people who provide them with support could work better in every situation.

a. People who employ PAs

During the early development of PBs and PHBs, this was frequently regarded as the 'gold standard' of how to hand power over to disabled people so they could take more control over their lives. It also offered financial benefits, because people who were prepared to take on the additional responsibility and effort of employing their own staff could get a lot more time for their money. Since the financial crisis of 2008, there is emerging evidence that people have felt forced into becoming employers because it is the only way they can afford the right level of care with the money they have. Some people are in a similar position because the Council does not have contractual relationships with the right kind of specialist PA, and so will not purchase support on their behalf. People in this group do not want the responsibility or risks of being employers. The following quote is from a mother who employs a team of PAs to support her daughter, in another part of the country:

"We drown in the whole Direct Payments dream. Self-directed support is a great concept. We doggy paddle in deep waves with no life jacket. No one there to come and rescue us. Feeling dumped by our local authority who are happy in the notion that we save them money. However, we never wanted to be unpaid managers (or even paid ones), who have HR policies and procedures in place at the risk of having to be sued and go to tribunal. The horrendous headaches of recruitment, the stress of rotas, of no emergency back up teams, of PAs going off on maternity and no budget to cover them, the never ending worry of the budget being cut and the social worker doing another bloody assessment."

Drowning in Direct Payments, available at: <https://katieclarke2014.wordpress.com/>

The approach we are recommending is that individual employers are provided with more support. Whether or not they are getting it right, the people that we spoke to often felt exposed and vulnerable. We recommend:

- That a peer network is developed so that people can get emotional support, and feel the confidence that stems from knowing others in the same situation.
- That the peer network is connected to experts on employment law, both in the statutory sector and in organisations such as Connections.

- That statutory bodies accept that people who are employing PAs will inevitably run into difficulties on occasions, and that they exercise their discretionary powers to provide higher levels of support in these situations. We know that staff time is severely constrained, but we expect that providing additional help when things get tough will inspire more people to take the risks of managing their own support, which fits better with the strategic long-term goal of helping communities to provide more support to one another in future.

b. People who work with self-employed PA's

Typically people who employ PAs take PB/PHB as direct payments and deduct Income Tax and National Insurance payments 'at source' before paying PAs. This system is almost universal for employees, and is called Pay As You Earn (PAYE). On the other hand, people who work with PAs classed as 'self-employed' do not have to do this work, and can potentially afford to pay more for support (because tax is not deducted). However, there are potentially big risks associated with this approach. It is not people themselves, but HM Revenue & Customs (the tax office) that decides whether people are actually employees, or are self-employed. We have heard of situations where PB/PHB users have been hit with large backdated tax bills when people who have been describing themselves as 'self-employed' have not been paying tax, or have been classified as employees by HMRC. Sometimes where people have had no money themselves, local Councils have had to pick up the bill. As well as causing huge distress, it has cost a lot of money and disrupted people's care and support. We are recommending a shared approach to

managing this risk, but accept that it cannot be eradicated altogether.

We recommend that the steering group takes responsibility for developing a shared approach agreed by statutory bodies, self-employed PAs and personal budget-holders. This should focus on managing and minimising the risks associated with working with self-employed PAs. We have three specific sets of suggestions, which the steering group might wish to consider.

- As it is HMRC that decides whether people are self-employed or not, a third party could hold the proportion of the PB/PHB used to pay tax and NI (calculated at the higher of the two possible rates) until a decision is made. This could be a statutory body, a connector organisation (such as a company providing managed accounts) or a new organisation.
- One of the criteria HMRC use when deciding if someone is self-employed or not is whether they are providing a whole service, and so are responsible for organising cover if they are sick or on holiday. The Council and CCG need to have access to emergency short-term cover in other situations, and this could be made available to self-employed PAs to purchase in emergencies. This could help them meet the legal criteria for being self-employed, help to manage risks to PB/PHB users, and would be largely cost-neutral for statutory bodies.
- Develop better support for PAs, possibly by further development of an existing forum hosted by OACP. This group could have access to free shared training, and to employment law and tax advice (see d., below).

c. People who work with PAs employed by another organisation.

For people who cannot or do not want to manage a PA themselves, it can be helpful for an agency to arrange support on their behalfs. Although people will not have a choice of individual carers, they can choose between the different agencies (where more than one is available), giving them some measure of choice and control. However, this is more expensive than employing people directly, or working with PAs who are self-employed. There are also risks. The original point of employing PAs instead of having Council-employed carers was so people could choose the PAs they wanted to be supported by, and pay them to perform tasks at the times and in the ways they wanted. Agencies cannot guarantee that it will always be the same PA who comes, and people we spoke to complained that the times of visits could vary widely. Recently many Councils have sought to try and maintain quality and control prices by reducing the number of agencies they contract with, meaning that in reality people have a limited choice of agency care if they still want the Council (or a third party such as Purple) to manage the finances on their behalfs.

Agencies are usually trying to do a hard job under difficult circumstances; statutory bodies have reduced the amounts they are prepared to pay for PA time, and staff turnover is high. We recommend that PAs employed by agencies also have access to the support offered to PAs in the other two types of employment relationship.

d. Providing better support for PAs themselves

We recommend that PAs themselves are better supported. This could be achieved for example by:

- Pooling training opportunities available through e.g. Support With Confidence, or purchased through grants available from Skills for Care.
- Creating opportunities for PAs to receive peer mentoring and off-line supervision.
- Helping PAs to gain easy access to legal information.

6. Improving the range of support available

People were sometimes concerned about the limited range of care and other support services available locally. This has a complex relationship with personal budgets; some people take payments as a personal budget because the Council or NHS does not have a contract with a specialist care provider, so they take the money as a Direct Payment and purchase it themselves. In rural parts of the County it can still be hard (and expensive) to find providers who will visit people in their homes. Personal budgets are only part of a much bigger picture, and improving the range of supports is dependent on other factors such as pay and conditions for personal assistants. Nationally, 35% of PAs are still on zero hours contracts, and 37% leave their jobs every year^{xxiii}. Nevertheless, we believe there are some ways in which Personal Budgets can be used to improve the range and quality of support available. There is also scope for commissioners to save money in the long-run, by investing in community supports and services. However we believe this will be part of a long-term shift in the balance of how support is provided, and chasing short-term cash savings risks some of the longer-term benefits.

a. Community enterprise

There are two main ways in which Personal Budgets can support very small businesses, sometimes known as micro-enterprises, which can themselves support PB and PHB users: by supporting specialist providers to get going (and keep going), and by creating work opportunities for people who might otherwise struggle to find employment.

Sometimes these two things can work together.

Firstly, people can use personal budgets to purchase very small-scale specialist support. As we say in Chapter 5, PAs with specialist skills may want the legal protection of setting up as a business, and a contract to provide supports to two or three people with PBs/PHBs may give them the financial security they need to make the jump. This approach was developed by an organisation called Community Catalysts, who originally called it 'micro-enterprise'. These days they describe their approach as Community Enterprise, but they are still helping communities to do interesting things with PBs and PHBs. A recent project in Somerset helped people to set up 133 start-up enterprises focussing on supporting people in their own homes.

“Older and disabled people living in rural parts of Somerset are supported at home by local people who can provide a flexible, responsive, consistent and high quality care service. People are able to work locally, earn an income and make a positive difference to the lives of people in their neighbourhood. Commissioners know that older people, including those in the most rural areas, can be supported well at home. Because of this people come home earlier from hospital, stay connected to their community, relieving isolation and loneliness.”

Community Catalysts^{xxiv}

Often community support can be structured as a social enterprise or social business. This means that activities are profit-generating, and these profits can be used to subsidise the social or community purpose of the organisation. Many of these types of project trade, for example by setting up a café or a shop which can also provide benefits for personal budget users. Locally, there have already been some great examples. Yellow Submarine is an organisation that allows people to access a variety of pro-

jects that can be paid for using their PBs. These are a combination of training opportunities and social activities. They offer sheltered work experience for people aged 18 and over, which can happen in a café.

Oxfordshire is already rich in social enterprises and social businesses which still have a community purpose, but which might not be set up to work with PB/PHB users. Examples are community businesses like the RAW recycled wood workshop, the Tap So-

The Compass project

From Yellow Submarine's award-winning training centres in central Oxford and Witney, and in a friendly group setting, members are supported through a range of bespoke training in topics including but not limited to: team working, health & safety and customer service. Learners also explore their interests and skills through undertaking a wide variety of practical work tasks on offer, both in-house and within community settings; for example, numeracy and literacy-based tasks, cash handling, purchasing ingredients, and/or creating enterprise products such as gifts and snacks for sale.



cial Movement, Flo's and Aspire. One of the principles that we agreed last year in developing this report was to maximise the benefit from the local knowledge, expertise and resources on our doorsteps. We recommend that the development workers begin to forge links with these organisations and groups to widen the options for people using PBs/PHBs.

b. Finding social spaces

When personal budgets were introduced in adult social care, it was with the idea of extending peoples choice of and control over the supports they needed to have a decent life^{xxv}. At the time, Day Centres were often regarded as stigmatising segregated environments, and there was a widespread aspiration for people to be able to use ordinary, everyday supports instead. Since then, research has shown that the reality for many people is that day centres have disappeared and there is nothing to replace them^{xxvi}.

“Interviews and survey responses indicated that day centres are being closed, following inadequate consultation, and that those that remain are limiting eligibility and increasing prices.”

Needham C (2014)
Personalisation: From day
centres to community hubs?,
page104

We have spoken to carers who argue strongly that while day centres are not for everyone, for some people they make an important contribution to a support package.

As well as retaining some sort of daytime social spaces, it is clearly also important to develop new opportunities for people. We know that local organisations like Community First Oxfordshire are trying to develop new social

spaces like community halls. We know that a number of pubs in our area have been saved by locals, sometimes with the help of national organisations like Power to Change and the Plunkett Foundation. We recommend that development workers engage with these groups to find ways of making them available as spaces for PB/PHB users.

c. Linking with other community support initiatives

We know that statutory services are working hard to improve their relationship with the wide range of supports that already exist in Oxfordshire. 2017's review of daytime support found that:

“There is already a thriving daytime support network in Oxfordshire, with over 200 services provided by community groups and charities – around three quarters of these groups receive no county council funding. The council recognises how important these services are, and how much they are valued by the people who use them, and through our support and advice we want to enable them to continue and grow.”

Terroni, K (2017) Daytime Support in Oxfordshire, page 2

We also know that statutory services are working hard with community initiatives on how to help them to prosper and grow. In our experience this type of support is vital. Planners often seem to think that small community initiatives will simply continue to survive and prosper on their own, when they are frequently the work of a few exhausted individuals, who keep them going at their own expense.

Fledgling community supports in Oxfordshire could be helped to survive and grow by making sure that people

who use PBs/PHBs are able to purchase their services easily, on a small scale to start with. We have heard that this is sometimes bureaucratically difficult. We recommend that development workers work alongside NHS and Council staff to try and reduce these barriers.

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Needham C (2014) Personalization: From day centres to community hubs? *Critical Social Policy* 34(1) pp.90-108

7. Helping PB/PHB users to work collaboratively

A principle both of community development and of the independent living movement which campaigned for direct payments was co-operation. This is also an essential component of the co-production model. We believe that co-operation should be encouraged for its own sake, because many of the creative ideas which will help PB/PHB users and other users of health and social care services will come out of it. It's also true that taking a collaborative approach helps to build the relationships which will help get the ideas off the drawing board and into practice. An essential role both of the steering group and the peer network we are proposing is to foster this type of co-operation. We also have three specific sets of recommendations that have come out of the groups and individual discussions we've been a part of. All three have a long history and have been the focus of work in other places.

a. Pooling PBs/PHBs

From the beginning of direct payments in the 1990s, people wanted to be able to purchase things together with one another. From our conversations, we know that this is bureaucratically difficult in Oxfordshire. There is also a risk that if people succeed in getting better value from their PBs/PHBs by pooling them, statutory bodies will reduce the amounts available on review.

In other parts of the country, this work has been taken forwards by a number of organisations, who have produced detailed guidance. One is Ruils (formerly Richmond Users Independent Living Scheme). They were com-

missioned by the Office for Disability Issues to develop the idea in 2013, and now have a dedicated web site and a printed guidebook available. Another is the Up2Us project developed by the housing association charity HACT and evaluated by the New Economics Foundation. Like us, they recommend taking a 'bottom-up' approach, working with people who want to try it out to identify and fix the problems. They also identified bureaucracy as a barrier. This is one of their recommendations.

“Ensure personalised practice is supported by organisational procedures, inspection, and auditing regimes. Many of the procedures that staff are expected to conform to have been developed in times when there was less emphasis on empowerment. This is evident in particular to how risk is approached. Organisations' efforts to become more personalised or to adopt co-produced approaches may be undermined by their own or external inspection or auditing regimes. Organisations' policies must support the cultural and systemic changes needed for personalisation to flourish. Some traditional organisational policies and procedures (such as approaches to risk) may no longer be fit for purpose. They must be reviewed and updated when they are found to restrict more personalised ways of working.”

Buying Things
Together p.146^{xxvii}

b. Integrating support across the LA and the NHS

As we have already said, integrating approaches to integrating PBs and PHBs across health and social care systems has been a part of NHS strategy since 2015. This is something that local people said they wanted and that Oxfordshire Family Support Network found at their Better Together event last November.

Last month's NHS Long Term Plan claimed that:

“By September 2018, over 200,000 people had already joined the personalised care programme and over 32,000 people had Personal Health Budgets (PHBs) – nearly a quarter of which were jointly funded with social care”

The NHS Long Term Plan, Page 25. ^{xxviii}

However, evidence from the independent evaluation suggests that the nineteen pilot sites that have been operating in England since 2015 are still experiencing some significant difficulties. Only two sites had managed to integrate PBs with PHBs, but this produced substantial benefits for PB/PHB users:

“They felt that having an integrated budget increased the flexibility of the resources that were available for the service user. This was because instead of having two pots of money, each one intended to be used on a specific list of services, all the funds were pooled together and could be used in a seamless way, because funds were not ring-fenced around services. Commissioners commented that integrated budgets also helped in preventing double funding of elements in

the care plan, because in setting up the budget the services took a holistic view of the care plan, set up the budget and pooled the funds from the relevant services.”

Second interim report (June 2018), p.17 ^{xxix}

We recommend that OCC and OCCG work towards a completely integrated approach to PBs and PHBs in the county. This work could also be co-ordinated through the steering group, informed by the peer network and supported by development workers.

c. Individual Service Funds

Typically these have been payments to residential care providers. These function in a similar way to personal budgets managed by the local authority, but with the provider helping residents to exercise choice and control over the type of support they want, and managing the money on their behalfs. Historically there have been some problems with this approach, for example where providers will only allow residents to purchase support from within the organisation. But recently there have been some important developments, with a new approach being developed mainly in the south-west of the country. Oxfordshire now borders two counties that are getting involved.

The first local authority to adopt the approach was Dorset, where people now have the choice of a Council-commissioned service, an ISF or a direct payment, with the ISF sitting in the middle in terms of the amount of work people do to manage their own care and support. They have developed approaches to pooling budgets that allows people to purchase support from inside and outside of provider boundaries. At the moment this option is usually only available for people needing

high levels of care, but there is no reason why people with smaller PBs or PHBs could not purchase the same day time supports as a part of the same user-designed service. We recommend that if ISFs are extended in Oxfordshire, integration with PBs and PHBs is considered. This could be another project for the steering group/peer network and development workers to take forwards.

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- xxvii. Stephens L. & Michaelson, J. (2013) Buying things together: A review of the up2us approach – supporting people to pool budgets to buy the support they want. Available at: <https://www.hact.org.uk/sites/default/files/uploads/Archives/2013/06/up2us%20report.pdf> Retrieved on: 27/1/2019
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- xxix. Social Policy Research Unit (2018) Summative Evaluation of the Integrated Personal Commissioning (IPC) Programme: Process evaluation – second interim report. Available at: <https://www.york.ac.uk/spru/projects/evaluation-of-integrated-personal-commissioning>. Retrieved on: 27/1/2018

8. Making the money work

We know that the amount of money funding public services is shrinking in real terms. This puts pressure on the relationships between people who might otherwise be collaborating more closely to support PB/PHB users. For example, the fact that local authorities are often reducing personal budgets on review discourages people from contacting their social workers. The reducing amounts in personal budgets then also encourage PB users to pay PAs at the lowest possible rate. The fact that this sometimes leads to tax irregularities is leading some local authorities to ask PB users to sign agreements indemnifying them against any financial risks. The overall effect has been to erode trust between the different groups, which makes it harder for them to co-operate in the future.

At the moment, reductions in funding seem to be creating a vicious circle, where the collective vision for more choice and control is being obscured by the need for individuals and groups to protect their own interests. We need to somehow turn this into a virtuous circle, where people learn to trust one another and build confidence in the PB/PHB process.

We believe that most of the benefits that could accrue from improving support for PB/PHB users are dependent on closer relationships, and rebuilding trust. We believe there is potential for things to improve, but this will take time, will need structured opportunities for collaboration (for example through the proposed steering group), and realistic plans for how things can be improved for everyone at the same time. Getting the best out of a limited pot of money is essential to make this happen.

Where PB and PHB users agree to participate in our shared goal of improving supports, we recommend that OCC and OCCG develop mechanisms to ensure that they will not lose out financially as a result of doing so. Their trust and confidence is essential to implement and sustain our proposals.

a. Advocacy at the point of assessment

Many people told us they were unhappy about the level at which their personal budgets were funded, and several told us stories about how they had successfully disputed the level at which PBs were set. The Adult Social Care Outcomes Framework (ASCOF) does not include data for the number of people disputing the initial level of support offered. However, related data sets support the idea of the increasingly adversarial nature of the assessment process. Between the introduction of Personal Independence Payments (PIP) and 2017, there have been 241,200 appeals, and 107,800 decisions were overturned^{xxx}. Nationally, there were 11,661 personal budgets in place for EHC Plans for children with SEND issued or reviewed during the 2017 calendar year, of which 2,497 cases were subject to formal mediation under the Children and Families Act 2014^{xxxi}. Of these, 630 (25.2%) were followed by appeals to the tribunal. All of this points to an increasingly polarised relationship between users of health and social care services and the agencies that are there to support them.

Personal budget users told us that they often had to wait until months after the initial assessment to challenge the support they were allocated, when what they really needed was advoca-

cy in the meetings. We are therefore recommending that existing advocacy services are commissioned to provide this service. In time, a 'peer advocacy' model could be developed using volunteers recruited through the peer network. Similar peer advocacy schemes are widely used for people in mental distress and with learning disabilities, and there are experienced local providers.

When we mentioned this proposal to local statutory sector staff, they were concerned that having an advocate present in the initial assessment meeting might create an adversarial atmosphere. While we accept this possibility, it is our experience that effective advocacy can help people using services to participate in meetings, and to route challenges to decisions through the most appropriate channels. We believe that a more equal power relationship in assessment meetings is likely to lead to a free and open discussion, and less likely to result in expensive and bureaucratically cumbersome appeals.

b. Preparing for Universal Credit

Personal budget users who were already claiming Universal Credit told us about the horrendous complexity of managing the impact on their other benefits, and the charges that are made by the Council for their contributions to the costs of their own care. We recommend that development workers liaise with experts in statutory and voluntary agencies to try and develop clear guidance in advance of the new benefit being rolled out further.

c. Pooling expertise

There is a great deal of expertise around financial matters dispersed within the local community, for example in the form of money managers and legal teams in statutory agencies, experienced family carers and connecting agencies, and stemming from the lived experience of PB and PHB users. However, this expertise is only rarely available to people when they need it.

People we spoke to have asked for a single point of information that will provide them with precise, up-to-date information about their personal budget, and how it links to other areas of their personal finance. However, because of the range of particular financial situations that people find themselves in, the speed with which complex rules change, and the variation in how they are applied, we do not believe this is achievable within the resource available. People's PBs and PHBs can affect their family finances, and in the case of social care budgets the reverse is also true. As we saw with Universal Credit, the rules are changing quickly. People we spoke to, including experts, said that rules are often interpreted differently in different situations. We propose that instead of having a single point of contact, we develop information-sharing systems to link the different sources of expertise already available locally. This will require staffing resource, for example in the form of development workers, who could meet with experts, ask questions (for example arising at meetings of the peer network, or shared on social media), and circulate answers to PB/PHB users and advisers working in organisations like Citizens Advice.

xxx. Department of Work & Pensions (2018) Letter to Sev Franklin, Freedom of Information Request. FoI 41

xxxii. Department for Education (2018) Statements of SEN and EHC plans: England, 2018, page 9. Available at: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/709590/Statements_of_SEN_and_EHC_plans_England_2018_Main_Text.pdf
Retrieved on: 6/1/2018

Appendix 1: Glossary

ASC	Adult social care. Following the Children Act 2004, local authority social services departments split into adult social care (for people aged 18 and over) and children's services (which also included schools and education).
ASCOF	The Adult Social Care Outcomes Framework is the main national data set returned by local authorities to the Department of Health and Social Care
Co-production	This is a new term for the ways in which people can work with services to sustain their own health and wellbeing.
DP	A Direct Payment is a way of receiving personal budget or personal health budget, in which a payment is made directly to the recipient (instead of being managed by the NHS, the Council or another organisation).
EHC Plan	Education and Health Care Plan for a child assessed as having Special educational needs and disabilities (SEND)
HMRC	Her Majesty's Revenue & Customs (the central government tax office formerly known as the Inland Revenue).
NDTi	The National Development Team for Inclusion is a social change organisation working to enable people at risk of exclusion, due to age or disability, to live the life they choose. They collaborated with us on the research for this report.
OCC	Oxfordshire County Council is the council with social services responsibility for the English county of Oxfordshire.
OCCG	Oxfordshire Clinical Commissioning Group is the organisation that plans, buys and oversees health services for people living in Oxfordshire.
PA	Personal assistant. Previously people in this group were often known as personal care assistants or social care assistants (or nursing assistants/nursing auxiliaries if their tasks were mainly health-related).
PB	Personal budget
PHB	Personal health budget
SCIE	Social Care Institute for Excellence
SEND	Special educational needs and disabilities. This is a term used in the Children and Families Act 2014 to describe a group of children for which the local authority has a duty to provide services, some of which may be purchased through personal budgets.

Appendix 2: Vision

This proposal was developed by Andrew Tyson, Volunteering Matters associate, Jon Hyslop and Keith Birnie both of Community Glue CIC. It follows two meetings in spring 2018 with colleagues from Oxfordshire County Council, Oxfordshire CCG, Oxfordshire Health NHS FT, and Connection Support. The meetings attempted to describe what we believe to be required for an effective local system of health and care, where the individual's needs and wishes are at its heart.

The proposal is high-level and provisional. It will require further discussion and refinement. It is based upon the work of those who attended the two meetings, over a period of several years, alongside local people with lived experience of the health and care system; it attempts to respect that experience and to learn from it. We hope that resources may be made available in the latter part of 2018 to progress the proposal.

Our vision

Our aspiration is to promote voice, choice and control for the citizens of Oxfordshire, particularly in relation to health and care issues; and to do this through a strengths-based approach which recognises and builds upon individual and community assets.

As citizens, each of us has health and care needs from time to time, and we believe that the support and services available to all should now be of a standard that we would want for ourselves and our loved

ones. To achieve this, this means that services will be readily available to all and will be easy to access and use. Staff will always respect personal dignity and human rights and will respond to all equally.

The first requirement in this is for people to be aware of what is possible for them; and for them to have an effective *voice* in setting out and making known what they want and need, both individually and collectively.

People using services will then have *choice*, about how their needs are met and about how the services they use are arranged and delivered. This will include the choice, if they wish it, to take cash in lieu of a service, as a personal budget or a personal health budget; and the person at the centre of this process will have *control* of that process (within the limits of the law), control both over what it is they purchase with their budget and how that budget is managed. This means that they will be provided with genuine options about who manages the budget on a day to day basis and how support is sourced and arranged.

Clinical, professional and care staff from across sectors and agencies will always seek to work closely together, with the individual's needs and preferences as their absolute priority. Where practical this integration will apply to personal budgets and personal health budgets too, with a single joint budget as the aim.

Health and care services will have co-production as a guiding principle. Co-production means doing things *with* people with care and support needs, rather than to or for those people. It means operating in ways which are as open, transparent and accountable as possible. It means that the views and wishes of families and other loved ones are listened to and given due weight. And it means that the expertise and contribution of professional, clinical and care staff is respected, and their perspective incorporated in decision making.

Our greatest assets in health and care lie within the fabric of our communities. These assets include, local voluntary and community organisations. We will now seek to maximize the contribution of those organisations and that of others who may not be part of formal organisations, into our work in health and care.

In all our work, we will aim to appreciate and build upon the strengths and expertise which all bring, and to recognize that by attending to “what matters most” to individuals and groups, we are seeking to put in place the building blocks of a compassionate and caring society.

Our priorities

After one year we would hope to have:

An active co-production group or network in the county. It would own the vision (above) and its purpose would be to assist in making that vision real. How the group or network is constituted and composed, and how it relates to other bodies would need to be agreed. We would expect it to

be led by someone with lived experience of health and care. At a minimum there would need to be representation from different geographic communities, from different “care groups,” from both people who use health and care services and their families, and from voluntary and community groups.

Getting these things right is important but it is also important not to spend too much time or resource on preliminaries or terms of reference.

The primary purpose at this stage will be *voice*, through creation of a functional group or network with its own ideas, views and perspectives, which has influence with decision makers.

After a further year we would hope to have :

An established, workable and sustainable peer support network. The aim of this network would be to provide information and advice, together with mutual support and sustenance for people using health and care services. This network might grow from the co-production group, but to be successful, it will also need a source of secure funding and will need paid staff. Like the co—production group or network, the peer support network will need to be led by individuals with lived experience; and it will need to reach all, regardless of geography or type of need.

The primary purpose at this second stage will be the promotion of *choice* and *control* for people using health and care services, and practical arrangements to support this.

After a further three years we would hope to have:

By this point we would hope to have key building blocks in place, bringing voice, choice and control to people in the Oxfordshire, and to be in a position to make some further major steps towards the genuine devolution of power and control to citizens and communities in the county. How this happens is to be determined, but it will almost certainly need to be a twin track approach, to build community capacity from the ground up; and to further promote voice, choice and control for individuals.

One mechanism may be a Section 75 agreement (NHS Act, 2006). Such agreements “can include arrangements for pooling resources and delegating certain NHS and local authority health-related functions to the other partner(s) if it would lead to an improvement in the way those functions are exercised.”

This and other approaches will need to be scoped.

Appendix 3: Local Data

Adult social care

Most people who have a PB or PHB receive them in lieu of adult social care services. In England, there were 128,487 people receiving either all or part of their social care as a personal budget in 2017-18, (about 28.5% of people receiving long-term support). In Oxfordshire there were 4,205 people receiving long-term support, 1,453 of whom were taking this as a Direct Payment (about 35%). The number of people using direct payments has remained fairly stable since 2014.

Both locally and nationally, the majority of these people say they are in control of the support they receive (77% nationally and 82% in Oxfordshire).

The numbers of family carers receiving support grants has fallen nationally, from around 134,000 in 2014-15 to 81,000 last year. The numbers receiving support locally has also fallen, as has the amount of money people receive.

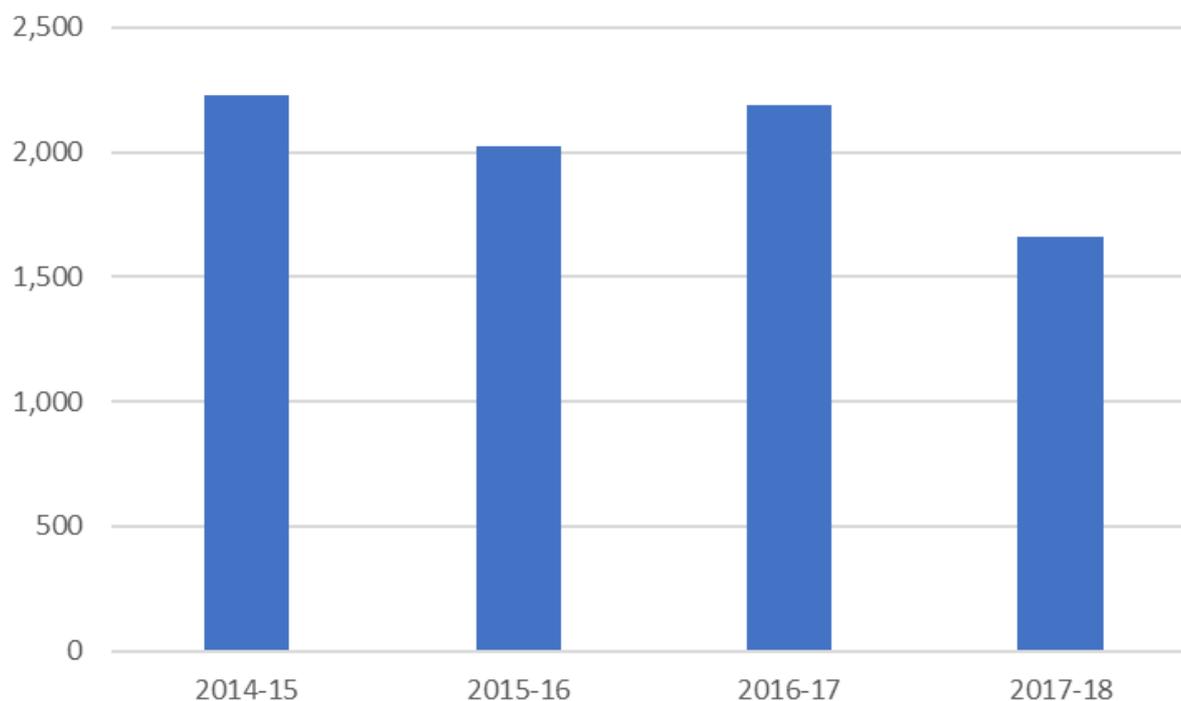


Fig. A1: Carers receiving grants as direct payments in Oxfordshire, 2014-2018.

Personal health budgets

There are currently 38 PHBs in Oxfordshire (split roughly 50/50 between notional budget-holders and people receiving direct payments). However, as a result of NHS England guidance that PHBs become the default for at home clients eligible for Continuing Health Care, the numbers are expected to rise sharply in the future. Nationally, NHS England claim that 30,000 people are using PHBs.

Personal budgets in SEND

Where children have special educational needs or disabilities (SEND), the local authority has a duty to provide services, some of which may be purchased through personal budgets. Figures for 2017 showed that there were 11,661 personal budgets allocated in England, of which 237 were allocated in Oxfordshire.

Personal budgets in SEND are meant to cover a range of different types of support. In some cases they are integrated to pay for support of different types, but progress towards achieving this appear to be slow, both locally and nationally.

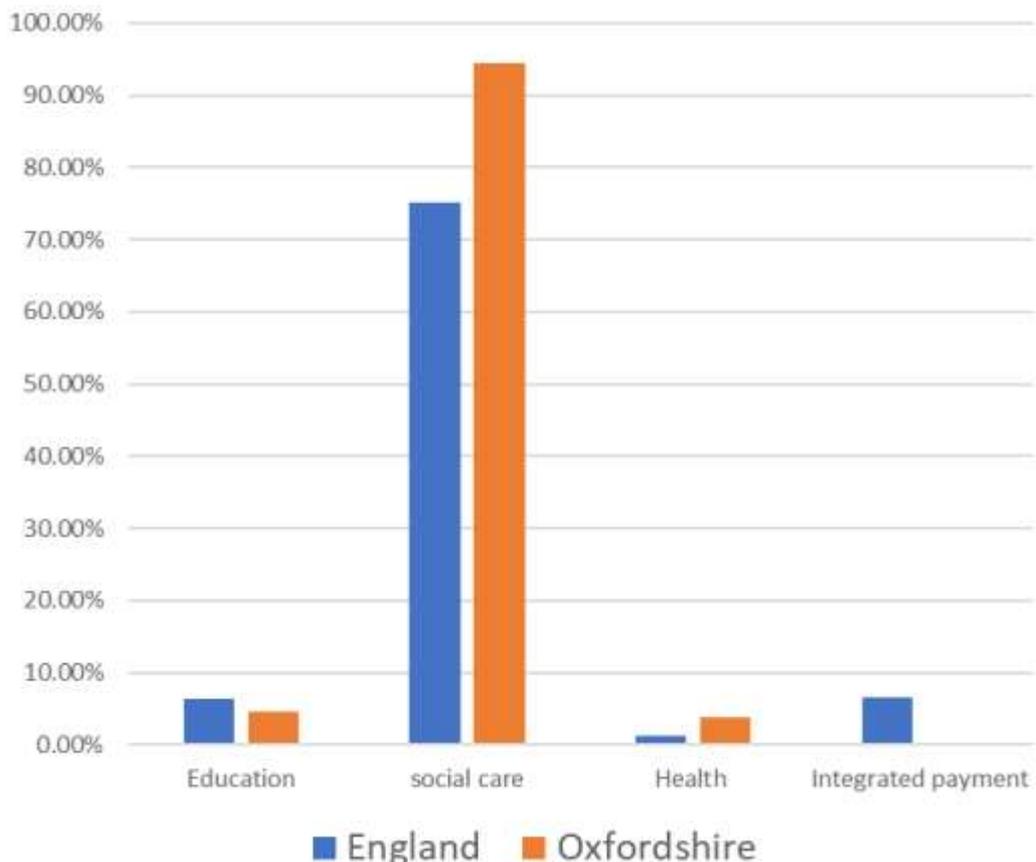


Fig. A2: Recipients of personal budgets in respect of EHC plans: proportions in Oxfordshire and England, 2017

Appendix 4.

Our 2014 Recommendations

With funding from Healthwatch Oxfordshire, Community Glue has been working collaboratively with other organisations to review Personal Budgets and their use in health and social care. Over the spring of 2014 we talked to people and ran workshops, eventually producing this report. At the launch event we ran another workshop looking at what we should do with our findings. This is an attempt to summarise the main points people thought we should make.

Resourcing of budgets and the infrastructure to support choice

We found evidence of budget cuts meant that people struggled to meet their basic needs, let alone choose services. People were worried by the proposed discontinuation of the brokerage/support planning service. Without adequate resources Personal Budgets cannot not deliver person-centred care.

Support throughout the process

People told us that there wasn't enough support for Personal Budget holders, and the support that was available was too focussed on setting up the support plan quickly. People wanted support throughout the process, including help with employing personal assistants.

Bureaucracy

- Not everyone wants to manage their budget as Direct Payment: for those who do not, we recommend a 'menu' of support options that still maximises the degree of control and choice available.
- Many people find the bureaucracy of holding a Personal Budget intimidating. Reducing the bureaucracy would make life easier for people who are already managing their own care, and potentially encourage more people to get involved.
- *Putting People First* set out a collaborative vision of person-centred care, but the bureaucracy involved in commissioning is making it hard or impossible for small community groups and organisations to get involved.

Peer Networks

Many of the important, creative elements of person-centred care can be supported or delivered by small community and voluntary groups, and user-led organisations. This includes providing information and advice, help with planning, timebanks, micro-enterprises and the development of individual service funds

Appendix 5. Meetings

23/8/2017	Private meeting with OCC and VM
12/10/2017	Co-production sub-group meeting hosted by OCC
16/11/2017	Regional network event for VM/NHS England
5/12/2017	Co-production sub-group meeting hosted by OCC
30/8/2018	Private meeting with OCC
8/3/2018	Public meeting hosted by OCC/OCCG
4/4/2018	Private meeting with OCC, OCCG, and VM
8/5/2018	Public meeting hosted by OCC/OCCG
26/7/2018	Public meeting hosted by OCC/OCCG
22/8/2018	Private meeting with OCC
23/10/2018	Public meeting hosted by OCC/OCCG
4/12/2018	Public meeting hosted by OCC/OCCG

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