



THE NATIONAL PERSONAL BUDGET SURVEY

June 2011



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In particular we would like to thank Martin Cattermole, Barney Stevenson and Simon Stockton for their support and assistance throughout, and the Department of Health for including POET in their vision for adult social care.

The authors are indebted to this group who made the work possible, however any errors of omission or interpretation, are wholly the responsibility of the authors.

Finally we also want to thank the 10 demonstration authorities who have been involved in this work, for their ongoing commitment to use the findings from the POET tools to further improve the delivery of personal budgets for people locally.

This report was delivered by In Control and Lancaster University and funded by Think Local, Act Personal.

Summary

Every year nearly one and a half million people in England look to their local authority for personal care and support due to their age or disability. Assistance can vary from a couple of hours 'sitting' to give a family member a break from caring, through to living permanently within a registered care home. There are over 17,000 organisations providing adult social care employing 1.6 million workers, across the private, voluntary and public sector. Over 6 million adults are believed to spend time caring for disabled or older family members.¹

In response to increasing demand and rising public expectations of choice and quality successive governments have committed to transforming the way in which care and support for older and disabled adults is organised.

At the heart of this transformation rests a simple yet potentially powerful idea. The idea is that instead of the local authority commissioning care and support services for people living in its area they should instead, provide individuals who are eligible for help with their own 'personal budget' so they can acquire help and assistance that is more attuned to their own individual needs and circumstances.

On the face of it, this is a relatively simple change, but in reality it presents local authority commissioners with a series of complex systemic and cultural challenges. Currently there are believed to be 250,000 holders of personal budgets across England. The current government is committed to ensuring personal budgets are available to all recipients of ongoing state funded social care by 2013.

With the support of the Think Local, Act Personal Partnership, In Control and Lancaster University worked with 10 local authorities between January 2010 and April 2010 to conduct a survey of personal budget holders and family carers of people holding personal budgets.

This report describes our work and sets out the findings from this first national survey.

The POET Surveys

The POET (Personal Budgets Outcome Evaluation Tool) surveys for personal budget holders and for carers of personal budget holders have been developed over several years as a way for personal budget holders and carers to report their experiences of personal budgets. For this report, the POET surveys were available in an online completion format and two paper formats (standard and easy-read, the latter designed by the Easy Read service at Inspired Services Publishing).

Ten local authorities in England volunteered to be demonstrator sites and each attempted to gain 100 responses from personal budget holders and carers. The POET surveys were also widely publicised throughout England for any personal budget holder or carer to complete online. All local authorities who supported the POET surveys and all personal budget holders and carers who provided us with information did so on the basis of anonymity, hence the demonstrator sites are not named in this report."

¹ Eborall, C., Fenton, W. & Woodrow, S. (2010). *The state of the adult social care workforce in England. 2010: the fourth report of Skills for Care's research and analysis units.* Leeds: Skills for Care. http://sfcnational.activclient.com/research/research_reports/annual_reports_SCW.aspx

In total, 1,114 personal budget holders completed the POET survey, including 832 returns from the 10 local authority demonstrator sites and returns from at least 76 other local authorities. 417 of these personal budget holders also wrote in a comment about their experience of personal budgets.

In total, 950 carers completed the POET survey, including 782 returns from carers in the 10 local authority demonstrator sites and returns from at least 66 other local authorities. 434 of these carers also wrote in a comment about the impact of personal budgets on their own lives.

For personal budget holders, there was some diversity in gender (61% women), ethnicity (11% non-White ethnicity) and religion (10% non-Christian religion; 14% no religion). Almost half of people responding to the survey were aged 65 years or more (43%); the social care needs of working age adults (aged 16-64 years) were largely split between learning disabilities (17%), mental health needs (8%) and physical disabilities (25%).

In most of the analyses in the report, we compared the experiences of older people (aged 65 years or more) with working age adults (aged 16-64 years) with learning disabilities, mental health needs or physical disabilities. We did not gain any information about people's self-rated capacity to take part in any of the aspects of their lives we asked about (for example people's self-rated capacity to undertake paid employment) and the findings of the report need to be considered with this in mind.

For carers, there was some diversity in gender (70% women), age (30% aged 65 years or more), ethnicity (11% non-White ethnicity), religion (9% non-Christian religion; 14% no religion), and carer self-reported disability (27%). Approximately equal numbers of carers were caring for a partner/spouse (31%), an older family member (33%) or a grown-up son or daughter (30%). Most carers (69%)

were living in the same house as the person they were caring for. As with personal budget holders, we did not gain information from carers about their self-rated capacity to take part in any of the aspects of their lives we asked about.

Personal budget holders and carers also varied in how long they or the person cared for had held a personal budget, whether they received social care support before their personal budget, how their personal budget was managed, what support people used in planning their personal budget, and whether the views of personal budget holders and carers were reflected in the support plan for the personal budget.

Major Findings

Overall, personal budget holders reported positive experiences of the impact of personal budgets on their lives, although experiences of the personal budget process were more varied:

- Most personal budget holders reported that the fundamental components of self-directed support were in place, including being told the amount of their personal budget (77%), getting help to plan their personal budget (81%) and having their views very much or mostly included in the support plan (87%). However, personal budget holders varied widely in their experiences of the personal budget process, with many people reporting difficulties at each stage.
- Most personal budget holders reported personal budgets having a positive impact on 10 of the 14 aspects of their lives we asked about, being supported with dignity and respect (76% reporting a positive impact); people staying as independent as they want to be (75%); people being in control of their support (72%); people having control over the important things

in life (68%); people's relationships with those paid to support them (67%); people's mental wellbeing (63%); people's physical health (59%); people's relationships with family members (58%); people feeling safe both inside and outside their home (57%) and people getting the support they need when they need it (72%).

- In the other four aspects of people's lives, most personal budget holders reported personal budgets making no difference in: people getting and keeping a paid job (68% of working age adults reporting no difference) and people volunteering and helping their local community (77% of adults of any age); people choosing where they live/who they live with (60% of all adults); and people's relationships with friends (52% of all adults).
- Overall, small numbers of people (between 3% and 8%) reported personal budgets having a negative impact on any of the 14 aspects of people's lives we asked about in the survey.
- In comments written in by personal budget holders, people were generally very positive about the impact of personal budgets on their lives, although there were clear concerns about money.

Most carers of personal budget holders also reported positive experiences but to a lesser extent:

- Most carers reported that their views were very much or mostly included in the personal budget holder's support plan (87%).
- Most carers reported a positive impact of the personal budgets held by the person they cared for on three of the nine aspects of their own lives as carers we asked about: support for them to continue caring (68%); their quality of life (60%); and their physical and mental wellbeing (55%).
- For the other five areas of carers' lives, carers were relatively evenly split on whether personal budgets for the person they care for had had a positive impact or made no difference in the areas of the carer's finances; the carer's social life; the carer's relationships with the person cared for and/or other family/friends; and the carer's sense of choice and control over their own lives.
- Most carers (68%) reported that personal budgets for the person they care for had made no impact on their own capacity to get and keep a paid job.
- Only small minorities of carers reported any areas of their lives getting worse as a result of personal budgets. In 4 of the 9 areas we asked carers about negative impacts rose above 10%, specifically in the areas of their physical and mental wellbeing (13%), their social life (12%), their quality of life (11%) and their choice and control over their own lives (11%).
- Comments written in by carers reinforced and extended these conclusions; carers were highly positive about the impact of personal budgets on the lives of the personal budget holder, themselves as carers and other family members, but were more negative about all aspects of the personal budget process and the stress and worry for them associated with personal budgets for the person they were caring for. In the POET surveys, several factors were associated with personal budget holders and carers reporting more positive impacts of personal budgets on their lives.
- Most strikingly, there is pervasive variation across councils in the outcomes reported by personal budget holders and carers. Councils clearly have a major impact on outcomes through the processes they put in place to help people through all stages of the personal budgets process and the methods they use to deliver personal budgets, both of which can have a profound influence on people's experiences of personal budgets. In particular:

- Who manages the personal budget is robustly linked to outcomes for personal budget holders. Whilst all personal budget holders reported positive outcomes, those managing the budget themselves as a direct payment reported significantly more positive outcomes than people receiving council managed budgets.
- It is important that personal budget holders and carers are kept informed of essential aspects of the personal budget. People who did not know how their personal budget was managed or did not know the amount of their personal budget reported less positive outcomes.
- The support planning process for the personal budget is critical. Personal budget holders and carers who felt their views were more fully included in the support plan were more likely to report positive outcomes across the board – where possible both personal budget holders and carers need to be fully involved in support planning.
- People who had been using their personal budgets for longer reported increasingly positive outcomes, suggesting that it may take some time to get an optimal pattern of support.
- A greater weekly amount of personal budget support was robustly associated with more positive outcomes.
- There is also variation in outcomes for personal budget holders across social care need groups, with older adults reporting less positive outcomes than other social care need groups in six out of the 14 outcome domains. However, these differences are ones of degree (older adults are more likely to record personal budgets as making no difference; they are not more likely to record personal budgets as making things worse).
- As with working age adults, it is also important to note that within the group of older adult personal budget holders direct payments were also associated with more positive outcomes in 9 of the 14 outcome domains. Clearly direct payments can work just as well for older people, but councils seem less likely to actively promote and support direct payments as a personal budget option to older people. Councils may need to conduct further market research with older people about this issue and to consider the assumptions being made about older people's capacities and willingness to manage direct payments in council policies, procedures and practices.
- For carers of personal budget holders, carers of older family members were less positive than other carers about the impact of personal budgets across five domains of carers' lives. Again, this may be a result of how personal budgets are likely to impact on carers in different circumstances rather than being about older people as such, particularly in terms of whether the carer is living in the same home as the person they are caring for and how much care and support the carer is providing.

In summary, it seems that personal budgets are likely to have generally positive impacts on the lives of all groups of personal budget holders and the people who care for them. The likelihood of people experiencing a positive impact from a personal budget is maximised by a personal budget support process that keeps people fully informed, puts people in control of the personal budget and how it is spent, supports people without undue constraint and bureaucracy, and fully involves carers. Under these conditions, personal budgets can and do work well for everyone.

Background

In November 2010 the Department of Health set out its vision for Adult Social Care. At the heart of the vision sits a commitment to the personalisation of care through the implementation of 'personal budgets'. The vision 'challenges councils to provide personal budgets, preferably as direct payments, to everyone eligible within the next two years'.

The vision says that 'A personal budget can be taken by an individual as a direct (cash) payment; as an account held and managed by the council in line with the individual's wishes; or as an account placed with a third party (provider) and called off by the individual; or as a mixture of these approaches'

There is recognition in the vision that personal budgets are not an end in themselves however, 'our focus is not on the process but on the outcomes of greater choice, control and independence, and ultimately better quality of life. Outcome-based tools including... POET... support a better understanding of whether people's expected outcomes are being met and the information used to commission differently.'

The need to ensure that councils understand how personal budgets are impacting on local people is picked up in the *Think Local Act Personal* sector agreement published in January 2011, which states:

'Councils and providers need to demonstrate the difference being made to someone's life. This can be done by putting in place independent processes to check that outcomes are achieved and publishing the results. As part of this, it will be important to include an understanding of the experience of local people who self-fund their care and support'.

Checking the Results published alongside the *Think Local Act Personal* sector agreement looked at the need for low cost approaches for benchmarking of user experience data in relation to personal budgets, and prompted ADASS to invest in developing the POET (Personal Budgets Outcome Evaluation Tool) survey and setting up the Demonstrator programme which has provided the majority of data for this report.

Development of POET survey tools

In 2003 In Control and Lancaster University came together to evaluate a small pilot that introduced personal budgets for 60 people with learning disabilities living in five local authority areas. Since then two further evaluation reports have been produced describing the introduction of personalised budgets on an ever increasing scale. The POET survey tools emerged over time from this work and have undergone a number of iterations to reach their current format. Each version has developed from the last in response to feedback from key stakeholders including people completing and implementing the survey. It is envisaged that the survey will continue to evolve overtime in this way.

The POET survey tool gathers views and experiences from personal budget recipients and their family carers, a version not featuring in this report, has also been developed for paid staff. The POET tool is designed to measure how well the local authority is managing to implement personal budgets and to what effect. Specific questions investigate people's experience of the 'personal budget process' and the impact of the personal budget on their everyday life.

The intention has been to provide local authorities with a way of measuring and understanding their performance as it is understood by local people who are looking to them for help. Rather than by setting defined standards for time, task and cost against which performance is judged, as has traditionally been the case. It is this shift to a focus on 'outcomes' and 'experience of process' that distinguishes the POET survey tool.

How this survey came about and how it worked

In January 2011 Directors of Adult Social Services were invited to volunteer to take part in the POET demonstration project. 10 local authority areas agreed to implement the POET survey tool, share the findings locally and nationally, and to incorporate the findings from the survey into their ongoing development plans.

This report presents the findings of the POET surveys of personal budget holders and carers, including:

- A brief description of the surveys and how we collected the information.
- Findings of the POET survey of personal budget holders in England, including:
 - Who responded to the POET survey
 - What personal budgets people are using and how people are supported in using them
 - What difference personal budgets make or don't make to people's lives
 - What factors are associated with better outcomes for personal budget holders.
- Findings of the POET survey of carers of personal budget holders in England, including:
 - Who responded to the POET survey
 - The circumstances of carers and the personal budgets used by the people they are supporting
 - What difference personal budgets make or don't make to carers' lives
 - What factors are associated with better outcomes for carers.

This report presents findings from both the numerical data and the free text data collected using the POET survey tool.

The POET Surveys

This section briefly describes the content of the POET surveys for personal budget holders and carers, and how people completed the questionnaires.

The survey for personal budget holders

The POET survey for personal budget holders was available in three formats:

- 1) An online completion format.
- 2) An easy-read paper completion format, designed by the EasyRead service at Inspired Services Publishing.
- 3) A standard paper completion format.

All three formats contained the same questions, including:

- Information about the personal budget (which council provides it, how long the person has held the budget, previous social services support, how the budget is managed, the amount of the budget).
- Information about personal budget support planning.
- Information about how supportive the council is throughout the personal budget process.
- Information about whether the personal budget has made a difference (either positive or negative) across 14 aspects of the person's life.
- Information about people's goals and whether they are reaching them.
- Information about whether people answered the questions on their own or had help.

- Equalities monitoring questions (gender, age, disability, ethnicity, religion, sexual orientation).
- Space for people to write in their opinions on personal budgets and the survey questionnaire.

In most of the analyses in the report, we compared the experiences of older people (aged 65 years or more) with working age adults (aged 16-64 years) with learning disabilities, mental health needs, or physical disabilities. We did not gain any information about people's self-rated capacity to take part in any of the aspects of their lives we asked about (for example people's self-rated capacity to undertake paid employment), and the findings of the report need to be considered with this in mind

The survey for carers of personal budget holders

The POET survey for carers was available in three formats:

- 1) An online completion format.
- 2) An easy-read paper completion format, designed by the EasyRead service at Inspired Services Publishing.
- 3) A standard paper completion format.

All three formats contained the same questions, including:

- Information about who carers are caring for and how much care they provide.

- Information about the personal budget held by the personal budget holder, whether the carer is also getting any personal budget or direct payment support, and whether the carer's views were included in the support planning process.
- Information about whether the personal budget holder's budget has made a difference (either positive or negative) across nine aspects of the carer's life.
- Equalities monitoring questions (gender, age, disability, ethnicity, religion, sexual orientation).
- Space for people to write in their opinions on personal budgets and the survey questionnaire.

As with personal budget holders, we did not gain information from carers about their self-rated capacity to take part in any of the aspects of their lives we asked about."

Gaining information from personal budget holders and carers

Because the POET surveys were designed for people to evaluate their experiences of existing personal budgets, the surveys were clearly service evaluation, rather than research, according to guidance from the National Research Ethics Service² and therefore did not require Research Ethics Committee approval.

All formats of both POET surveys explained how the information would be used. Anonymity and confidentiality were guaranteed – we did not ask for people's names and the information was held on an electronic database that was not accessible to councils.

Before completing the survey everyone was asked to indicate if they agreed (or not) for their information to be used in reports such as this one before they completed the survey.

There were many ways for personal budget holders and carers to complete the POET surveys.

First, the online versions of the surveys were widely publicised, with links to the surveys on the in Control and Putting People First websites.

Second, ten local authorities who volunteered as POET survey demonstrator sites were advised and supported by in Control, Putting People First and Lancaster University to aim for 100 POET survey returns per local authority from personal budget holders and carers. The 10 local authorities used a range of methods to promote the POET survey in their area, typically with additional phone support available if required, including:

sending paper easy-read POET surveys to personal budget holders and carers for FREEPOST return to Lancaster University for data entry (4 local authorities);

- Sending paper standard format POET surveys to personal budget holders and carers for FREEPOST return to Lancaster University for data entry (2 local authorities);
- Contacting personal budget holders and carers and asking them to complete POET surveys either online or by returning paper surveys back to the local authority for data entry (3 local authorities);
- Asking people to complete POET surveys in face-to-face interviews or as part of ongoing reviews (1 local authority).

² National Research Ethics Service <http://www.nres.npsa.nhs.uk/applications/is-your-project-research/>

In total, 1,114 personal budget holders had completed the POET survey and given their agreement for the information to be used by the preliminary deadline of 15 April 2011. Of these, 832 returns were from personal budget holders in the 10 local authority demonstrator sites (average 83.2 returns per local authority, ranging from 9 to 161 returns). Of the remaining 282 personal budget holders, 185 people responded across 76 local authorities and 97 did not name a local authority.

In total, 950 carers had completed the POET survey and given their agreement for the information to be used by the preliminary deadline of 15 April 2011. Of these, 782 returns were from carers in the 10 local authority demonstrator sites (average 78.2 returns per local authority, ranging from 13 to 189 returns). Of the remaining 168 carers, 138 people responded across 66 local authorities and 30 did not name a local authority.

Local reports to participating councils concerning personal budget holders and carers were produced separately if there were more than 50 returns from personal budget holders and 50 returns from carers in that local authority area.

In both personal budget holder and carer versions, responses to most of the POET survey questions were recorded numerically within Limesurvey, then converted in a statistical software package, SPSS, to allow us to statistically analyse the responses. All between-group differences and associations were conducted using the appropriate non-parametric test; due to the number of comparisons we made the statistical significance level was set at $p < 0.01$ (i.e. the odds of the result occurring by chance was less than 1 in 100).

Throughout this report, where we refer to a difference between groups or a significant association between factors, this is underpinned by a non-parametric statistical test with $p < 0.01$. For ease of reading the test results themselves are not presented in this report but are available on request from the first author.

For the open questions asking if people wanted to write in anything about their experiences of personal budgets, we used a complete list of what people wrote to develop a set of themes summarising people's experiences from what they had written. Each quote was then examined and assigned to one or more themes depending on what the person had written – for most comments a judgement was also made on whether the comment was mainly positive, negative or neutral in relation to the theme. This was done separately for personal budget holders and carers.

For both personal budget holders and carers, people were more likely to write in a comment if they were having either very positive or very negative experiences of personal budgets.

In total 417 personal budget holders (37%) made comments about their experiences of personal budgets. The proportion of people choosing to make a comment varied widely across councils (from 29% to 58%). In total 434 carers (46%) made comments about their experiences of personal budgets.

Findings – Personal Budget Holders

This section of the report presents findings for personal budget holders responding to the POET survey

These include:

- Who responded to the POET survey
- What personal budgets people are using and how people are supported in using them
- What difference personal budgets make or don't make to people's lives
- What factors are associated with better outcomes for personal budget holders

Who responded to the POET survey?

As mentioned earlier, a total of 1,114 personal budget holders completed the POET survey and gave their agreement for the information to be used. As people could choose not to complete particular questions within the survey, the totals reported throughout the report are unlikely to add up to this overall total.

Equalities monitoring information is presented in detail in *Appendix 1*. In outline, this information shows:

- Almost half of personal budget holders (48%) had some form of help in answering the POET survey, 36% answered the survey on their own and for 16% the survey was largely answered on their behalf by someone else.

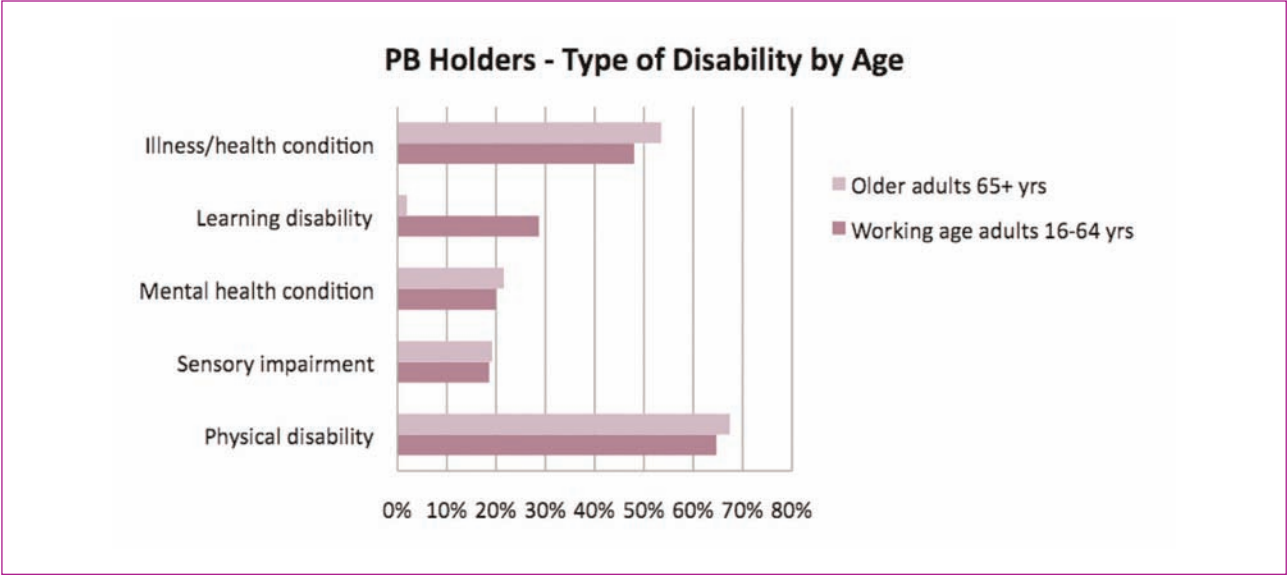
- Most respondents (61%) were women.
- In terms of age, 26% of personal budget holders were aged 16-44 years, 31% were aged 45-64 years, and 43% were aged 65 years or over.
- Most respondents were White (75%), with 14% of respondents not giving this information and significant representation from Asian/Asian British people (5%) and Black/Black British people (5%).
- Most respondents were Christian (60%), with 16% of respondents not giving this information and 14% reporting themselves to have no religion.
- Most respondents reported themselves to be heterosexual/straight (72%), with 25% of respondents not giving this information.
- Almost all respondents (96%) reported themselves to have a disability.

The POET survey also asks personal budget holders about the nature of their disability, with people able to endorse as many types as were relevant to them. Figure 1 shows the nature of people's self-reported disabilities, broken down into those for working age adults (aged 16-64 years) and older adults (65+ years). In both age groups, physical disabilities and longstanding illness/health conditions were reported by a majority of respondents.

There was only one difference between age groups, with learning disabilities much more likely to be reported by working age adults. Working age adults reported an average of 1.8 different types of disability, with 22% of people reporting three or more types of

disability. Older adults reported an average 1.6 types of disability, with 17% of people reporting three or more types of disability.

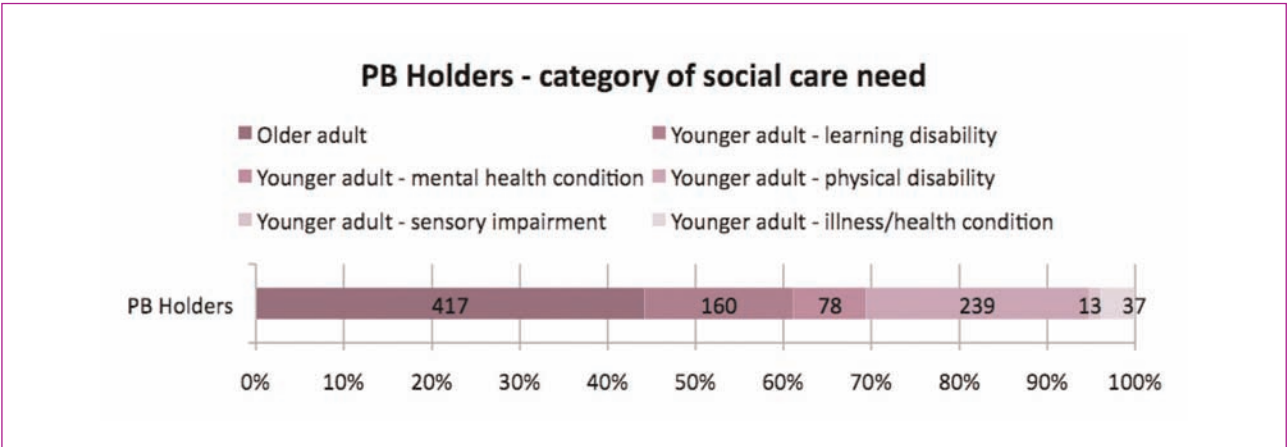
Figure 1: Type of disability reported by personal budget holders of working age (16-64 yrs) and older (65+ yrs)



Because multiple disability types were reported by respondents, we also placed people into particular mutually exclusive categories of social care need, described in Figure 2 below. There were enough numbers of older adults and younger adults with learning disabilities,

mental health conditions and physical disabilities to conduct further analyses exploring potential differences between these groups in people's experiences of personal budgets.

Figure 2: Category of social care need for respondents



How are people using personal budgets?

The POET survey asks personal budget holders several questions about how they are using personal budgets and what support people have had throughout the personal budget process.

As well as looking at overall levels of usage and support, we investigated differences between people in the broad social care need groups outlined above. We also checked for any differences in personal budget usage and support by gender, ethnicity and religion. Finally, we also explored whether there were significant variations in personal budget usage and support across councils. We only report findings here where there are substantial differences.

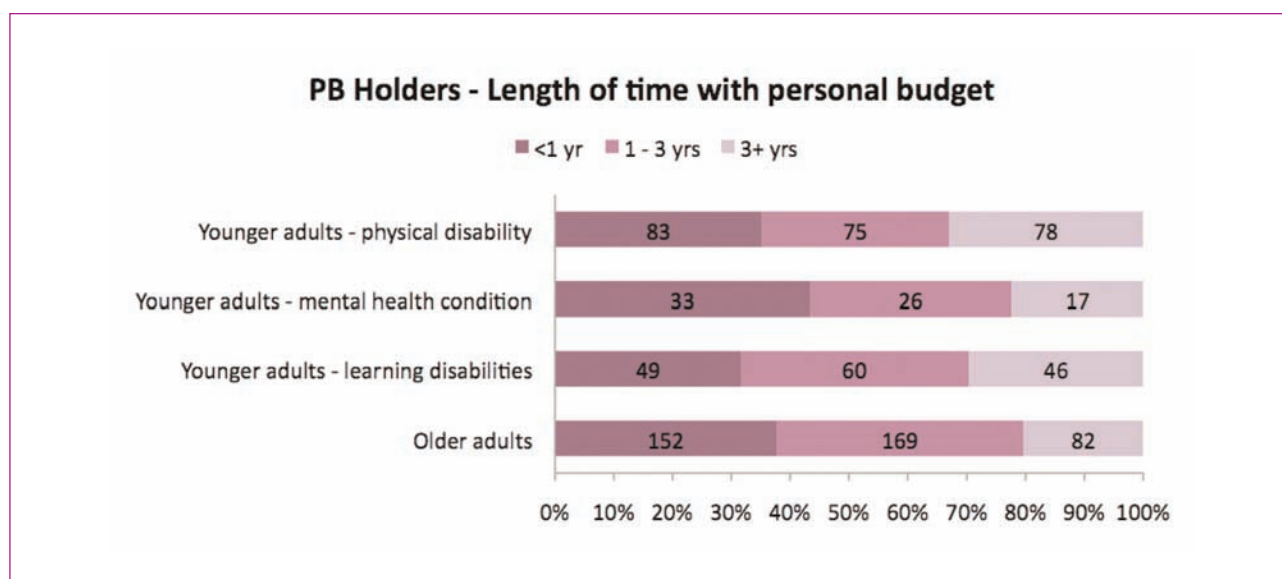
How long have people held a personal budget?

Figure 3 below shows how long POET survey respondents have held personal budgets, broken down into the social care need categories outlined earlier. Overall, 38% of respondents had held their personal budget for less than a year, 37% for between 1 and 3 years, and 25% for more than three years.

Younger adults with physical disabilities and younger adults with learning disabilities were more likely to have held their personal budget for longer than older adults and younger adults with mental health conditions.

There were also marked differences across councils in the length of time people had been using personal budgets – for example the percentage of personal budget holders having held personal budgets for more than three years varied from 5% to 47% across councils.

Figure 3: Length of time people had held their personal budgets by social care need



Did people get local authority support before their personal budget?

Figure 4 below shows how many personal budget holders had been receiving local authority support before they got their personal budget, broken down by social care need category. Overall, 66% of respondents had been receiving social care support before the start of their personal budget.

Younger adults with physical disabilities and younger adults with learning disabilities were more likely to have received social care support before their personal budget than older adults and younger adults with mental health conditions.

There were again substantial differences across councils in whether they had received social care support before their personal budget – for example the percentage of personal budget holders having previous social care support varied from 51% to 74% across councils.

Figure 4: Previous social care support before the personal budget by social care need

How do people manage their personal budgets?

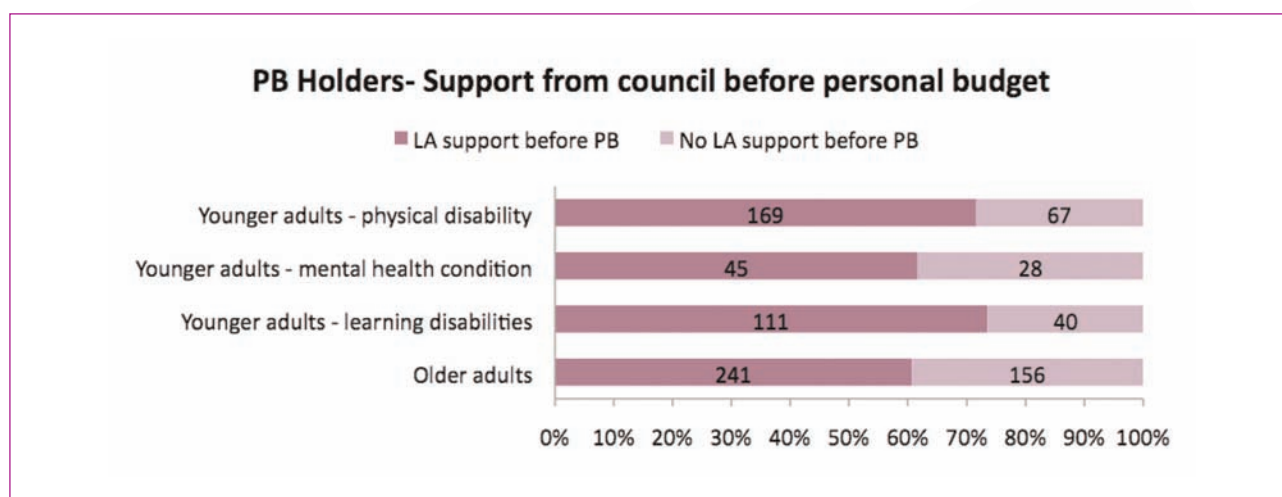
Figure 5 following shows the different ways that people managed their personal budgets, broken down by social care need category.

Overall, people most commonly managed their personal budget through direct payments paid to them (54%), followed by direct payments looked after by someone else (28%). Individual service funds (6%) and personal budgets managed by the council (10%) were less common, and 6% of people did not know how their personal budget was managed.

However, within these overall figures there were substantial differences across social care need groups.

Younger adults with physical disabilities and younger adults with mental health conditions were more likely to use direct payments to themselves than older adults and younger adults with learning disabilities.

Younger adults with learning disabilities were more likely than other groups to have a direct payment looked after by someone else.



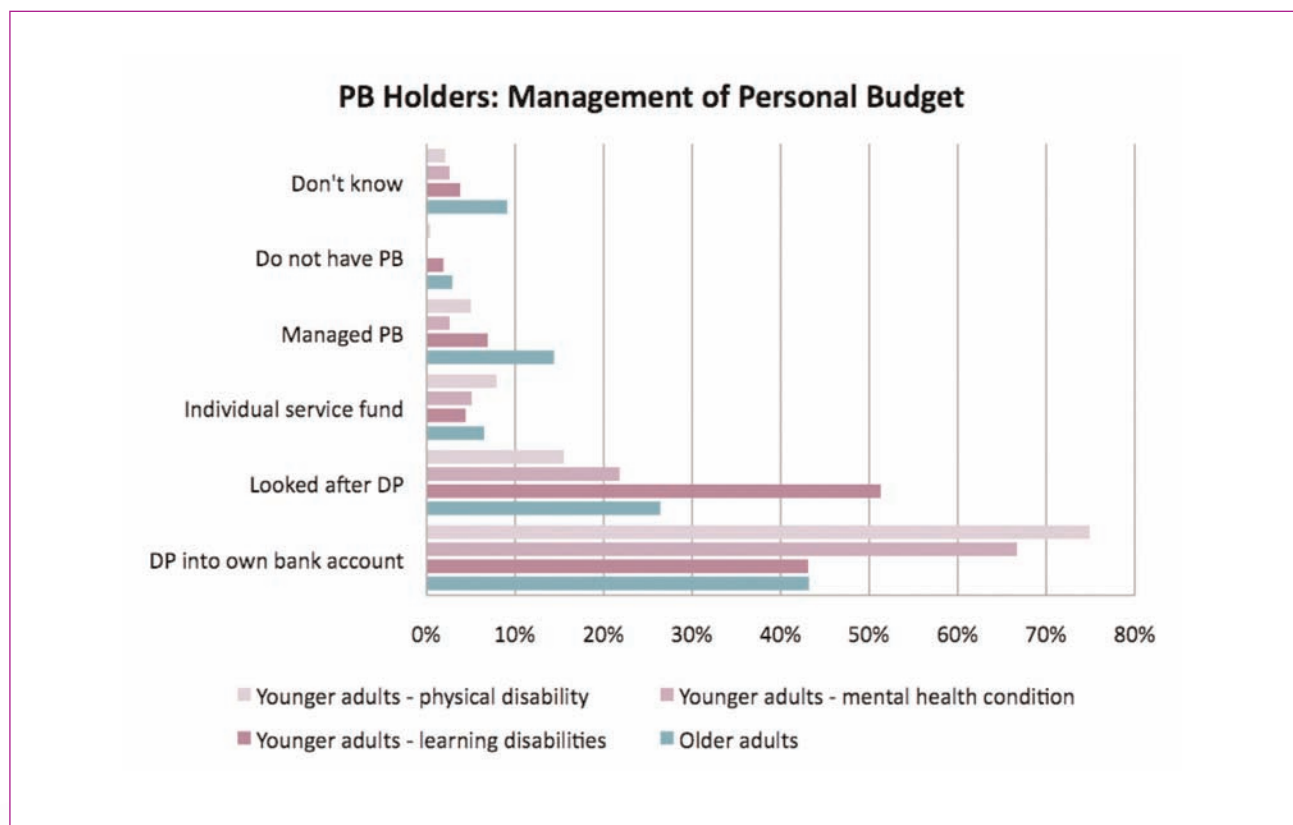
Older people were more likely than other groups to have a personal budget managed by the council.

Older people were more likely than other groups to not know how their personal budget was managed.

Councils varied substantially in the extent to which people used every method of managing their personal budget, including the number of people who did not know how their personal

budget was managed. This is illustrated in Figure 6, which shows the variation across (anonymous) councils in the percentage of personal budget holders getting a direct payment paid to them, having a personal budget managed by the council, and not knowing how their personal budget was managed.

Figure 5: Management of personal budgets by social care need



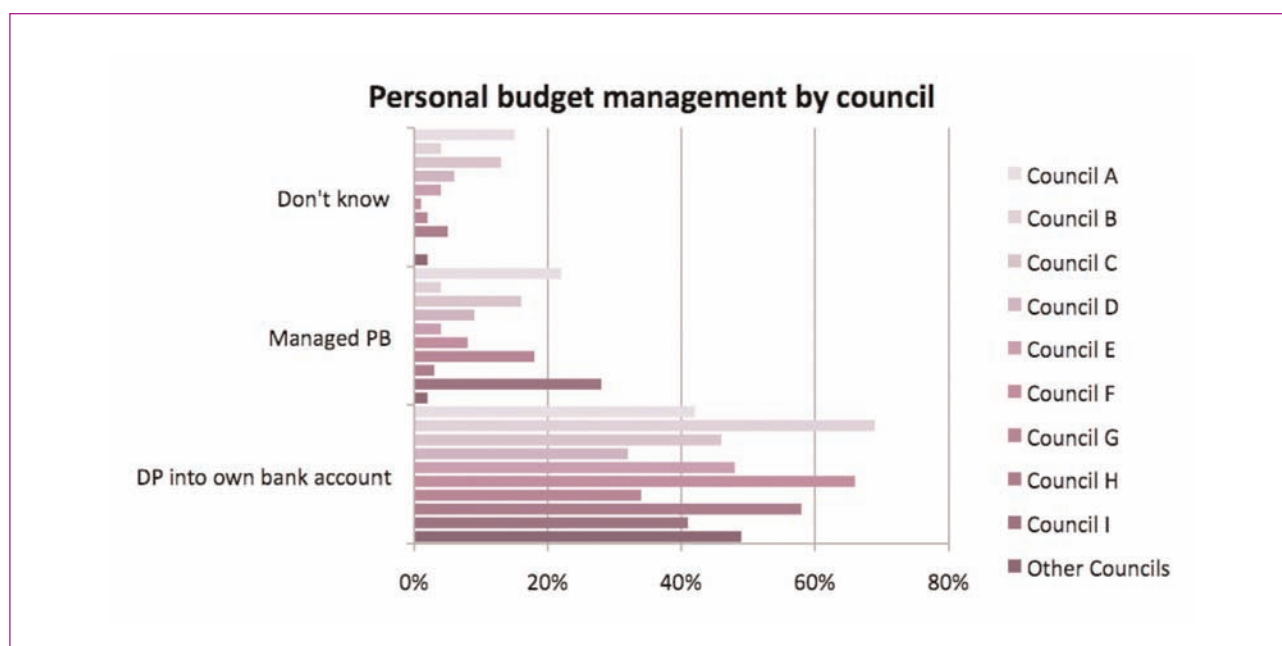


Figure 6: Variation across councils in personal budgets managed as direct payments to the person, personal budgets managed by the council, and people not knowing how their personal budget was managed

The cost of personal budgets

The POET survey asked personal budget holders whether they were told the weekly amount of their personal budget and whether they could provide an estimate of the amount.

Overall, 77% of respondents reported that they had been told the costs of their support. There were no differences between social care need groups (see *Appendix 2* for details), but there was substantial variation across councils, with 61% to 92% of people being told their weekly support costs.

For those who could provide an estimate of the weekly cost of their personal budget, Figure 7 and Figure 8 following summarise these estimates across social care need groups.

As Figure 7 and Figure 8 show, there was substantial variation in the amount of personal budgets within and across social care groups. The median weekly amount of personal budgets was lowest for older adults (£133 per week), compared to younger adults with mental health conditions (£160 per week), younger adults with physical disabilities (£188 per week) and particularly younger adults with learning disabilities (£221 per week). Older adults and younger adults with mental health conditions were more likely to have lower value personal budgets (£1-£200 per week), and less likely to have high value personal budgets (£501 or more per week) than younger adults with learning disabilities or physical disabilities.

Again, there was substantial variation across councils in the weekly cost of personal budgets, with median weekly amounts varying from £90 per week to £213 per week.

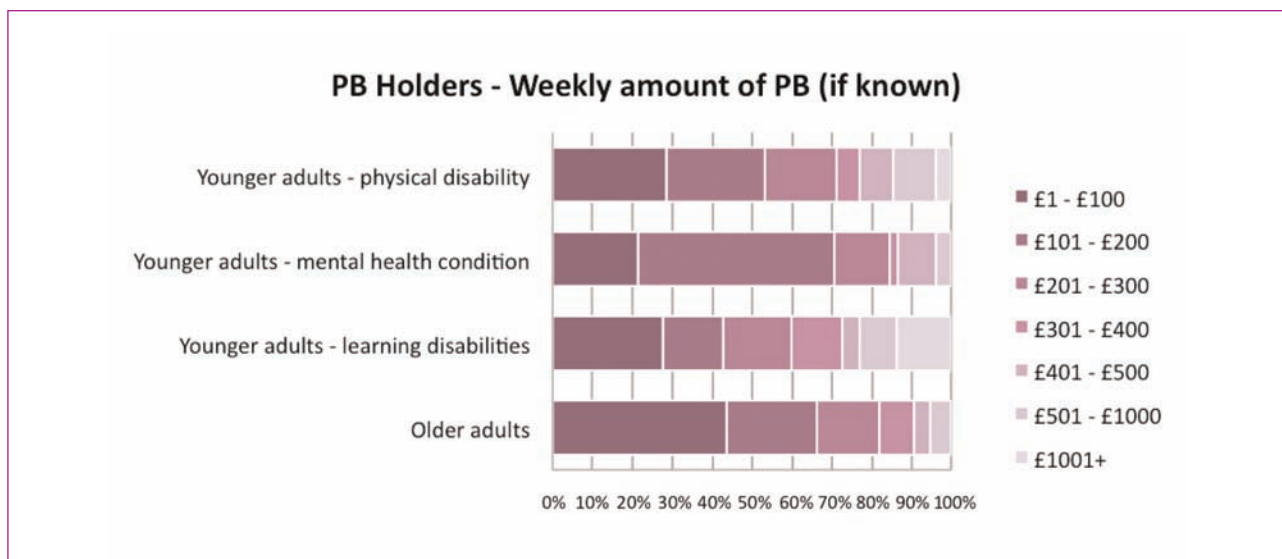


Figure 7: Weekly amount of personal budgets by social care need

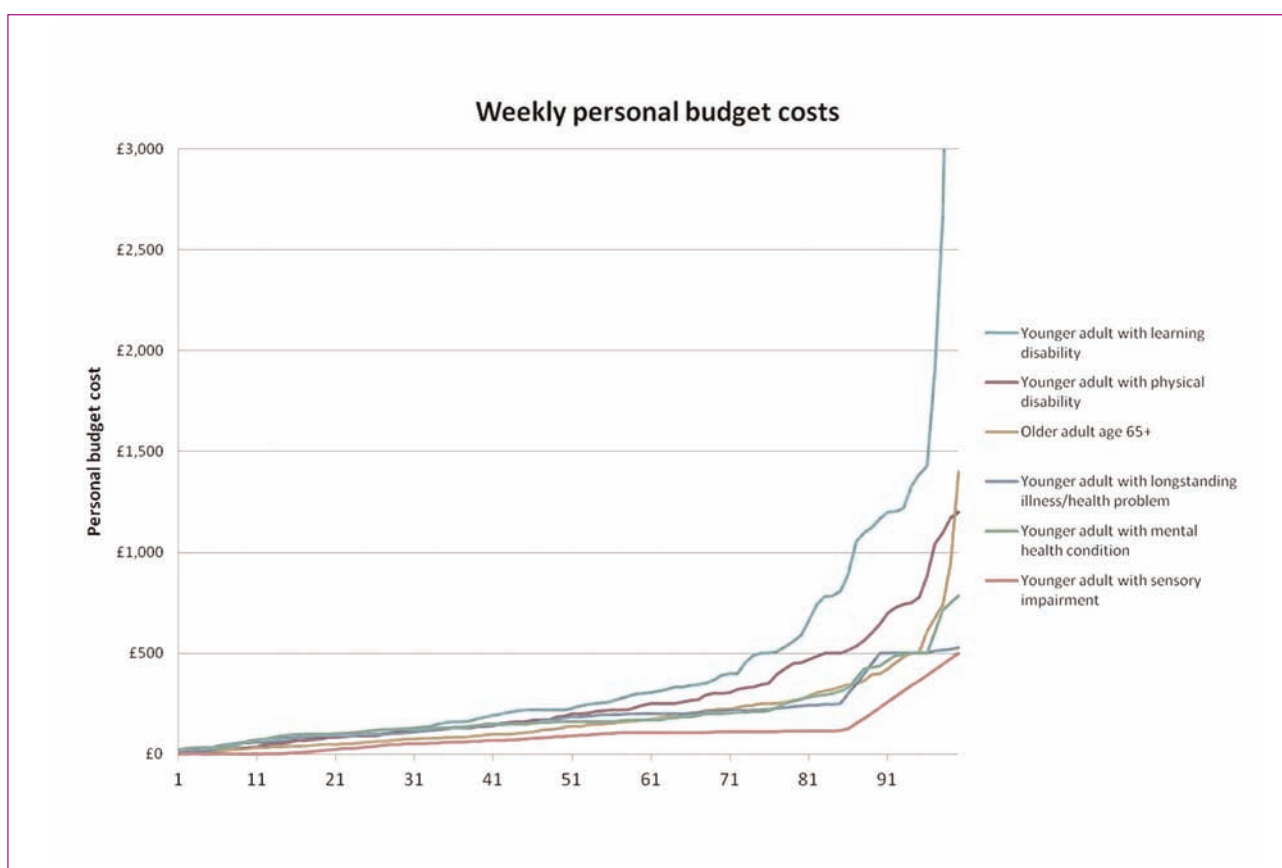


Figure 8: Distribution of weekly personal budget allocations by social care need group

Support for planning personal budgets

The POET survey asked a range of questions about how people were supported when planning their personal budget, who supported them, and whether their views were included in the personal budget support plan.

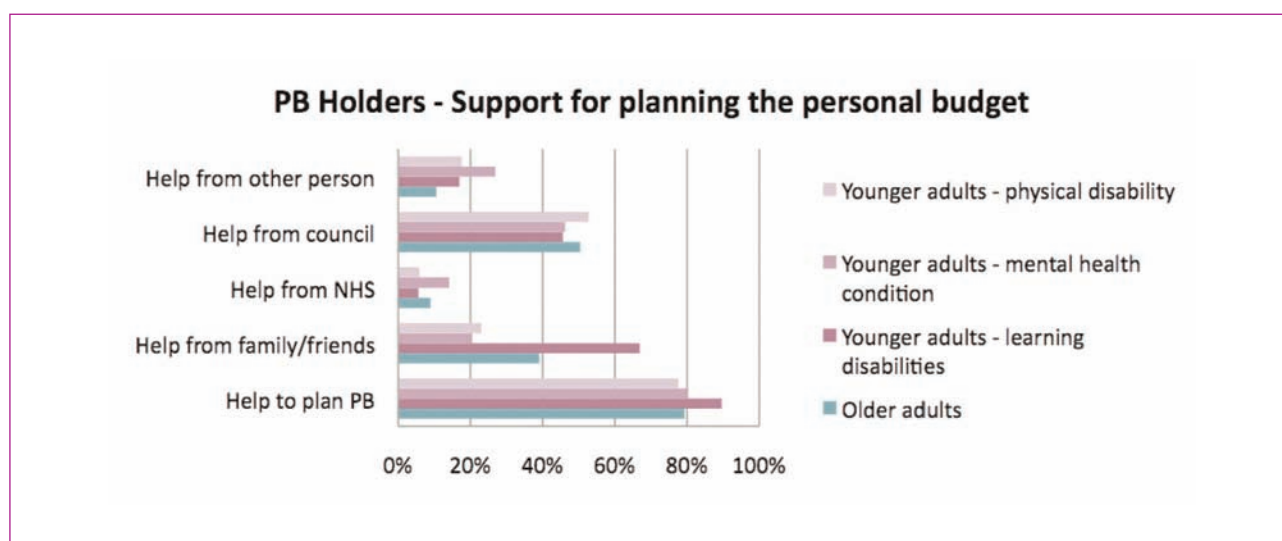
Figure 9 firstly shows that overall the vast majority of personal budget holders (81%) had received help to plan how to use their personal budget. There were no major differences across social care need groups, but once again there was major variation across councils, with the proportion of people reporting help with planning varying from 69% to 98%.

Figure 9 also shows how many people used various sources of support in planning their personal budget. Overall, people most commonly got help in planning personal budgets from the council (50%), and family or friends (38%), and were less likely to get help from others independent of the council/NHS (15%) or the NHS (8%).

Younger adults with learning disabilities and older adults were more likely to get help from family or friends than other groups, and younger adults with mental health conditions were more likely to get help with planning from someone independent of the council/NHS; there were no differences across social care need groups in planning support from council or NHS workers.

However, there were big differences across councils in all these types of support planning, including help from family and friends (from 24% to 59% of people across councils), help from the NHS (from 2% to 14% of people across councils), help from the council (from 38% to 85% of people across councils), and help from someone independent of the council/NHS (from 4% to 23% of people across councils).

Figure 9: Support for planning personal budgets by social care need



PB Holders - How easy or difficult has the council made it to do these things?

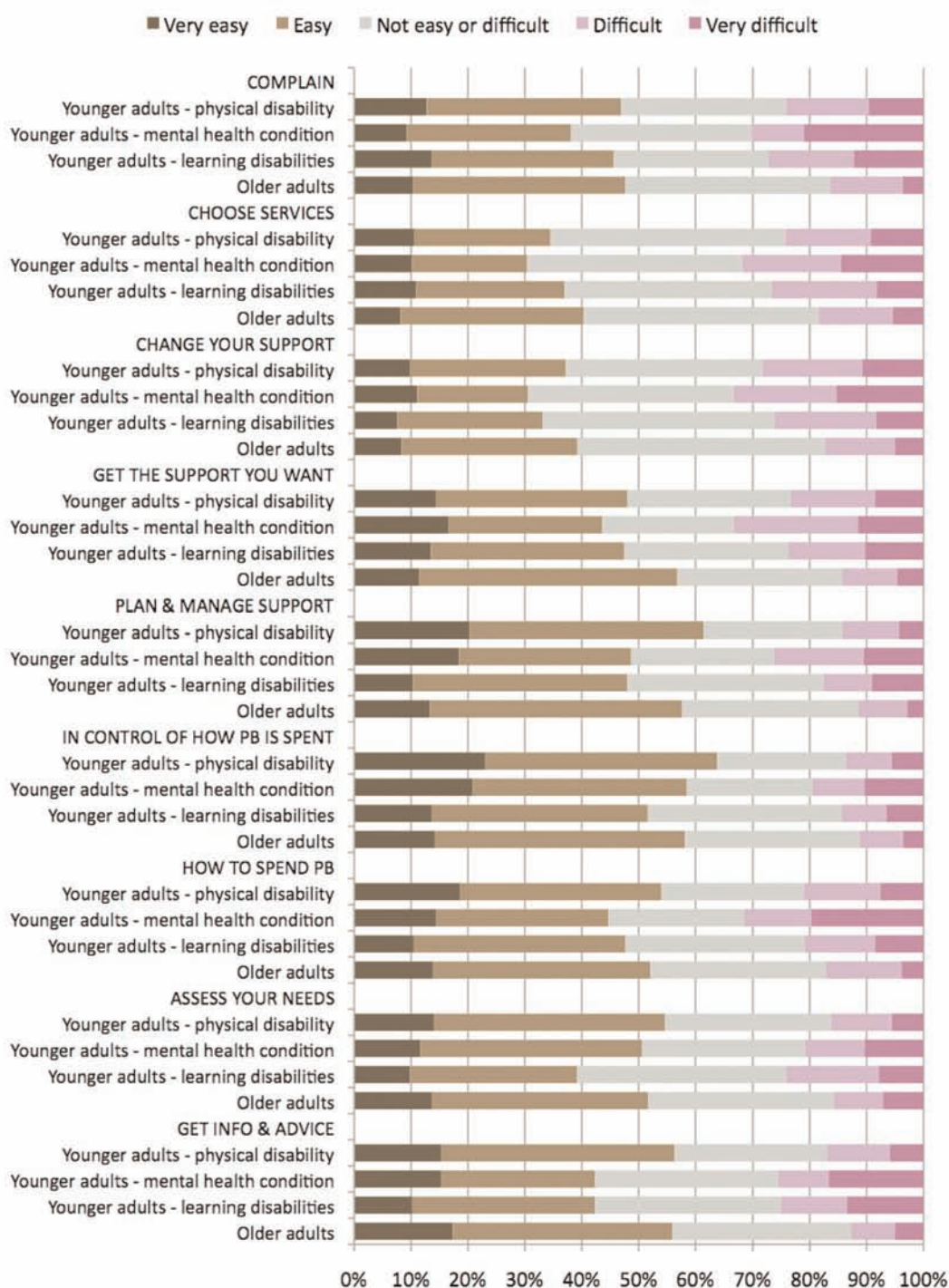


Figure 10: Council support for various aspects of the personal budget process by social care need

Finally, the POET survey asked respondents whether their views were included in their support plan. Overall a vast majority of respondents (87%) reported that their views were very much or mostly included in their support plan, with no differences across social care need groups (see *Appendix 2* for details).

The role of the council in supporting personal budgets

As Figure 10 reports, the POET survey asked several questions to personal budget holders about whether the council was helpful or not throughout the personal budgets process.

As Figure 10 shows, overall a bare majority of respondents (between 50% and 59%) felt that the council had made it easy or very easy to get information and advice, assess the person's needs, understand what a personal budget could be spent on, be in control of what the personal budget was spent on, and plan and manage the person's support.

Overall, fewer respondents (between 37% and 46%) felt that the council had made it easy or very easy for people to change their support, choose the best option from a range of services, or voice their opinions or complain.

Overall, substantial numbers of people (between 13% and 24%) reported that councils had made it difficult or very difficult in each aspect of the personal budgets process.

In terms of getting information and advice, older adults and younger adults with physical disabilities reported that the council made it easier to get information and advice than younger adults with learning disabilities and younger adults with mental health conditions. There were no other differences between social care need groups.

However, again there was substantial variation across councils in how easy or difficult they made all aspects of the personal budget process.

Experience of the personal budget process

As mentioned above, personal budget holders had the opportunity to write in comments about their experiences of personal budgets.

In total, 163 personal budget holders commented on at least one aspect of the personal budget process. Table 1, following, outlines the major themes of people's comments about the personal budget process, together with information on how many personal budget holders made positive or negative comments in relation to each aspect of the personal budget process.

As Table 1 shows, the vast majority of comments were negative and covered most aspects of the personal budget process, with the exception of brokerage which was largely commented on positively. The single most commonly commented upon issue in the survey was a lack of clarity, often regarding how money could or couldn't be used, but also concerning other aspects of personal budgets as well.

Table 1: Personal budget holder experiences of the personal budget process

Theme	Description of theme	Number of positive comments	Number of negative comments
Assessment	Experience of assessment, determining level of need and or level of allocation, included general comments on initial setup	1	26
Review and reassessment	Process of making changes to support, formal review processes (or lack of them)	2	24
Timeliness	Speed of personal budget process, getting services, responses to enquiries	2	30
Paperwork	Complexity or simplicity. Quantity and burden, recognition of or questioning the need for records.	3	21
Employment	Experience of employing or recruiting and retaining support staff	8	20
Restrictions	Restrictions (or the lack of restrictions) on how the personal budget can or cannot be used.	7	34
Clarity (policy information)	Clarity of information about policies, procedures, processes, and the nature and availability of service choices	2	64
Brokerage	Help with managing the process (in the main from formal independent services)	14	5

“It was very difficult to set up originally. I need to use contingency fund but have no idea how? Once set up there is no info on how to change/alter/reassess it. Once set up you are discharged from social services and have no ideal back up to contact on who to contact. Money is held by [broker] who don’t know much about it!!”

Have personal budgets made a difference to people’s lives?

The POET survey asks personal budget holders whether their personal budgets have made a difference to various aspects of their lives, and if so whether this difference has been positive or negative. Figure 11 below summarises the impact of personal budgets on seven areas of people’s lives, broken down by social care need group.

PB Holders - Has your personal budget changed these things?

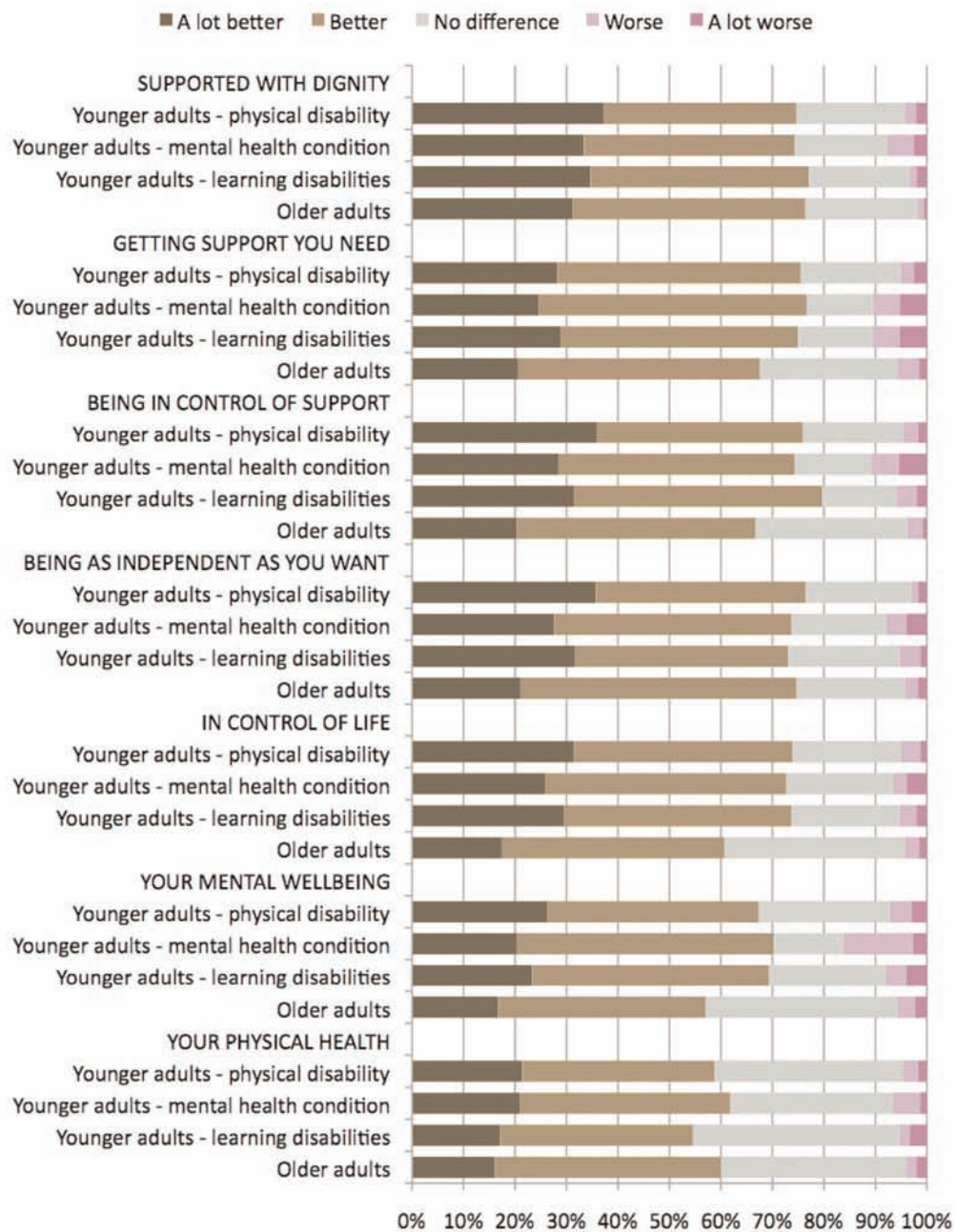


Figure 11: Outcomes of personal budgets by social care need

As Figure 11 shows, overall substantial majorities of people reported personal budgets having a positive impact on all seven aspects of people's lives reported here. Large majorities (70% or more) of people reported personal budgets having a positive impact on people being supported with dignity and respect (76%), people staying as independent as they want to be (75%), people being in control of their support (72%), and people getting the support people need when they need it (72%). Smaller majorities reported positive impacts of personal budgets on control over the important things in life (68%), mental wellbeing (63%) and physical health (59%).

Overall, small numbers of people (between 3% and 8%) reported personal budgets having a negative impact on any of these seven aspects of people's lives.

Figure 12 below presents information in a similar format on a further seven outcomes for personal budget holders. Overall, majorities of personal budget holders reported a positive impact of personal budgets on people's relationships with people paid to support them (67%), people's relationships with family members (58%) and people feeling safe both in and outside the home (57%).

However, very few people (between 3% and 4%) reported negative impacts of personal budgets in any of these seven areas. Instead, a majority of people reported personal budgets making no difference on people getting and keeping a paid job (no difference 88%), people volunteering and helping their local community (no difference 77%), people choosing where they live and who they live with (no difference 60%), and people's relationships with friends (no difference 52%).

PB Holders - Has your personal budget changed these things?

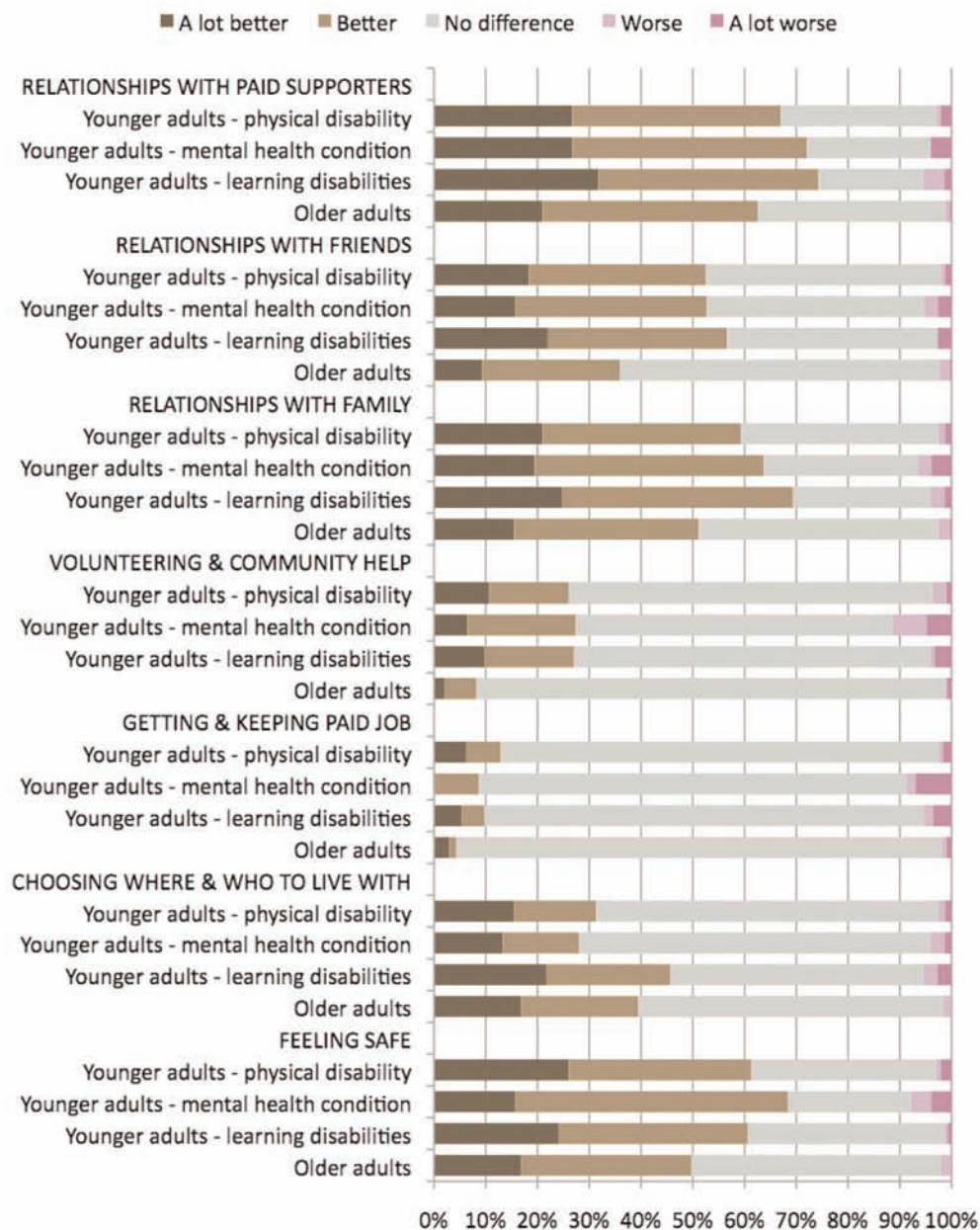


Figure 12: Outcomes of personal budgets by social care need

Experience of the impact of personal budgets

As mentioned above, personal budget holders had the opportunity to write in comments about their experiences of personal budgets.

Of the 417 personal budget holders who commented, 364 gave some general indication of their experience of personal budgets, with slightly more positive (193) than negative (143) comments (28 comments were mixed or neutral). In addition, 24 personal budget holders took the opportunity to express their gratitude to the local authority.

"I would like to take this opportunity to thank you for my personal budget, it has made life much better and easier because I have the right to choose and pick who I want as my carer. I can tell them what I want them to do without any fears when even I have a question I only have to phone and the staff are very helpful."

In total, 163 personal budget holders commented on the impact of their personal budget on a specific aspect of their day to day life. Table 2 outlines the major themes of people's comments about the impact of personal budgets, together with information on how many personal budget holders made positive or negative comments in relation to each aspect of the personal budget process.

Table 2: Personal budget holder experiences of the impact of personal budgets on their lives

Theme	Description of theme	Number of positive comments	Number of negative comments
Stress and worry	Impact on the person's emotional wellbeing	13	9
Home	This included impact on person's capacity to maintain their home and the value of life at home	23	3
Community	Keeping connected to the local community, including avoidance of residential care	34	3
Independence	Most often included an explicit use of the term 'independence'	34	1
Choice, flexibility and freedom in life	The impact on choice in life (as opposed to control over support), including the terms 'choice' 'freedom', and 'flexibility'	41	1
Money	The level of money or support available or the value of having money for support	17	51
Personalised care	The impact of the personal budget on care and support, including support being more tailored to the individual's needs and circumstances	89	21
Relationships with staff/system	Impact on relationships with staff and the system, including experiences of dealing with individuals such as care staff	26	48
Relationships with family/friends	Impact on friends and family members	31	11
Future	Comments about the future, including comments concerning money, hopes and concerns	3	32

As Table 2 shows, personal budget holders making comments almost universally described positive impacts of personal budgets on their home life, their connections with their local community, their independence, and their levels of choice and control over their lives, although comments concerning the impact of personal budgets on levels of stress and worry were more mixed. Most personal budget holders making comments also reported a positive impact of personal budgets on the personalised care that they used, principally in terms of being able to choose and manage support that really fitted into people's lives and met their needs. Most people also reported a positive impact of personal budgets on their relationships with family and friends, where negative comments were principally concerned with worries about potential burdens being placed on family and friends.

"Having the personal budget has completely changed my life and of those around me. My husband who is 75yrs was finding things increasingly difficult to support me, and my daughter who was recovering from breast cancer was worried about the way things were breaking down and was unable to help. I rang social services one day in tears to see if there was a possibility of any help and within a few days I saw a social worker who told me about the budget and how he thought it would work for me. I have never looked back and the stress and worry has been taken from us. I have lovely carers who support us in every way. They help with personal care, help in the home, shopping take me to my voluntary work and meetings which I would have to give up without them as my husband couldn't take me and we have trips out which stops me from being confined to 4 walls. My life is happier and more fulfilling now and I don't know what would happen if the support was withdrawn. I have independence now and hopefully can help others along the way."

I run a swimming group for patients from my health centre and help out at a leg ulcer club doing reception and treasurer. I have also joined a residents' disabled group for our housing association, none of this I could do without my carer taking me and helping me when I am there."

However, personal budget holders were generally more negative about the financial impact of personal budgets, principally where personal budgets were associated with demands for increasing personal financial contributions at short notice. It is also worth noting that people's comments about the future were also mainly negative, and principally concerned with worries about potential cutbacks to personal budgets or associated care and support services.

"[The] Adult learning disability team took 14 months to process a claim for direct payments. I then was told at the time I would not have to pay a contribution. 4 months later I was then told I had to pay half my carers allowance towards my care. I had also to back pay my contribution using up all my savings. It has been a disgrace. I am still unsure how to spend it, or on what except my carer. The whole process has taken 2 years and been so stressful."

Comments concerning relationships with staff and the 'system' were also mainly negative. Positive comments about staff were on the whole directed towards care and support workers rather than social workers, though a very small number of people commented very highly on their social worker.

"Social services staff come from a different planet and have great difficulty speaking understandable sensible plain English and being answerable to their clients."

My social worker has been excellent throughout, nothing is too much trouble. This whole experience has been excellent AND uplifting."

What factors are associated with positive outcomes for personal budget holders?

Figures 11 and 12 show that personal budgets are perceived by personal budget holders to have a broadly positive impact on their lives. In this section of the report we will ask three further questions:

- 1) Are there inequalities in the outcomes of personal budgets depending on gender, ethnicity, religion, or social care need?
- 2) Are there variations in the outcomes of personal budgets across councils?
- 3) Are aspects of personal budget usage (length of time with personal budget, previous local authority support, method of personal budget management, knowledge of the cost of personal budget support, weekly cost of personal budgets, support in personal budget planning, council support in the personal budget process) associated with the outcomes of personal budgets?

To address these questions, we checked whether there were associations between all the factors mentioned above and better or poorer outcomes on all the outcome indicators. Where the associations we found were highly unlikely to happen by chance (i.e. where there was a less than 1 in 100 probability of the findings occurring by chance), they are included in Tables 3 and 4 below.

For each table, if the factor listed on the left of the table is associated with a more positive outcome, then the cell of the table is filled in green. For example, Table 3 shows that people who have had personal budgets for a longer time are more likely to report a positive impact of personal budgets on whether they are in control of their support.

If the factor on the left of the table is associated with a less positive outcome, then the cell of the table is filled in red. For example, Table 3 shows that older adults report less positive outcomes in the areas of being in control of important things in life and being in control of support.

A special case is made for variation across councils – where outcomes vary across councils the cell of the table is shaded red/green stripes, to indicate that there is significant variation across councils but we cannot reveal which councils are associated with better or poorer outcomes.

Taking both tables together, there are some general conclusions that can be reached:

- In terms of equalities monitoring, there are no differences in outcomes according to gender, ethnicity or religion (there were too few people in certain categories to enable us to investigate sexual orientation).
- In terms of social care need groups, older adults tend to report less positive outcomes than other social care need groups in six out of the 14 outcome domains. However, it is worth recalling from Figures 11 and 12 that these differences are ones of degree (older adults are more likely to record personal budgets as making no difference; they are not more likely to record personal budgets as making things worse). It is also important to note that less positive outcomes for older adults may not be a function of age as such, but could reflect the fact that older adults are less likely to use personal budgets in ways that are associated with positive outcomes. For example, older adults are less likely to use direct payments, less likely to know how their personal budget was managed, and more likely to have a personal budget managed by the council – all these factors are associated with less positive outcomes (see following).

- As we have seen throughout the findings, there is pervasive variation across councils on 13 of the 14 outcome domains. This suggests that councils can have a major impact on outcomes by considering how they help people through all stages of the personal budgets process. This is reinforced by the findings that people reported more positive outcomes across the board if they felt their council had made all aspects of the personal budget process easier.
- People who had been using their personal budgets for longer reported increasingly positive outcomes in the domains of being in control of their support, relationships with friends and paid support, and volunteering/helping in the community. This firstly suggests that the positive impact of personal budgets is not simply a short-term 'bounce' that wears off over time. Secondly, it suggests that getting your support right in ways that work for you may take some time to achieve.
- How personal budgets are managed is robustly linked to outcomes for personal budget holders. People with direct payments paid directly to them tended to report more positive outcomes across eight of the 14 outcome domains. Conversely, people with personal budgets managed by the council tended to report less positive outcomes across four of the 14 outcome domains.
- It is important that personal budget holders are kept informed of essential aspects of their personal budget. People who did not know how their personal budget was managed or did not know the amount of their personal budget tended to report less positive outcomes across 12 and 13 of the 14 outcome domains respectively.
- Of those personal budget holders who could report the weekly amount of their personal budget, a greater weekly amount was associated with more positive outcomes across 11 of the 14 outcome domains.
- The support planning process for the personal budget is critical. People who felt their views were more fully included in their support plan were more likely to report positive outcomes across all 14 outcome domains. The source of support for planning with the most positive impact appeared to be getting help from someone independent of the council or NHS – people getting help from this source reported more positive outcomes particularly relating to getting and controlling better paid support.
- Finally, it is worth noting that relatively few factors were associated with positive outcomes around getting and keeping a paid job, although we did not collect information on people's self-rated capacity to undertake paid employment or the levels of support people felt they would need. Given the large numbers of people in all social care groups reporting no impact of personal budgets on paid work, it seems that barriers to paid work stretch beyond the current reach of the personal budget process.

Factor associated with outcome	Outcome Measure						
	Your physical health	Your mental wellbeing	Being in control of life	Being independent	Being in control of support	Getting support you need	Being supported with dignity
Characteristics of personal budget holders							
Older adult							
Variations across councils							
Councils							
Usage of personal budgets							
Longer time with PB							
PB direct payment to person							
PB managed by council							
Don't know how PB is managed							
Know amount of PB							
Higher weekly amount of PB							
Support for personal budgets							
Help in planning from council							
Help in planning from someone else							
Views more fully included in plan							
Council making PBs easier							

Table 3: Factors associated with outcomes for personal budget holders

Factor associated with outcome	Outcome Measure						
	Feeling safe	Choose where/ who live with	Get/ keep a paid job	Volunteering and helping community	Relations with family	Relations with friends	Relations with paid supporters
Characteristics of personal budget holders							
Older adult							
Variations across councils							
Councils							
Usage of personal budgets							
Longer time with PB							
PB direct payment to person							
PB managed by council							
Don't know how PB is managed							
Know amount of PB							
Higher weekly amount of PB							
Support for personal budgets							
Help in planning from family/ friends							
Help in planning from someone else							
Views more fully included in plan							
Council making PBs easier							

Table 4: Factors associated with outcomes for personal budget holders

Findings – Carers

This section of the report presents findings for carers responding to the POET survey, including who responded; the circumstances of carers and the personal budgets used by the people they are supporting; what difference personal budgets make or don't make to carers' lives; and the factors are associated with better outcomes for carers.

Who responded to the POET survey?

As mentioned earlier, a total of 950 carers completed the POET survey and gave their agreement for the information to be used. As people could choose not to complete particular questions within the survey, the totals reported throughout the report are unlikely to add up to this overall total.

Equalities monitoring information for carers is presented in detail in *Appendix 3*. In outline, this information shows:

- Most respondents (70%) were women.
- In terms of age, 15% of carers were aged 16-44 years, 56% were aged 45-64 years, and 30% were aged 65 years or over.
- Most respondents were White (81%), with 8% of respondents not giving this information and significant representation from Asian/Asian British people (5%) and Black/Black British people (4%).

- Most respondents were Christian (66%), with 11% of respondents not giving this information and 14% reporting themselves to have no religion.
- Most respondents reported themselves to be heterosexual/straight (77%), with 22% of respondents not giving this information.
- Just over a quarter of carers (27%) reported themselves to have a disability, most commonly a physical disability (14%) and/or a longstanding illness/health problem (13%).

What are the circumstances of carers?

The POET survey asked carers a number of questions about their current circumstances regarding their caring role.

Figure 13 below shows who carers in the POET survey were offering care and support to. Approximately equal numbers of carers were caring for a partner/spouse (31%), an older family member (usually a parent; 33%) or a grown-up son or daughter (30%). Figure 13 also shows that just over two-thirds of carers (69%) were living in the same house as the person they were caring for.

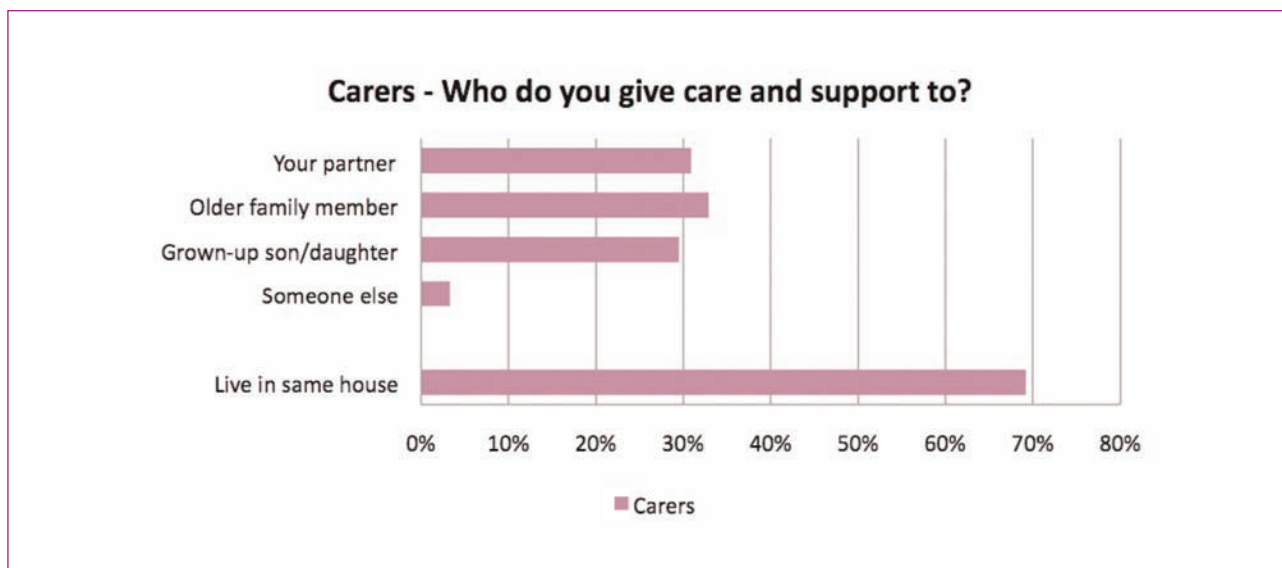
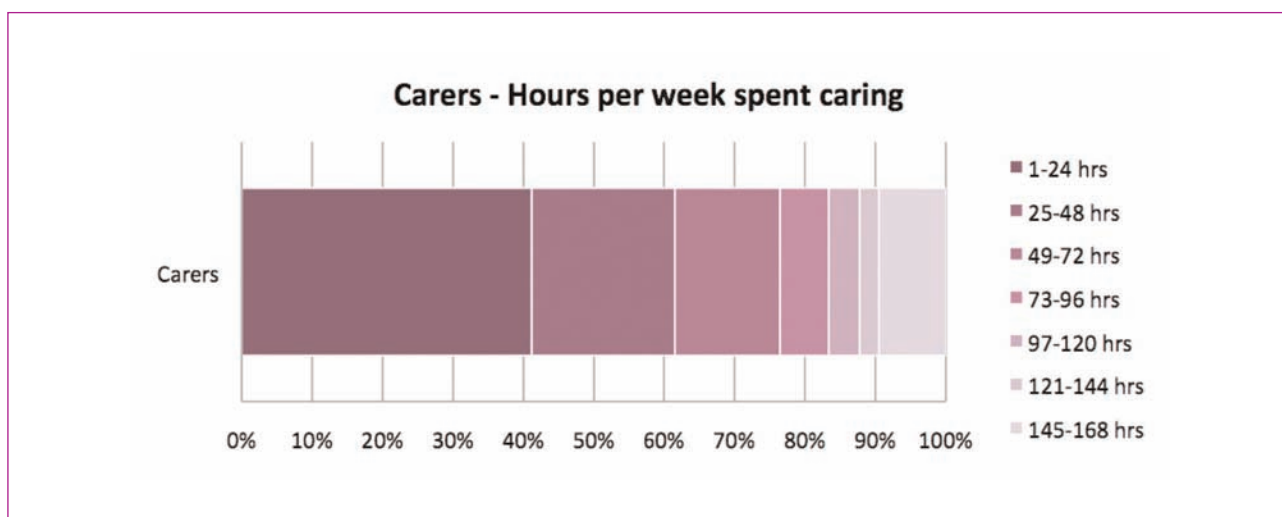


Figure 13: Who carers give care and support to, and if carers live in the same house as the person cared for

The POET survey also asked carers to estimate how many hours per week they would typically spend caring for the person they were supporting. As Figure 14 below shows, substantial numbers of carers were caring either up to 24 hours per week or virtually caring 24 hours a day, 7 days a week.

Carers who were living in the same house as the person they were caring for and carers who were caring for their partner/spouse on average reported spending more hours caring. Carers who were caring for an older family member on average reported spending fewer hours caring.

Figure 14: Estimated hours per week spent caring



Carers and personal budgets

As with the POET survey for personal budget holders, the POET survey asked carers how long the person they were caring for had been using a personal budget, whether the person had been receiving support from the local authority before getting a personal budget, whether the carer's views had been taken into account when the personal budget was drawn up for the person they were caring for, and whether they were getting personal budget support.

Details of these findings are presented in *Appendix 4*. In outline, this information shows:

- Of the personal budget holders being supported by carers, 40% had had their personal budget for less than a year, 41% had had their personal budget between one and three years, and 20% had had their personal budget for over three years.
- Over half (57%) of the people being supported by carers had received social care support before their personal budget.
- Three-quarters of carers (75%) felt that their views had been very much or mostly taken into account in formulating the support plan for the person carers were supporting.
- Just over a quarter of carers (27%) reported that they were receiving a carers' personal budget, and 5% of carers reported that they were receiving their own personal budget for their own needs.

People caring for their partners were more likely to have a carers' personal budget and more likely to have their own personal budget for their own needs. People caring for an older family member were less likely to have their own personal budget for their own needs. People caring for a grown-up son or daughter were less likely to have a carers' personal budget.

There were large variations across councils in the length of time the person cared for had held a personal budget, whether the person cared for had received social care support before their personal budget, whether the carer received a carers' personal budget, and whether carers felt their views were included in the person's support plan.

Carers' experience of the personal budget process

Many carers (163) wrote in comments about their experience of the personal budget process involving the person they were caring for. Table 5 outlines the major themes of people's comments about the personal budget process, together with information on how many carers made positive or negative comments in relation to each aspect of the personal budget process.

As Table 5 shows, carers' comments about all aspects of the personal budget process were overwhelmingly reported as negative, with negative comments about the initial set up process for the personal budget mentioned most frequently.

Table 5: Carers' experiences of the personal budget process

Theme	Description of theme	Number of positive comments	Number of negative comments
Timeliness	Experiences of prompt or delayed services, including contact with council workers	0	15
Getting going	Comments concerning the initial establishment of support arrangements	2	43
Assessment	Experiences of the process leading to council judgements on eligibility for or the amount of funding or support	1	18
Paperwork	The level or complexity of associated paperwork, normally connected to monitoring expenditure	1	29
Clarity	Confusion or uncertainty concerning rules, regulations and policies, information about services and other choices	0	32
Flexibility	The restrictions or explicit lack of restrictions placed by the council on the usage of money	4	14
Service availability	The availability or lack of suitable services or facilities locally	0	10
Review and monitoring	Arrangements for the review and monitoring of support once the personal budget was established	1	16
Cuts	The experience or fear of reduced services or budgets	0	19

'The local authority exercises far too much control over how the direct payment is used – unacceptable powers of veto over expenditure. Other people receiving state support for various disadvantages do not have this level of interference – it amounts to disability discrimination.'

'Personal budgets do take time in: Recording income and expenditure; Completing monitoring forms; Keeping up to date

with changes/requirements; Reviewing annually including updating requirements and support plan; Chasing social services to get job done – it was finalised 3.5 months late! PBs do incur considerable extra work'

'Would like to know how much things cost before accepting a personal budget. Impossible to budget otherwise. No clear guidelines on what can or cannot spend the money on.'

Have personal budgets made a difference to carers' lives?

The POET survey asks carers whether personal budgets for the person they are supporting have made a difference to nine aspects of the carers' lives, and if so whether this difference has been positive or negative. Figure 15 below summarises the findings for carers.

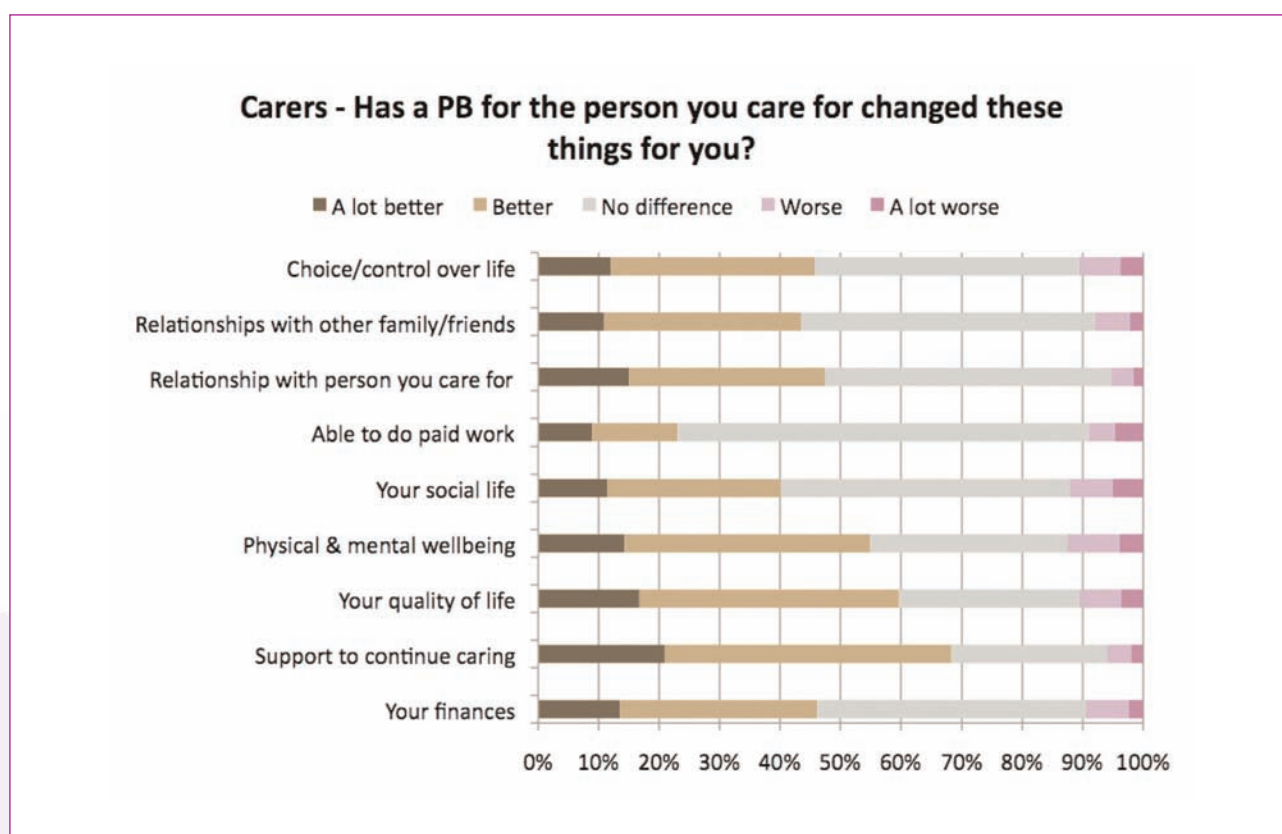
Most carers reported a positive impact of personal budgets held by the person they care for on three aspects of their own lives as carers: support for them to continue caring (68%), their quality of life (60%) and their physical and mental wellbeing (55%).

Most carers (68%) reported that personal budgets held by the person they care for had made no impact on their own capacity to get and keep a paid job.

For the other five outcome domains for carers, carers were relatively evenly split on whether personal budgets held by the person they care for had had a positive impact or made no differences in the areas of the carer's finances, the carer's social life, the carer's relationships with the person cared for and other family/friends, and the carer's sense of choice and control over their own lives.

Small minorities of carers reported any areas of their lives getting worse as a result of personal budgets. However, more than 10% of carers did report personal budgets making their lives worse in the areas of their physical and mental wellbeing (13%), their social life (12%), their quality of life (11%) and their choice and control over their own lives (11%).

Figure 15: Outcomes for carers



Carers experience of the impact of personal budgets on them

Of the 434 carers who provided comments, 338 gave some general indication of their experience of personal budgets, with slightly more positive (164) than negative (141) comments (33 comments were mixed or neutral). In addition, 14 carers took the opportunity to express their gratitude to the local authority.

"...We can't thank you enough for everything and all the happiness personal budgets bring."

In total, 263 carers commented on the impact of the personal budget on a specific aspect of their day to day life. Table 6 outlines the major themes of people's comments about the impact of personal budgets, together with information on how many carers made positive or negative comments in relation to each aspect of the personal budget process.

Table 6: Carers' experiences of the impact of personal budgets on their lives

Theme	Description of theme	Number of positive comments	Number of negative comments
Stress and worry	Impact on the person's emotional wellbeing	8	38
Carer's life	Effect on carer's day to day life, including their caring role	97	15
Life of personal budget holder	Effect on the life of person being cared for, including their care and support	127	3
Family life	Impact on other family members and references to 'family life'	39	2
Money	The level of money or support available or the value of having money for support	17	48
Relationships with staff/system	Impact on relationships with staff and the system, including experiences of dealing with individuals such as care staff	12	21

As Table 6 shows, carers making comments almost universally described positive impacts of personal budgets on life in general for the personal budget holder (i.e. the person they were caring for), other family members and themselves as carers.

Comments concerning the impact of personal budgets on levels of stress and worry and the amount of support or money were much more negative. Similarly to personal budget holders, carers' comments about relationships with staff were more frequently negative than positive.

What factors are associated with positive outcomes for carers?

Figure 15 shows that personal budgets held by the people they care for are perceived by carers to have a broadly positive or neutral impact on their own lives as carers. In this section of the report we will ask three further questions:

- 1) Are there inequalities in the outcomes of personal budgets for carers depending on their age, gender, ethnicity, religion or disability?
- 2) Are there variations in the outcomes of personal budgets for carers across councils?
- 3) Are aspects of carer circumstances (who the carer is caring for, weekly hours of caring, support for carers from the council), or personal budget usage (length of time with personal budget, previous local authority support, inclusion of carer views in the person's support plan) associated with the outcomes for carers?

To address these questions, we checked whether there were associations between all the factors mentioned above and better or poorer outcomes on all the outcome indicators. Where the associations we found were highly unlikely to happen by chance (i.e. where there was a less than 1 in 100 probability of the findings occurring by chance), they are included in Table 7 below.

As with Tables 3 and 4 earlier, if the factor listed on the left of the table is associated with a more positive outcome, then the cell of the table is filled in green. If the factor on the left of the table is associated with a less positive outcome, then the cell of the table is filled in red. A special case is made for variation across councils – where outcomes vary across councils the cell of the table is shaded red/green stripes, to indicate that there is significant variation across councils but we cannot reveal which councils are associated with better or poorer outcomes.

Looking at Table 7 as a whole, the following conclusions can be drawn:

- In terms of equalities monitoring, there are no differences in outcomes according to carer gender or disability (there were too few people in certain categories to enable us to investigate sexual orientation). There were some specific associations regarding carer age (younger carers were more positive about the impact of the person's personal budget on the carer's capacity to find paid work and on the carer's relationship with the person cared for), carer ethnicity (non-White carers were more likely to report positive impacts on their finances, the capacity to find paid work and their relationships with friends and others), and carer religion (carers with non-Christian religions were more likely to report positive impacts on their capacity to find paid work).

- There was significant variation across councils in how positive carers were about the impact of the person's personal budget on the carer's finances. This may partly be explained by the fact that carers with their own carer's personal budget were also more positive about the impact of personal budgets on their finances.
- There seemed to be specific impacts of personal budgets for carers in different circumstances:
 - Carers who spent fewer hours caring were more positive about the impact of personal budgets on their capacity to find paid work.
 - Carers living in the same house as the person they are caring for were more positive about the impact of personal budgets on their quality of life.
 - Carers of a partner/spouse were more positive about the impact of personal budgets on their finances.
 - Carers of a grown-up son or daughter were more positive about the impact of personal budgets on their quality of life in general and their social life in particular.
- In contrast, carers of older family members were less positive about the impact of personal budgets across five domains of carers' lives – finances, support to carry on caring, carer quality of life, carer physical and mental wellbeing and carer social lives.
- It is possible that carers of partners/spouses or a grown-up son/daughter, who are more likely to be living with the person they are caring for, to be caring longer hours, and to be already involved in organising paid care and support, are more likely to perceive a positive impact of personal budgets on their lives as well as the life of the person they are caring for. In contrast, carers of older family members, who are less likely to live with the person they are caring for and to care for fewer hours, may feel that the personal budget brings with it greater organisational responsibilities with few accompanying benefits for them.
- Finally, it is worth noting that the only factor associated with all outcome domains for carers was carers feeling that their views were more fully included in the person's personal budget support plan. Clearly the meaningful involvement of carers in the support planning process is important for carers to feel committed to and benefitting from the personal budget for the person they are caring for.

Factor associated with outcome	Outcome Measure								
	Finance	Support to continue caring	Carer QoL	Well-being	Social life	Paid work	Relations with person cared for	Relations with friends/ others	Choice and control
Characteristics of carers									
Younger age									
Non-White ethnicity									
Non-Christian religion									
Variations across councils									
Councils									
Carer circumstances									
Fewer hours caring									
Caring for partner/ spouse									
Caring for grown-up son/ daughter									
Caring for older family member									
Living with person cared for									
Personal budgets and carers									
Carer gets carer's PB									
Carer's views included in PB support plan									

Table 7: Factors associated with outcomes for carers

Conclusions

Overall, personal budget holders reported positive experiences of the impact of personal budgets on their lives, although experiences of the personal budget process were more varied:

- Most personal budget holders reported that the fundamental components of self-directed support were in place, including being told the amount of their personal budget (77%), getting help to plan their personal budget (81%) and having their views very much or mostly included in the support plan (87%). However, personal budget holders varied widely in their experiences of the personal budget process, with many people reporting difficulties at each stage.
 - Most personal budget holders reported personal budgets having a positive impact on 10 of the 14 aspects of their lives we asked about, most commonly: being supported with dignity and respect (76% reporting a positive impact); people staying as independent as they want to be (75%); people being in control of their support (72%); and people getting the support they need when they need it (72%).
 - In the other four aspects of people's lives, most personal budget holders reported personal budgets making no difference, principally in people getting and keeping a paid job (68% of working age adults reporting no difference) and people volunteering and helping their local community (77% of adults of any age). It is important to note that we did not collect information on people's self-rated capacity to undertake paid employment or volunteering activities and so cannot explore this issue further in this report.
 - Overall, small numbers of people (between 3% and 8%) reported personal budgets having a negative impact on any of the 14 aspects of people's lives we asked about in the survey.
 - In comments written in by personal budget holders, people were generally very positive about the impact of personal budgets on their lives, although there were clear concerns about money.
- Most carers of personal budget holders also reported positive experiences but to a lesser extent:
- Most carers reported that their views were very much or mostly included in the personal budget holder's support plan (87%).
 - Most carers reported a positive impact of the personal budgets held by the person they cared for on three of the nine aspects of their own lives as carers we asked about: support for them to continue caring (68%); their quality of life (60%); and their physical and mental wellbeing (55%).
 - For the other five areas of carers' lives, carers were relatively evenly split on whether personal budgets for the person they care for had had a positive impact or made no difference.

- Most carers (68%) reported that personal budgets for the person they care for had made no impact on their own capacity to get and keep a paid job.
- Only small minorities of carers reported any areas of their lives getting worse as a result of personal budgets. In 4 of the 9 areas we asked carers about negative impacts rose above 10%, specifically in the areas of their physical and mental wellbeing (13%), their social life (12%), their quality of life (11%) and their choice and control over their own lives (11%).
- Comments written in by carers reinforced and extended these conclusions; carers were highly positive about the impact of personal budgets on the lives of the personal budget holder, themselves as carers and other family members, but were more negative about all aspects of the personal budget process and unsurprisingly the stress and worry for them associated with personal budgets for the person they were caring for.

In the POET surveys, several factors were associated with personal budget holders and carers reporting more positive impacts of personal budgets on their lives.

- Most strikingly, there is pervasive variation across councils in the outcomes reported by personal budget holders and carers. Councils clearly have a major impact on outcomes through the processes they put in place to help people through all stages of the personal budgets process, which can have a profound influence on people's experiences of personal budgets. For example:
 - How personal budgets are managed is robustly linked to outcomes for personal budget holders. People with direct payments paid directly to them reported more positive outcomes and people with personal budgets managed by the council reported less positive outcomes.
 - It is important that personal budget holders and carers are kept informed of essential aspects of the personal budget. People who did not know how their personal budget was managed or did not know the amount of their personal budget reported less positive outcomes.
 - The support planning process for the personal budget is critical. Personal budget holders and carers who felt their views were more fully included in the support plan were more likely to report positive outcomes across the board – where possible both personal budget holders and carers need to be fully involved in support planning.

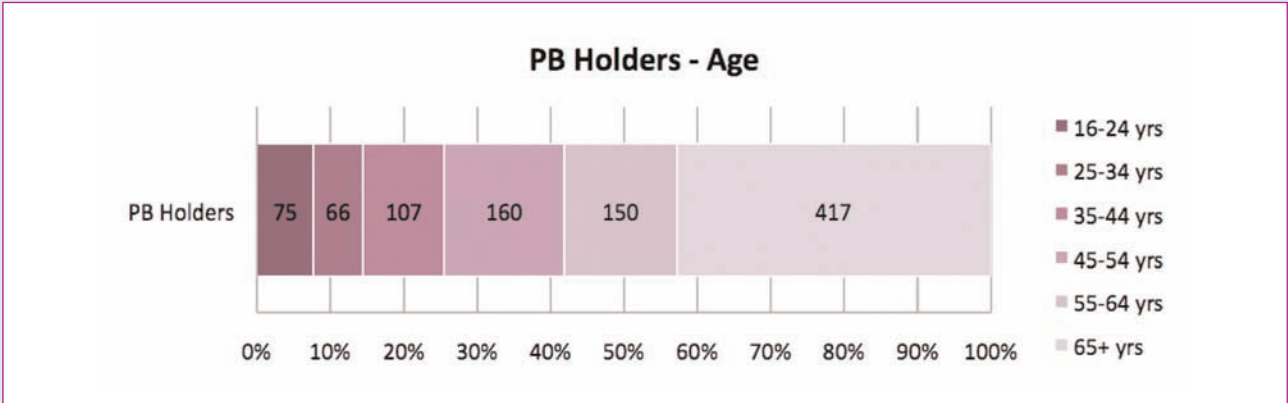
- People who had been using their personal budgets for longer reported increasingly positive outcomes, suggesting that it may take some time to get an optimal pattern of support.
- A greater weekly amount of personal budget support was robustly associated with more positive outcomes.
- There is also variation in outcomes for personal budget holders across social care need groups, with older adults reporting less positive outcomes than other social care need groups in six out of the 14 outcome domains. However, these differences are ones of degree (older adults are more likely to record personal budgets as making no difference; they are not more likely to record personal budgets as making things worse).
- As with working age adults, it is also important to note that within the group of older adult personal budget holders direct payments were also associated with more positive outcomes in 9 of the 14 outcome domains. Clearly direct payments can work just as well for older people, but councils seem less likely to actively promote and support direct payments as a personal budget option to older people. Councils may need to conduct further market research with older people about this issue and to consider the assumptions being made about older people's capacities and willingness to manage direct payments in council policies, procedures and practices.
- For carers of personal budget holders, carers of older family members were less positive than other carers about the impact of personal budgets across five domains of carers' lives. Again, this may be a result of how personal budgets are likely to impact on carers in different circumstances rather than being about older people as such, particularly in terms of whether the carer is living in the same home as the person they are caring for and how much care and support the carer is providing.

In summary, it seems that personal budgets are likely to have generally positive impacts on the lives of all groups of personal budget holders and the people who care for them. The likelihood of people experiencing a positive impact from a personal budget is maximised by a personal budget support process that keeps people fully informed, puts people in control of the personal budget and how it is spent, supports people without undue constraint and bureaucracy, and fully involves carers. Under these conditions, personal budgets can and do work well for everyone.

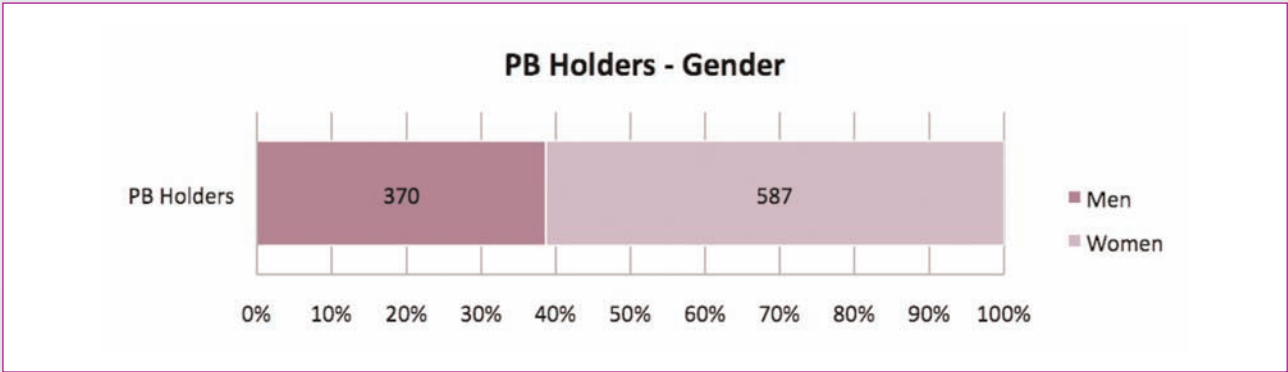
Appendix 1:

Personal Budget Holder demographic information

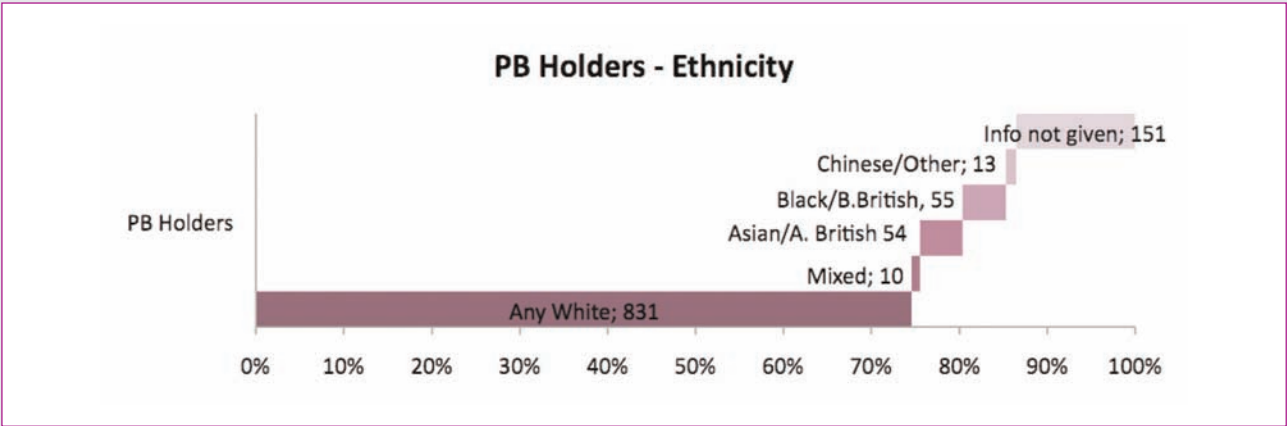
Age



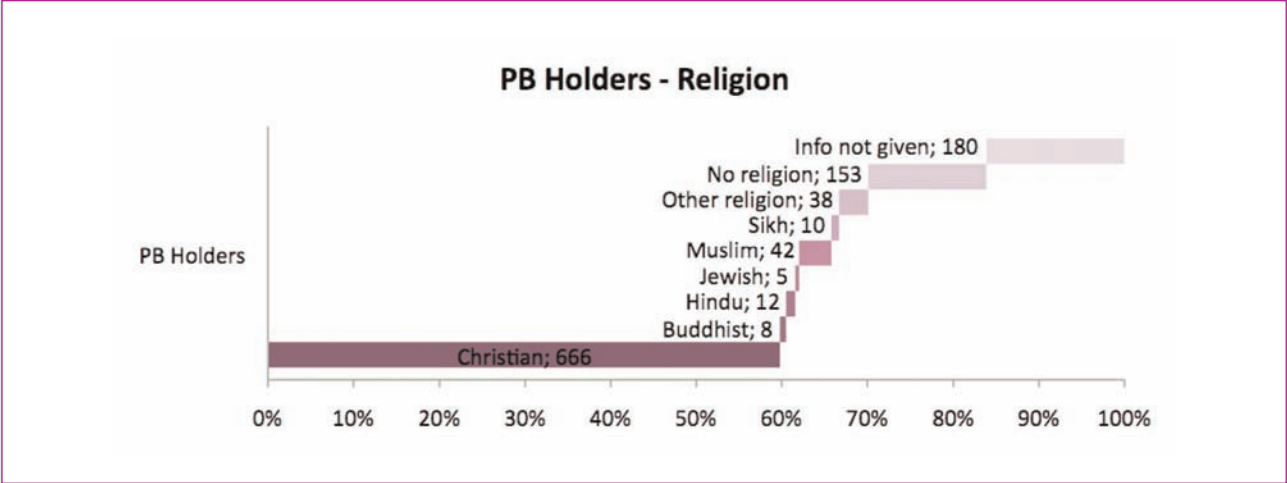
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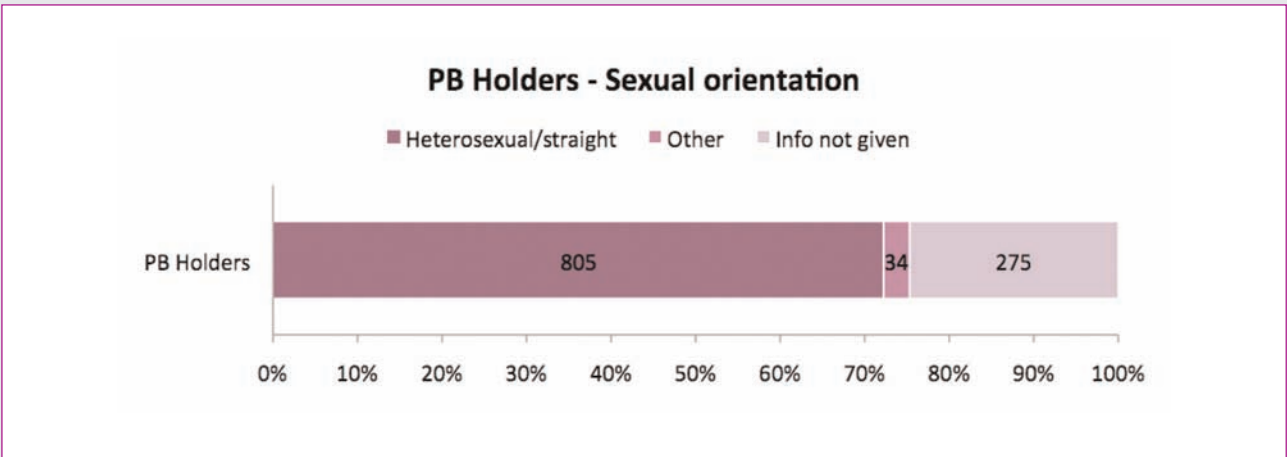
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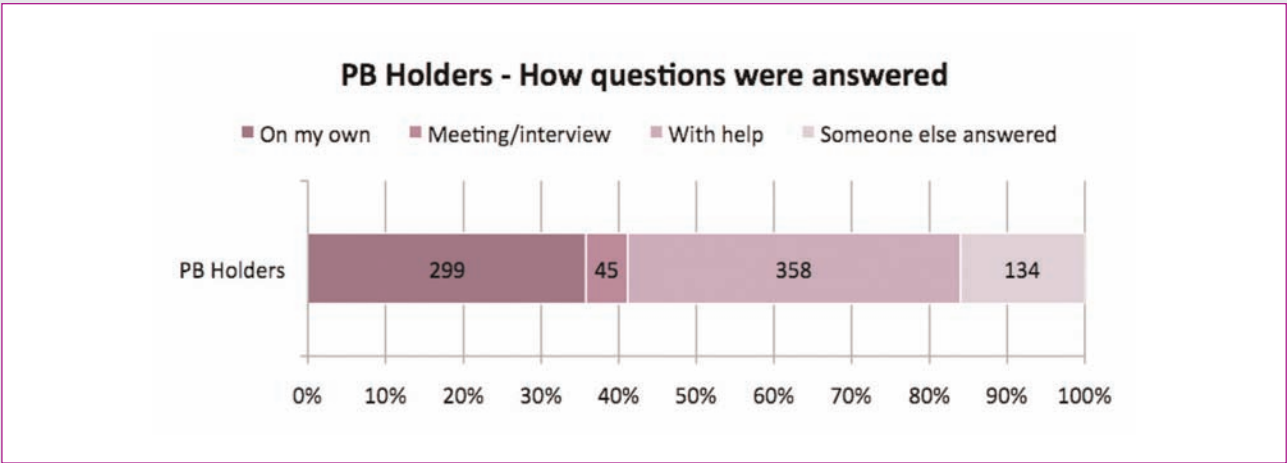
Religion



Sexual Orientation



How respondents answered the POET survey

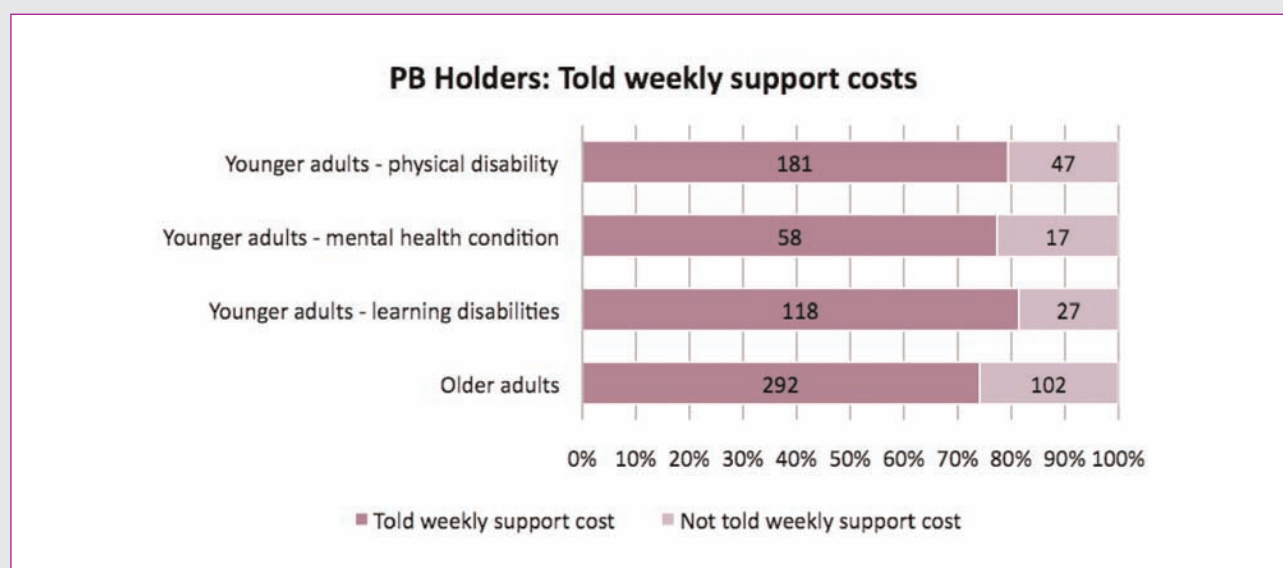


Note: there were no statistically significant associations between how the questions were answered and any of the 14 outcome domains, suggesting no systematic response bias.

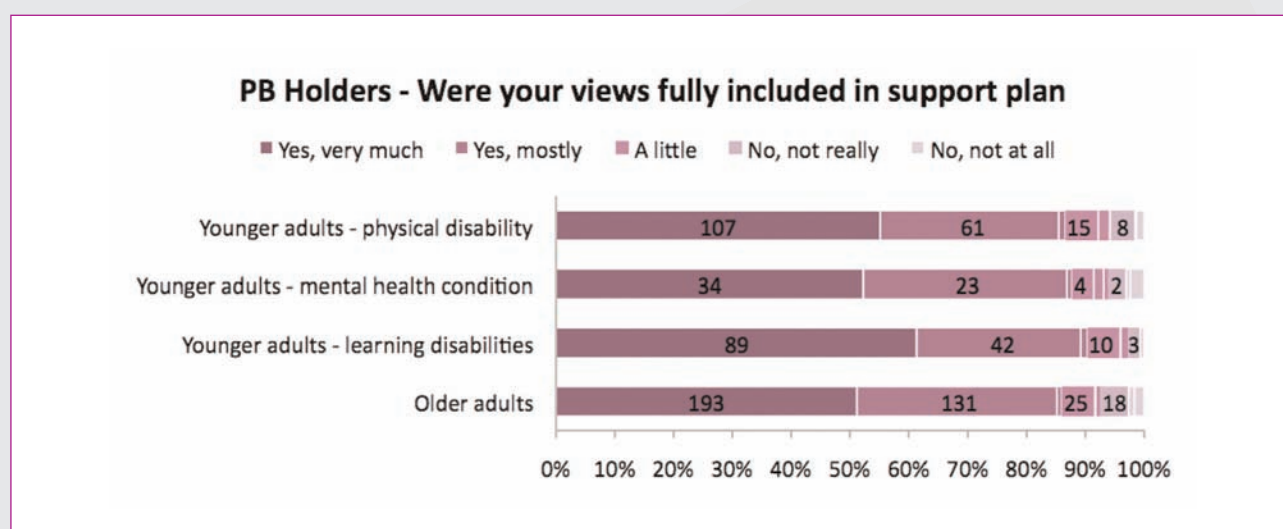
Appendix 2:

Personal Budget Holder survey – personal budget usage and support

Had respondents been told the weekly costs of their support by social care need



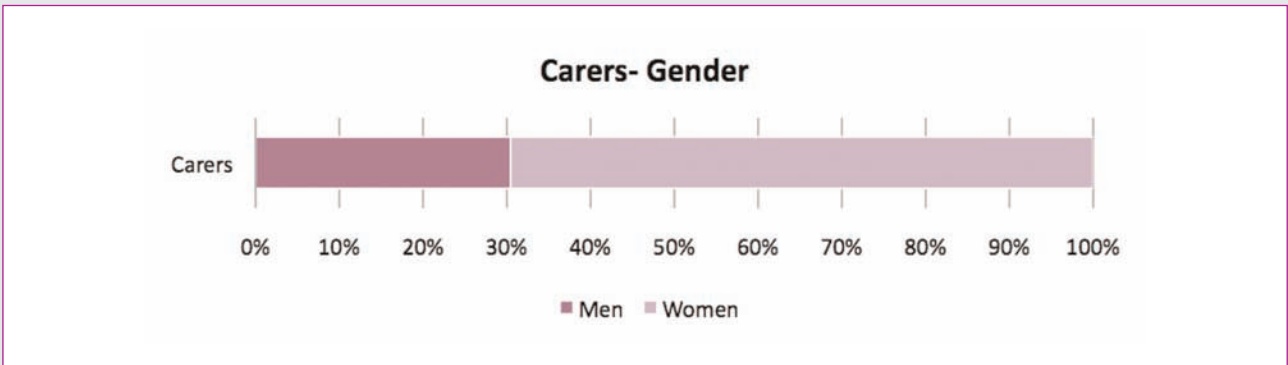
Were the views of personal budget holders included in the support plan by social care need



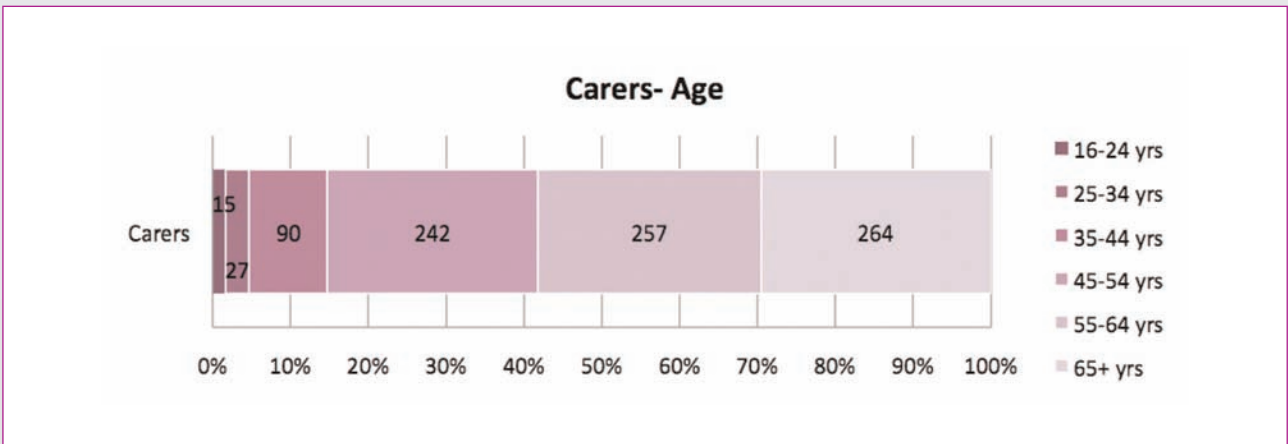
Appendix 3:

Carer survey demographic information

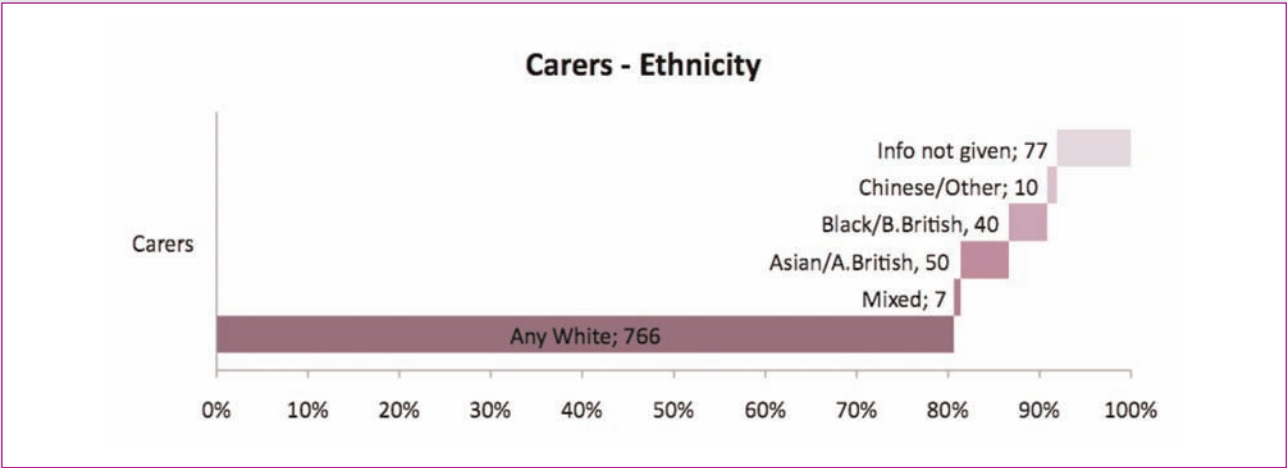
Gender



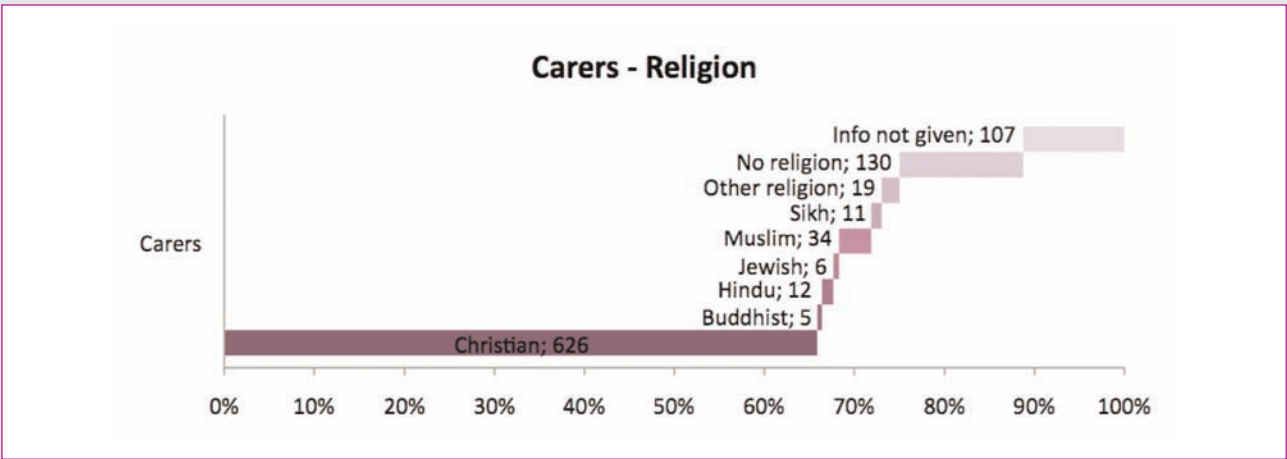
Age



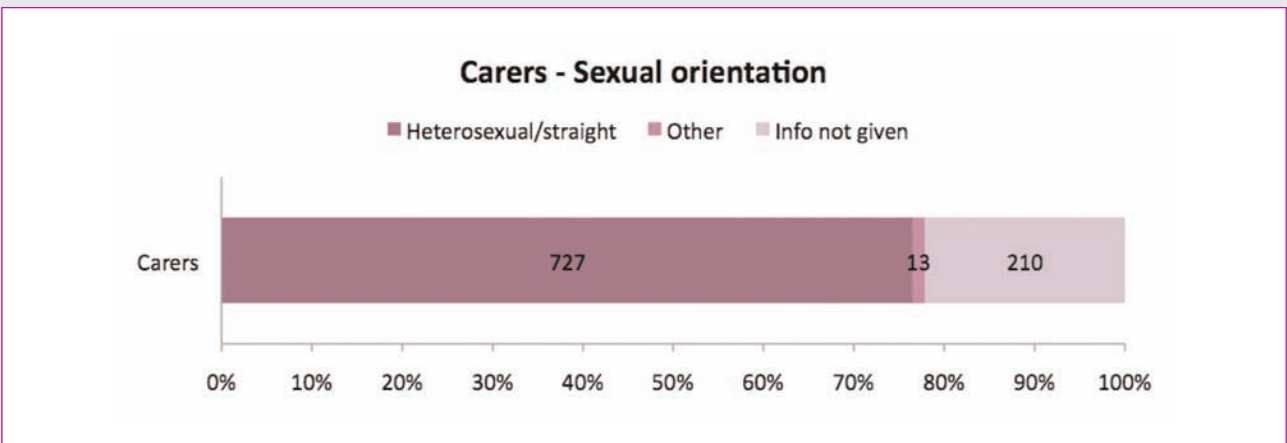
Ethnicity



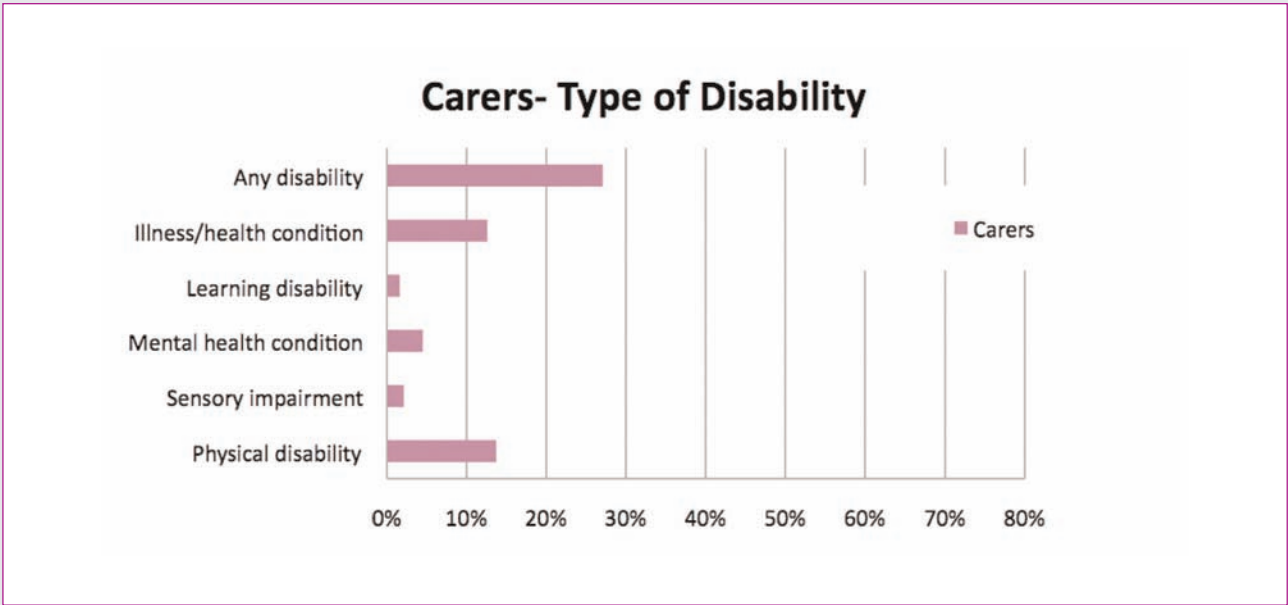
Religion



Sexual orientation



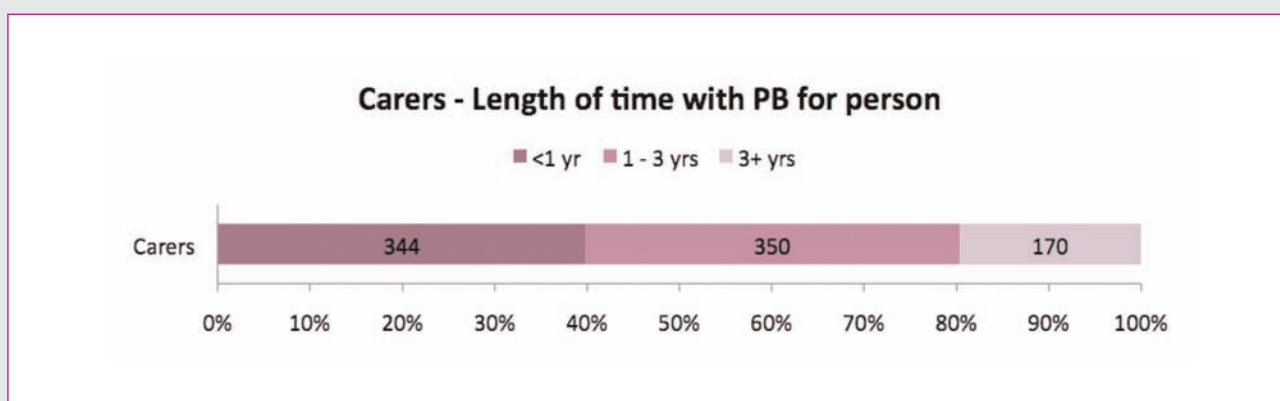
Type of disability



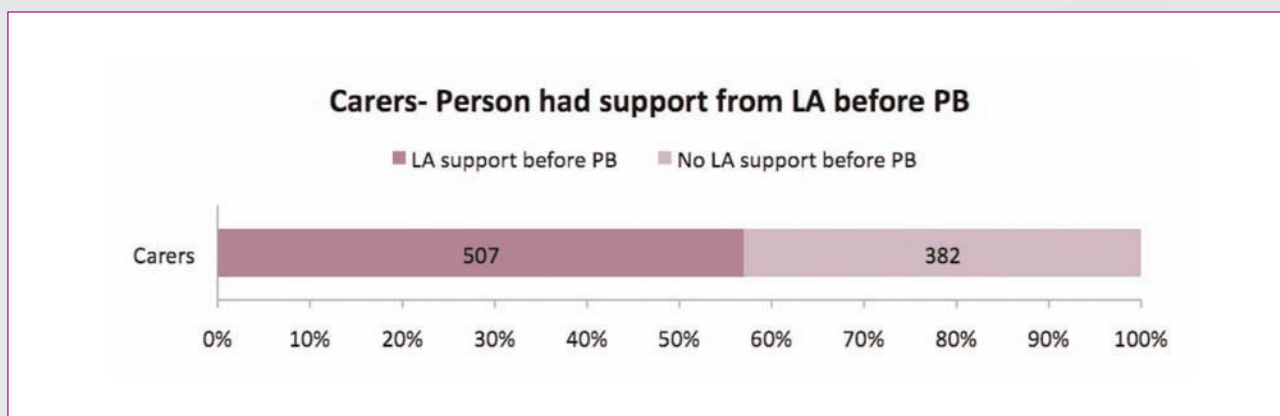
Appendix 4:

Carer survey: personal budget usage and support for carers

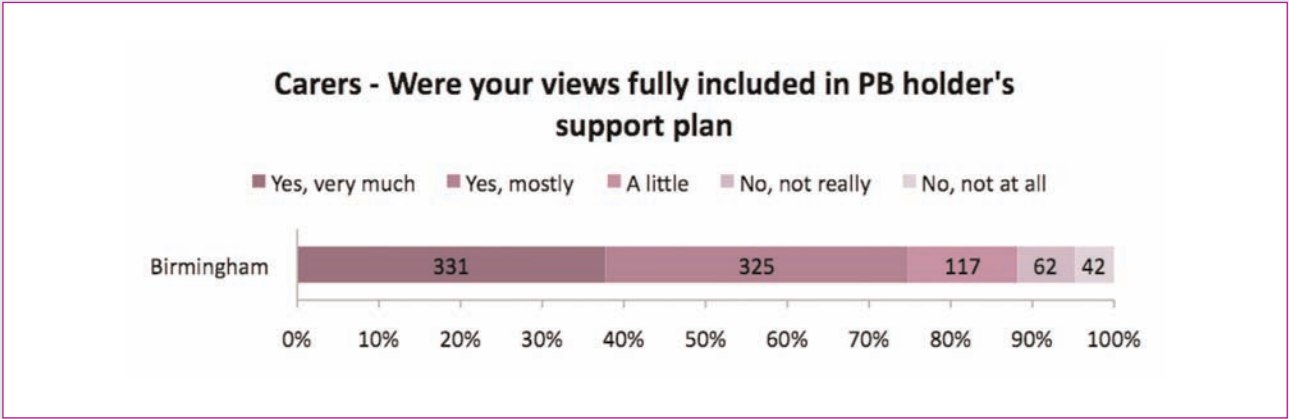
Length of time the person cared for has had a personal budget



Had the person being supported had social care support before their personal budget



Were carers' views taken into account in the personal budget holder's support plan



Support from social services for carer

