Your Life, Your Choice

Qualitative research carried out as part of the ‘Support Planning and Brokerage’ Initiative

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- Rachell Purcell (Director of Folk.Us, Exeter)
- Suzanne Pearson (Chair of Bristol Mind)

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Summary

Key messages from the qualitative research

- Support planning and brokerage from user led organisations (ULOs) could give disabled people more choice and control. This research showed how the ULO service was felt to be a more ‘human’ system than that of the local authority (LA). People particularly appreciated the ULO role in reducing bureaucracy and challenging them to think about their lives.

- Peer support and connections with other disabled people during the support planning process gave personal budget (PB) users the best way of achieving control to manage things for themselves.

- Information is vital, and in this study it was often obtained by PB users from ULOs and user networks. A good information strategy was called for, both to ‘advertise’ the PB system to disabled people, and also to explain clearly what the steps in a personal budget are. Both staff and service users were said to need training.

- Family carers regularly performed a key role in supporting their disabled family member. In this study, it was clear in many cases that the PB system would not work without them. Person-centred ways of planning were spoken of, which enabled both LA and ULO support planners to work with both the carer and the service user.

- People are all different. ‘Choice and control’ may be the ultimate goal, but people commented that it might be approached differently by someone with a physical impairment, than by someone with a learning disability.

- Overall, support planning and brokerage could be thought of as a continuum, from ‘Hands off’ (where users essentially wrote their own plan after being given good information and their indicative budget); ‘Hand over’ (where there was more initial input from the support planner and possible continuing
contact): and ‘Hand in hand’ (where help with support planning was more intense and contact continued).

- Participants in this study argued strongly that cuts in public spending should not affect disabled people’s life chances. Cuts could affect the ability of user networks to continue to function. There were many worries that progress made in ULO support planning would be eroded by financial cuts.

**Background**

- This report is about the qualitative research carried out in 2009-10 by staff at the University of Bristol, as part of the ‘Support, Advocacy and Brokerage’ (SAB) project, funded by the Office for Disability Issues. The full integrated report is available on the ODI website. (1.1)

- The Support, Advocacy and Brokerage (SAB) project was set up to demonstrate how resources could be transferred from traditional, local authority, assessment and care-management systems to user-led support, advocacy and brokerage. The aim was to enable disabled people to have more choice and control over the support that they need.

- The project formed part of the wider context of the personalisation of adult social care, and the increasing attention being paid to the role of non-statutory organisations, the third sector and user led organisations in the reform of public services.

- The project operated in three demonstration sites, each comprising a Local Authority (LA) and a partner User Led Organisation (ULO). The three sites were:
  - Essex (Essex County Council and ecdp, formerly Essex Coalition of Disabled People)
  - Richmond (London Borough of Richmond and Richmond Users Independent Living Schemes: RUILS)

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1 References are made in the summary to sections of the full qualitative report.
Southampton (Southampton City Council and Southampton Centre for Independent Living: SCIL)

- The qualitative research aimed to assess, from the point of view of service users, whether and in what ways the user-led 'support, advocacy and brokerage' model delivered greater choice, control and independence to personal budget (PB) users than the LA led equivalent. (1.2)

Research methods

- Eighty (80) service users were recruited to the study, over the three sites. 41 had support plans facilitated by the ULO, and had been referred to them as part of the SAB project. The comparison group of 39 were either new or existing service users who had support plans from the local authority (LA). These groups are referred to in this report as the ULO group and the LA group. Recruitment and interviewing started first for the LA group, during the period when the ULO support planning activities were starting up. (1.3)

- Participants were interviewed twice: once shortly after their support plan had been written and again roughly six months later. (In practice, this time gap ranged from three months to a year.) In 10 of the 80 cases it did not prove possible to interview participants a second time. (1.2)

- Forty (40) participants in the study had family carers who were involved both in helping with support planning, and subsequently managing their budget. The proportion of family carer involvement was similar in both ULO and LA groups. (6.5)

- There were some key differences in the primary impairments of participants across the sites. In the LA group, 19 of the 22

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2 Qualitative research aims to understand phenomena, not to quantify those findings. Numerical values are only given in this report to describe the participants, and also on occasions to report on trends in ULO support planning. They are not to be taken as implying significance in a statistical sense.
people sampled in Essex described their primary impairment as physical. In Richmond the spread was much more even between all impairment groups. In Southampton, there were no people with physical impairments in the LA group, while four of the five LA group had a learning disability. (1.3)

- Sampling from different age groups was reasonably even in both the LA and the ULO groups, with an age range from 18 to 102, and a mean age of 53, as was the gender balance. However, BME groups were under-represented. (1.3)
Findings

Experiences before support planning

- People’s experiences of their initial contact with social services were often problematic. In both the ULO and LA groups, people described feeling lost and powerless at this time. Those in both groups who had prior contact with ULO or user networks had a better entry point into the personal budget (PB) system. Other routes into the system included Connexions and occupational therapists. (3.1)

- Access to information was clearly a key to people enjoying more choice and control in their lives. However, no one (in either group) had been given clear information at the outset about the whole ‘route map’ of a PB. As a result, there was much confusion and misunderstanding about PBs. (3.2)

- ULO participants had a firmer grip than their LA counterparts on what a support plan was: they were informed about its purpose.

- Some participants referred to positive information strategies, including a leaflet produced jointly by Richmond Social Services and by RUILS, and a DVD about individual budgets that people had seen at meetings for service users in Essex. (3.2)

- On the negative side, accessible information was often missing in what was offered by both ULOs and LAs. (3.2)

- The assessment process was experienced by many participants as problematic, partly because of the time delays involved, but also because of the difficulty of having to ‘say the worst’ about their needs and showing their vulnerability. (3.3)

- Those in the ULO group tended to see assessment as clearly separate from the support planning stage. LA
participants often remained ill-informed and muddled about what support planning was. (3.3)

- In a few cases, the LA social services assessor and ULO had worked together at the assessment stage: for example, some people in Southampton had benefited from advice from the ULO in completing their assessment forms, which they said had helped them enormously. (3.3)

**Support planning and brokerage practices**

- ULO participants regularly experienced a genuine, empathetic approach from their support planner, and were challenged to think more deeply about their lives. (4.1.1 and 3) Those in the LA group occasionally talked about similar practices, but attributed this to individual social services staff who stepped outside their role. (4.1.4)

- Those in the ULO group felt they were treated as equals, and that support planners who came from a disabled people’s organisation were experts by experience. This was not mentioned at all in the LA group. (4.1.2 and 4.3)

- Good support planners were said to be those able to encourage participants to widen their horizons and think more deeply about what they wanted. This was particularly true of ULO support planners, but occasionally mentioned in relation to LA support planners too. (4.1.3)

**Systemic features of support planning and brokerage**

- People in the ULO group were far more likely than those in the LA group to know their indicative budget before planning. This was felt to be essential as a basis for planning. (4.2.1)

- Thirty of those in the ULO group took up the option of becoming direct payments employers, as opposed to 17 in the LA group. (4.2.1)
• Being offered choices about how to use their personal budget was important to people. Some new customers in the LA group felt that a direct payment had been foisted on them, because of local authority cuts. (4.2.2)

• The amount of time spent on support planning visits appeared to be less important to people than the availability and efficiency of the support planner. In the LA group, participants were more likely to experience the process as protracted, with the care manager often unavailable when needed. In the ULO group, the process was generally described as far more efficient, with an intensive period of contact via visits, phone calls and emails. (4.2.7)

• Some participants said that ongoing advice and signposting were vital, and an element of brokerage and information about local opportunities was often appreciated by the ULO group. (4.2.8)

• Peer support was important to those in the ULO group. Those who were aware of the ‘lived experience’ of the support planner felt that the support planner approached them as an equal and had personal knowledge and information about personal budgets. (4.3)

• The experience of ULO support planning by itself did not appear to lead to a heightened political awareness in relation to disability rights. However, where people had ongoing contact with the ULO, there was an indication that they experienced a sense of greater control and an opening up of their lives as result of becoming part of a larger collective of disabled people. (4.3.2)

Validation of personal budget

• Although both ULO and LA participants experienced long delays at the validation stage (an average of five months from support planning to release of the budget), those in the ULO group were more likely than the LA group to be well informed and to feel that the ULO support planner was
fighting their corner. By contrast, those in the LA group often did not know what ‘validation’ meant. (5.2 and 5.3)

- Experiences of LA finance departments were often described both by ULO and LA groups as difficult. From the service users’ standpoint, they appeared to be ill-informed and not to understand the ethos and purpose of personal budgets. (5.4)

**Putting the personal budget into action**

- Having a personal budget was generally seen as a liberating experience for people, whether they received support planning from the LA or a ULO. The creative options made possible by PBs were valued in both groups. (6.1)

- The most valued aspect of PBs was the additional choice and control they gave, and the consequent increase in people’s sense of their own self-determination. This was particularly marked for the new service users in the ULO group. (6.1)

- Brokerage (in the sense of signposting or recommendations) was appreciated by many participants, in both ULO and LA groups. However, since LA participants tended to lose contact with their named social worker, ongoing brokerage was not available to them, as it was for most of the ULO participants. (6.6)

- Those using LA support planning were more likely than the ULO group to express feelings of gratitude for their PB, or even guilt. Within the ULO group, people said that the PB was a way of enabling them not only to make choices, but also to feel that they were not relying on charity in managing their lives. (6.1)

- One of the most important aspects of putting a personal budget into action was the employment of personal assistants, who were said to be far more flexible and person-centred than previous carers from agencies. Those in the ULO group were more likely to have chosen this route. (6.2)
People using ULO support planning were more likely to employ friends or family, and to adopt a flexible approach to their support plan. By contrast, those in the LA group sometimes talked about the difficulties of finding personal assistants (PAs), and sometimes talked about feeling constricted by their support plan. (6.2)

On the negative side, a large number of participants in the study experienced periods of anxiety concerning what could be purchased with a PB, and about closure of services. ULOs and user networks were used to provide support and advice here; such advice was not readily available from social services. (6.4)

Managing services and funding

Family carers of people with complex or substantial needs often took on the management of a whole service for their son or daughter, sometimes feeling that they had no choice in the matter. This was true for people in both LA and ULO groups. (6.5)

Some service users and carers were proud to be independent and some could draw on past skills in bookkeeping, to help manage all that was involved. But many family carers and service users experienced worry and stress: over the amount of paperwork involved, about particular sources of funding being cut back (eg. the Independent Living Fund), the responsibility of managing pooled budgets, about what was eligible expenditure, and the effect of their impairments on their ability to cope with everything. (6.4 and 6.5)

People in the ULO group appreciated being able to go back to the ULO to ask for advice on managing their budget, and also appreciated ongoing trouble-shooting. (6.6) By contrast, those in the LA group were often left without any social services contact. (6.7)
People’s experiences of choice and control

- Participants were asked to rate their ‘choice and control’ over a range of areas in everyday living. Although this was quite a crude measure, it provided some indication that ULO support planning led to increased feelings of choice and control. (7.1)

- At the second interview, people were also asked to say whether they felt that overall they had gone forwards in achieving their goal(s), or backwards, or whether they felt that things had stayed the same for them. The scores were generally more positive for those who had received ULO-led support planning than those whose support planning had been facilitated by the LA. (7.3)

- About a quarter of all participants felt that their lives had gone backwards, six months or so after their first interview. These were spread across both ULO and LA groups. This was often due to deteriorating health or increased frailty. (7.3)

- Some people expressed concerns about the future, particularly fear of cuts. The relative unavailability of (re)assessment by social services was seen as a problem. (7.3)

- Those who were most satisfied with the choice and control in their lives, after a period of 6 months, were more likely to have had ULO support planning. The satisfied customers all referred to the good information they received early on in their personal budget journey. By contrast, those who had poor outcomes had received information that was muddled, conflicting or incorrect. (7.5)

- It would seem that the feelings of being in control experienced by people through the support planning process led to them feeling more in control in their lives generally. (7.5)
What worked best for whom?

- ULOs attempted to differentiate support planning for different groups of service users, who valued different styles of support planning. (8.1) People who were newly disabled appreciated a relatively proactive style of support planning, as they tended to downplay their needs. (8.1.2)

- Where individuals had a lifelong impairment, it was important for support planners to draw on the expertise and knowledge of both service users and family carers. However, there were also very strong comments about the need to have continuing offers of services (particularly for people with learning disabilities and people with mental health needs) as well as ongoing, responsive support planning. (8.1.2)

- Accessible information was often missing in what was offered by both ULOs and LAs. When attention was paid to making information accessible it was greatly appreciated by all those who had particular needs in this area. (8.1.3)

- Where people had learning disabilities or dementia, family carers were almost universally involved in their support planning, in both ULO and LA groups. A key issue in support planning for family carers was the ability of the support planner to get the right balance between focusing on the service user, while involving the family carer. (8.1.4)

- Specific strategies for involving people with cognitive impairments were praised in both ULO and LA groups, including person-centred planning; separate meetings with carer and disabled person; personalisation of the support plan. (4.2.4 – 4.2.6)

- Those who had peer support from other disabled people fared better in the PB process, whether or not they were part of the ULO group. For instance, that type of peer support happened regularly through the Direct Payments Users Network (DPUN) in Essex. (8.1.5)
• People with dementia often drew on voluntary organisations for back-up support. This group appreciated time and support from the support planner, who needed to learn how to communicate with each individual. (8.1.6)

• Those with mental health needs generally had poor experiences of support planning, including the closure of group services which they had valued and a lack of information, which had left them feeling muddled and disempowered. However the two people who had received ULO-led support planning were very happy with their personalised services and particularly appreciated the advice and encouragement they received from the support planner. (8.1.6)

• People with learning disabilities and their carers generally needed far more time than people from other user groups, a multi-agency and person-centred approach, and an ongoing point of contact to discuss and implement change. (8.1.6)

• Support planning and brokerage may best be thought of as a continuum, as expressed in the ‘Hands’ framework. This is an attempt to capture the continuum of models to suit different needs, ranging from ‘hands off’, through ‘hand over’ to ‘hand in hand’ (8.2). ULOs in this study were concerned to differentiate, and to ensure that their practices were sensitive to the needs of individuals.
The structure of this report

From the point of view of the service user, support planning is inextricably linked with the whole journey towards a personal budget that has to be undertaken. The success of support planning to some extent depends on the ways in which it works with these other processes, and so this report follows through the whole journey, starting in:

- **Chapter 2** with the people themselves, and a description of why they were and what mattered to them.

- Following that, **Chapter 3** starts with what happens before support planning:
  - Making contact
  - Getting information
  - Assessment

- **Chapter 4** focuses specifically, and in more detail, on the topic which is at the centre of this project, namely support planning.

- **Chapter 5** will then look more briefly at the processes that happen after the support plan is submitted.

- There is life after support planning, and Chapters 6 and 7 deal with the outcomes, both in terms of managing the budget (**Chapter 6**) and the independent living outcomes for people's whole lives (**Chapter 7**).

- Finally, **Chapter 8** offers some tentative conclusions about the types of support planning that might best be suited to different groups of customers, and suggests a way of thinking about a continuum of support planning.
Chapter 1 - Background and methodology

1.1 Background to ‘Your Life, Your Choice’

Over the past six years, the Government has set out its vision for personalised services in England (DH, 2006; DH, 2008). There is currently a cross-departmental government programme by which social care will move towards ‘putting people first’ (DH, 2007). Local authorities are expected to implement change (DH, 2008a) by 2011, in order to shift social care for disabled and older people towards:

- A more preventative and less crisis-driven mode (DH, 2008: p. 4)
- A less bureaucratic and more ‘personalised’ form of service ‘which is on the side of the people needing services and their carers’ (DH, 2007: p. 1)
- A system which should ‘empower citizens to shape their own lives and the services they receive’ (PMSU, 2007).

The move towards personalisation is driven by the need to progress independent living outcomes for disabled people, as defined by the Disability Rights Commission:

“All disabled people having the same choice, control and freedom as any other citizen - at home, at work, and as members of the community. This does not necessarily mean disabled people 'doing everything for themselves’, but it does mean that any practical assistance people need should be based on their own choices and aspirations.” Disability Rights Commission (2002) Policy Statement on Social care and Independent Living.

It is suspected that, if personalisation is to make a difference, then it is important that service users experience choice and control, both in the process and outcomes of support planning (DH, 2008b: 4). Having taken some years to be set in motion, personalisation has gained momentum with the new Coalition Government which announced in November 2010 its ‘New Vision’ for social care,
which promises a continued strengthening of the focus on personal budgets. The government is aiming for one million people to be in receipt of personal budgets by 2013. In order to make this happen, there is an acknowledgement that support services need to be in place:

“To have real autonomy and choice people need information and advice. Lack of good, accessible information to help support their choices is a real concern for people. Councils’ role here is to ensure that everyone – whether using a personal budget or their own funds – can get the information and advice they need.” DH, 2010: 18

It was within the context of the Independent Living Strategy (ODI, 2008) that the Office for Disability Issues (ODI) established the ‘Support, Advocacy and Brokerage’ project, which aimed to test out and demonstrate the hypothesis that user led organisations (ULOs) would be in a better position than local authorities (LAs) to give personalised, peer-led support planning and brokerage to disabled service users.

Three demonstration sites agreed to take part, all chosen for their strong ULO tradition: Essex, Richmond and Southampton. All sites set up project boards which remained active throughout the SAB project, and contributed quantitative data, as well as information about the process of change management. The qualitative findings feed into the final integrated report (ODI, 20113), which discusses all elements of the SAB project. The current report concerns the detailed findings of the qualitative research, which was referred to as ‘Your Life, Your Choice’.

1.2 Aims, methodology and research design

The overall goal of the qualitative research was to gather evidence directly from service users about their experiences of support planning within the SAB project. We set out to document and to

understand the mechanisms which support people to achieve the outcomes of independent living, and to gain greater choice and control in their lives. The primary aim was therefore:

To assess whether and in what ways the 'support, advocacy and brokerage' model does indeed deliver greater choice, control and independence.

The research adopted a comparative design, aiming to recruit 40 participants who had received ULO support planning services, and 40 who had received LA support planning. The aim was that these 80 participants would be evenly spread over the three areas in the study, and that we would interview them at two time points, once shortly after their support plan had been written, and again after a period of at least six months.

Over the different sites, we aimed to represent equally each of the main service-user groups, those with physical and/or sensory impairments, people with mental health support needs, learning disabilities, and those with dementia.

This was therefore a research design which would allow for:

a) maximum coverage of the possible issues and needs of different service users;

b) examination not only of the initial view of support planning, but also the eventual outcomes for service users;

c) a way of highlighting the factors in ULO support planning which really were distinctive for service users.

Within a qualitative approach, comparative designs do not generally aim to directly contrast participants on a one-one basis. Particularly within this project, this would not have been possible, because people were not randomly assigned to one group or the other. The overall goal was rather to obtain a wide sample of people with differing experiences, in order to understand more deeply the difference which ULO support planning and brokerage could make.

The qualitative research recruited an advisory group, which consisted of disabled people, a family carer and representatives of disabled people’s organisations and voluntary sector groups. The
group met three times during the course of the project, and was invaluable in reviewing the recruitment materials produced by the research from the point of view of disabled people, reviewing and commenting on the interview topic guide and offering views on emerging themes from the data, and their relative significance.

Data were collected from participants by the researcher visiting the person in their own home. Two people were visited, by their preference, in day centres or elsewhere and one took part by telephone. During the second part of the project, which included some Stage 1 interviews and all of Stage 2, one of the researchers carrying out interviews had lived experience of disability, and thus mirrored one of the central features of this project, which is about peer support. Interviews lasted between one and two hours, and were usually broken up with pauses for refreshments. We followed a topic guide which had been piloted with five direct payments users in the Bristol area, and also discussed with our advisory group (see Appendix A). Some key points about the topic guide were:

a) An accessible version of the questions was produced as a pictorial booklet, which we could use with those who preferred that type of information.

b) We started the interviews by asking about what was important in the life of the interviewee. This was usually successful in focusing the person on their life goals.

c) We followed what people wanted to discuss, and aimed for a free-flowing conversation wherever possible.

d) We had specific questions which we aimed to find answers to, relating to the support planning process in particular.

e) The interview was broken up into different ‘chunks’, one of which was to ask participants to rate their choice and control in different areas of their lives, on a 1-5 scale, both before and after their support plan.

f) We were aware from the pilot stage onwards that carers would also be present during many interviews. We endeavoured to ensure that we spoke directly with service users, but (with their permission) asked the carer to clarify or to expand on information that we needed.
The data from the first set of interviews (with all 80 participants) were all fully transcribed, and the second set of face-to-face and phone interviews were audio recorded, and scanned for relevant themes and responses which were recorded on a proforma. Three second stage interviews were done via a postal questionnaire. All data were analysed using a methodology grounded in what participants said, so that the themes were both set by the research topic guide, but also reflected what was important in the lives of the 80 people who took part in this study. Line-by-line coding of all interviews in Stage 1 took place via a software package (NVivo 8), which was used in order both to organise the data and construct a coding scheme for analysis.

Through the use of NVivo, we were also able to classify interviews according to a range of additional features, and then to review data for particular groups of individuals. These features were discussed at a three-site meeting with the brokers and support planners towards the end of the project. They are given in Appendix B. By coding against these classifications in the ‘Casebook’ facility, we were able to run queries, save them in an overview table and review quickly the data for different groups.

1.3 The sample

As the research was set up at the same time as the ‘SAB’ project, there were by definition no ULO service users at the start of the study. Therefore, a decision was made to recruit local authority group members first, and carry out their first interviews during the first six months of the research in 2009. Participants for the local authority group were sought who:

- had some form of individual, or self-directed, support package;
- had received support planning, or a review of their package, within the last six months.

In view of the fact that we were also seeking to obtain an even spread over the three areas and over the four primary impairment groups, recruitment of the sample was far from easy. Each site had set up a project board, and the chair of that board was the primary ‘gatekeeper’ for the local authority group participants. However,
problems were encountered at two sites; these included the fact that another major research study on personal budgets was in progress in Essex, and Southampton project board experienced a bereavement. Additionally, participation in a research study about ULO support may not have been such an attractive option for those outside the ULO group. Specific efforts to solve the recruitment problems in Essex and Southampton were discussed with the ODI project board on repeated occasions, and two in particular were successful:

1) A personal meeting between the researcher and a direct payments user network in Essex (DPUN). Thirteen participants came from this source.
2) Recruitment of four people with learning disabilities via an independent broker in Southampton.

Both these strategies, while successful, meant that the local authority group tended to be skewed, numerically, towards people who had had a relatively empowering experience of individual services.

The composition of the ULO group was led entirely by the actual referrals in the three sites. In other words, those who were offered a support planning service by the ULO constituted the sampling frame, and the research team was dependent on gatekeepers in the ULO to pass on research information so that service users could give informed consent.

In the event, recruitment for both the local authority group, and subsequently the ULO group, was very slow, and carried on until a very late stage of the research, with the final participants in the ULO group being recruited as late as September 2010, and interviews conducted in the final months before this report. In one sense this was positive for the research, since by then the SAB services could have been expected to have solved any teething problems. However, this lateness largely accounts for the fact that there are more postal/phone interviews in the ULO than in the local authority group, since the research team was not able to manage more face-to-face interviews after November 2010. The attrition rate at Stage 2 was 12.5 per cent (ten individuals). The research was eventually successful in meeting its numerical target collectively over all three sites. However, the different numbers in
each site means that it is hard to draw direct comparisons between sites.

Throughout this report, participants are identified as belonging to the ULO group which refers to those receiving ULO support planning, or to the local authority group (LA), those whose support services were organised with them by the local authority.

Figures for interviews at Stage 1 and at Stage 2 (ideally at least six months later) are given in Tables 1 and 2.

### Table 1: Interviews with people who received LA support planning

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<tr>
<th>Location</th>
<th>Stage 1 Interviews</th>
<th>Stage 2 interviews</th>
<th>Stage 2 interviews by post or phone</th>
<th>Stage 2 not completed</th>
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<tr>
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<td>Richmond</td>
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<td>Southampton</td>
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<tr>
<td>Total</td>
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### Table 2: Interviews with people who received ULO support planning

<table>
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<th>Location</th>
<th>Stage 1 Interviews</th>
<th>Stage 2 interviews</th>
<th>Stage 2 interviews by post or phone</th>
<th>Stage 2 not completed</th>
</tr>
</thead>
<tbody>
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</table>

Those interviewed were asked what they saw as their primary impairment (since a significant proportion of people had more than one). Table 3 shows that around two thirds of people in both LA
and ULO groups had primarily physical impairments. People with learning disabilities constituted just over a quarter of both ULO and LA groups (nine out of 41 and 39 respectively). There were six to seven people with dementia in both LA and ULO groups. Adults with mental health needs, however, were in a minority, four in the LA group and two in the ULO group.

Table 3: People's primary impairment: local authority group

<table>
<thead>
<tr>
<th></th>
<th>Essex Site</th>
<th>Richmond Site</th>
<th>Southampton Site</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical and sensory impairments</td>
<td>19</td>
<td>3</td>
<td>0</td>
<td>22</td>
</tr>
<tr>
<td>Mental health needs</td>
<td>0</td>
<td>3</td>
<td>1</td>
<td>4</td>
</tr>
<tr>
<td>Dementia</td>
<td>2</td>
<td>4</td>
<td>0</td>
<td>6</td>
</tr>
<tr>
<td>People with learning disabilities</td>
<td>1</td>
<td>2</td>
<td>4</td>
<td>7</td>
</tr>
</tbody>
</table>

Table 4: People's primary impairment: ULO group

<table>
<thead>
<tr>
<th></th>
<th>Essex Site</th>
<th>Richmond Site</th>
<th>Southampton Site</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical and sensory impairments</td>
<td>6</td>
<td>9</td>
<td>8</td>
<td>23</td>
</tr>
<tr>
<td>Mental health needs</td>
<td>0</td>
<td>2</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Dementia</td>
<td>3</td>
<td>4</td>
<td>0</td>
<td>7</td>
</tr>
<tr>
<td>People with learning disabilities</td>
<td>5</td>
<td>3</td>
<td>1</td>
<td>9</td>
</tr>
</tbody>
</table>

There were some key differences in the primary impairments of participants across the sites. In the LA group, 19 of the 22 people
sampled in Essex described their primary impairment as physical. In Richmond the spread was much more even between all impairment groups. There were no people with physical impairments in the Southampton LA group, while four of the five LA people interviewed here had a learning disability (the fifth had a range of needs, with primarily mental health support needs).

Sampling from different age groups was reasonably even in both the LA and the ULO groups, with an age range from 18 to 102, and a mean age of 53. This reflects the fact that the sample included both young people at the stage of transition, and also older people who were often new to social care. As Table 5 shows, the LA group included slightly more people in later middle age (56-65), while the ULO group included more in the 26-35 age range.

**Table 5: Ages of participants**

<table>
<thead>
<tr>
<th>Age</th>
<th>LA</th>
<th>ULO</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>18 - 25</td>
<td>6</td>
<td>6</td>
<td>12</td>
</tr>
<tr>
<td>26 - 35</td>
<td>1</td>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>26 - 45</td>
<td>5</td>
<td>6</td>
<td>11</td>
</tr>
<tr>
<td>46 - 55</td>
<td>5</td>
<td>5</td>
<td>19</td>
</tr>
<tr>
<td>56 - 65</td>
<td>10</td>
<td>7</td>
<td>17</td>
</tr>
<tr>
<td>66 - 75</td>
<td>7</td>
<td>5</td>
<td>12</td>
</tr>
<tr>
<td>76+</td>
<td>5</td>
<td>7</td>
<td>12</td>
</tr>
</tbody>
</table>

For 40 participants in the study, family carers were involved both in helping with support planning, and subsequently managing their budget. This proportion was similar in both ULO and LA groups. Five people mentioned an advocate being involved during their support planning, three in the LA and two in the ULO group. Four of these service users were people with learning disabilities and one was a woman with physical impairments, whose son was her family carer. In all cases, the advocate was said to enable the service user to have an independent voice, separately from family members.

Table 6 shows the ethnicity and gender of research participants. Thirty four of the 39 research participants in the LA group characterised themselves as white British; a similar proportion to those in the ULO group (38 of 41). The gender balance was also
pretty even. Of the eight participants from black and minority ethnic groups (10 per cent of the total), two in the ULO and two in the LA group had cultural preferences which were taken into account in their support plan, including the ethnicity and gender of personal assistants.

Table 6: Ethnicity and gender

<table>
<thead>
<tr>
<th>Ethnicity / gender</th>
<th>LA</th>
<th>ULO</th>
</tr>
</thead>
<tbody>
<tr>
<td>White British</td>
<td>34</td>
<td>38</td>
</tr>
<tr>
<td>BME background</td>
<td>5</td>
<td>3</td>
</tr>
<tr>
<td>Male</td>
<td>18</td>
<td>17</td>
</tr>
<tr>
<td>Female</td>
<td>21</td>
<td>24</td>
</tr>
</tbody>
</table>

**Ethical considerations**

Since we wished to include participants who lacked capacity to consent to research, we gained approval for our research protocol from a national NREC committee, the Research Ethics Committee for Wales which is flagged for Mental Capacity Act proposals (09/MRE09/19). The main ethical considerations related to the way in which we would assess capacity for those who may be considered to lack capacity to consent. We managed this by asking carers and others who were close to the person for their views about capacity, and any carers or supporters who agreed that the person should take part were asked to sign a consultee form. In addition, those individuals often acted as supporters in the actual interview, and enabled the person to have a voice.

Additional ethical considerations related to the demands on participants in terms of time and energy. Those with impairments which caused them extreme pain sometimes had difficulty in taking part in an interview, and one agreed to do an interview by telephone rather than face-to-face for that reason. However, the vast majority of participants were very interested to take part in the project, and saw it as a way of expressing their views. We hope that this report does them justice.
Chapter 2 - Introducing the participants

2.1 Goals and aspirations

When we asked people what was important to them they told us of their ‘ordinary’ desires for social interaction, to be able to participate in activities, and to live both independently and comfortably.

“It’s just the ordinary things. To be as...you know...as non-different - I hate the word normal. Yeah, but it’s just pursuing your own interest.”
ULO participant

People also told us of their fears of isolation, forced inactivity and dependency, and stressed the primary importance of choice. In addition to their caring relationships with family and friends, participants also spoke of the importance of being a good parent/grandparent for their children or grandchildren:

“So my goal - you asked me what my goal is - well to be a good mum. To be the best mum I can be.”
LA participant

The theme of isolation was significant for many participants, and contact with friends and neighbours was repeatedly cited as being most important. For many, sustaining a circle of friends was problematic, with several people telling stories of losing friends after becoming disabled. Others described their experience of a steadily reducing social circle due to increasing age and the death or growing incapacity of their friends. For these people, access to activities that enabled them to make new friends and acquaintances became important.

“I like to keep in touch with friends. I’ve got three or four very good friends, they come and take me out. I would hate to be one of those that have to sit, never see a soul. So this is my most important thing.”
ULO participant
Participants described a wide range of activities that gave them pleasure and a sense of identity, including travel, photography, music, football, cinema and theatre, and pride in learning new skills. The ordinariness of some of the activities described was striking, as was the frequent mention of the obstacles to participation for some. ‘Getting out’ assumed a particular significance for participants. It could encompass opportunities for social contact, as well as access to nature and being able to select your own goods when shopping. Some interviewees stressed the value of active agency to mental health:

“Being active and getting out of the flat. Because otherwise it’s just staring at the four walls. I need to get out and I need to be motivated to do things and I need to get up in the morning.”
LA participant

Specific aids to getting about, such as cars, mobility scooters, powered wheelchairs, being able to afford taxis, and the support of PAs, were mentioned frequently.

“So … it’s being about to get out and about and sort of…because when I go out on my scooter, whizzing around town, I feel free. I feel I’m there on the same basis as everybody else.”
LA participant

2.2 Past and present identities

Participants in the study came from many walks of life and professional groups; some had travelled widely, some were ‘homebodies’, they included single people and busy parents, students and teachers. In their spare time some were writers, sports people (at least one at Para-Olympic standard), ramblers, artists and photographers. Here we deal specifically with the aspects of their identities which had been affected by impairment.

Those whose impairment was recent referred to shifts in their roles and abilities, which contributed to a revised sense of their own identity, whether as a professional, a parent or a ‘useful’ member of the community. For many interviewees this was a regretful
reflection on their sense of their past identities, however for others there was (also) a strong sense of being a member of a group of disabled people, and several people reported active and growing participation in ULOs and similar groups. Several people mentioned volunteering, as well as involvement in ULOs, and these activities seem to contribute to a positive self-image. The beneficial aspects of reciprocity would suggest implications for support planning led by ULOs, and continuing involvement in groups such as DPUN for those able and interested in being involved.

The struggles to retain a sense of self, as well as a sense of what was happening as their condition progressed, were particularly challenging for those experiencing memory loss and the effects of dementia. Paradoxically the exercise of choice and control itself could be an unwelcome reminder of disability, as one person explained:

“I think I’ve got quite a lot of choice now. I mean I’m…I think it’s as things have gone on I’ve made decisions, and each time you make a decision it does sort of bring it up to you; yes, I’m disabled.”
LA participant

Our participants mentioned a number of strategies for retaining a positive sense of themselves, and for keeping connected to friends, neighbours and those who supported them. These included ‘staying positive’, and adopting what was described as a ‘philosophical’ attitude. A number of participants spoke of periods of depression, directly related to their experience of impairment, and for some this had the effect of further isolating them socially. Acceptance and accommodation of impairment were mentioned by many participants as part of the process of revising their sense of their own identity(s). Managing their condition was an issue for many participants, and it should be noted that this included people with learning disabilities and with mental health needs. People described how they learned to listen to their minds and bodies and to make informed choices about what to undertake.
2.3 Problems faced by participants

Help and support can come at a price to a disabled person’s sense of themselves. Participants said that if they want to live independently this may mean that the disabled person may need to have others around when they would prefer it otherwise.

“I really appreciate the help on one hand - of course I do. And I need it. But it bugs me. I’ll be honest with you. Not everybody wants to be followed around all the time and...I’ve tried to do so much for myself, I’d much rather do things myself if I can.”
LA participant

Conversely, at least one participant with a learning disability complained of social isolation, and wanted the company of support staff.

We heard stories of participants’ experience of living in a disableist society, as they spoke of being ignored or actively discriminated against, and how they felt undermined by the experience, ‘I’ve got my faculties. I’m not stupid, you know’. Some people spoke angrily of the way that they felt diminished, judged or ignored by other people, and some also identified their own attitudes to disability as causing issues for them:

“Seriously, I’ve lived with [this label] long enough, I’m used to a stigma.”
ULO participant

For those with physical impairments, using a wheelchair or crutches could pose a particular barrier, as it came to represent crossing from the community of the able to that of the disabled:

“And I don’t want to go in the wheelchair. Because the way people look at you... And then some of the people, they want to get away from you. It’s like you’re contaminated. So it’s not easy.”
ULO participant
One participant was kept housebound unless he had assistance, only because of a lack of a permanent ramp from his ground floor flat onto street level. Other people were stranded in unsuitable accommodation, struggling to get in or out of their homes, or had their independence compromised through the lack of suitable equipment or adaptations. One person in the ULO group told us that he fell repeatedly at night going downstairs to the toilet. He had not had an OT assessment, and had not been provided with extra handrails or a commode, and was saving up for a portable toilet from his direct payment (DP). The majority of the people in our sample were living on very restricted incomes, and could not afford to save for servicing and repairs on their basic incomes.

Once out of the house people reported limits to the things they could do because of poor access; this included using facilities such as restaurants, pubs, public transport, shops, banks and visiting other people’s houses. As one person pointed out, referring to the DDA 4: ‘So many of them are still breaking the law’ (LA participant). The effect of this lack of accessibility made going out a mammoth logistical challenge for some participants, both those with physical and with other impairments.

2.4 Specific barriers to speaking for yourself

Articulating and organising your own support requires a degree of insight, and most of those with a learning disability had family carers who had spoken up for them, sometimes with the help of a circle of friends, as this parent explained:

“I’m concerned about [this being] a parent-centred plan rather than person-centred plan, which is why we have a circle of support with eight people sat round looking at what is best for Andrew.”

LA carer

In fact, for some of these people, there was felt to be a necessity to shield them from ‘too much information’. Additionally, some support plans had to take into account the subtle need for a support worker or personal assistant who would be able to advise

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4 Disability Discrimination Act, 2005
people who lacked insight into their own best interests, for instance about diet. That type of impairment-specific need sits unhappily with the spirit of ‘choice and control’ in support planning.

One of the people who had mental health needs in this study felt that her views were not always taken seriously, since there was always an undercurrent of suspicion that people in her situation lacked insight into their own needs. In addition to the very general issue about articulating their own support needs, some twenty-three of our participants faced particular problems in verbal expression, in understanding information, or in memory. All these aspects of communication had made support planning difficult.

“I’m quite ok when I’m talking to someone. But there’s a good chance that after a little while I will forget that you’ve been here.”
ULO participant

Some of these people would need specific strategies to enable them to recall and retain what they have said about their plan. Five participants in our study had severe communication difficulties which were associated with a learning disability, and needed someone to learn to understand their body language, or to simply observe. As one carer explained:

“I think before Francis moved into his place now it was clear that he was unhappy living with people.”
LA carer

Pain was another very important theme. For someone in pain, it is often hard to communicate, or even to think about constructing a support plan:

“At the very worst all I could do was raise a hand and grunt. We do have a little bit of a joke now that I had my own language back then.”
LA participant

People spoke of medication which made them feel drowsy, confused, or forgetful. The frequently reported ‘need to keep going’, to continue to ‘cope’, as well as the impact of pain and fatigue, was likely to affect a person’s ability to engage with the
processes of support planning and the day to day exercise of choice and control.

2.5 Advocacy and carers’ roles

Although neither ULO nor local authority care managers officially provided advocacy in this project, nevertheless participants in both groups occasionally mentioned advocacy as something important for them. The 40 family carers in this study were natural advocates for their disabled family member. One family carer said that, without her own input, her husband would have had great difficulty in saying what he wanted.

“An advocate would be the person who would sit with you before the broker came…it needed me to say to Bertie, look, you’ve got to sit and think about what you most want to do, because (ULO support planner) is going to come, and you haven’t done any thinking.”
ULO carer

Another family had been careful to involve an independent advocate, as well as a support planner, so that other family members would appreciate his mother’s views. People with learning disabilities had also used advocates on occasions. One parent felt that independent advocacy would help her son to have a voice separately from their family’s wishes. However, a woman with a physical impairment found that, in a slightly wider and more empowering sense, it was the advocacy of other disabled people that had, in the past, been life-changing for her:

“He was my advocate, yeah. He arrived outside the house, and he used to drive from his wheelchair…He was such a brilliant man. And it was him that really - sort of opened my eyes to all of this.”
LA participant
Chapter 3: Engaging with the system: what happens before support planning

3.1 Making the initial contact

A common theme amongst all participants was the difficulty of making the first contact with social services, or even knowing what department or organisation to ask for. These difficulties were not trivial. For some people, the initial attempt to make contact with social services had taken over a year, and more than one person spoke of wanting to kill themselves during this period. One man who had suddenly lost his sight, expressed eloquently how lost he felt:

“So then the worst thing then was at the hospital when I was finally signed off as blind it was “well what do I do now mate?” “Well, I suggest you get in touch with social services or something like that”. And bear in mind you can’t see anything, and it’s,” I’ll give you some forms”. And you’re alone. You’re helpless. Absolutely helpless.”
ULO participant

A first port of call was often a particular professional or service contact. Occupational therapists in particular were mentioned by 19 participants. For more than one person, the first contact was instigated because of a crisis situation, in which a provider organisation helped them to access the physical support they needed. For instance, an older woman in the ULO group spoke of having a fall in her home:

“Not surprisingly, I had to have a bleep. And with the bleep was all this information about things I was entitled to.”
ULO participant

There was a very general feeling that the responsibility lay squarely on the potential service user to shout loudly in order to get access to any support at all:
“But it was all down to us. There was nothing that was offered to us, we had to fight for it”
LA participant

One person in that situation had gone to her local MP. By comparison with the difficulties of making the first contact, support planning can seem like a ‘breath of fresh air’, and one ULO participant spoke of: ‘The novelty of someone that actually wanted to help’.

More positive routes into the system emerged amongst younger people who were already service users, whose families mentioned Connexions, and also the importance of person-centred planning (see 4.2.4). Voluntary sector organisations were also mentioned by our participants included MENCAP, local Alzheimer’s Society groups, local Mind associations, the RNIB. There was plenty of evidence that people trusted these contacts, especially because of the feeling that they had specialist knowledge relating to their impairment. However, those who were members of user-led networks or organisations, and had regular contact with other disabled people, had by far the best chance of a positive entry-point into the personal budget system.

“Well I read about it (PBs) from ECDP. I go to a few of their meetings… And then I spoke to social services, and they said to me, ‘Well you can go over to (a PB), but you can’t do it until you’ve been…you’ve got a plan set up.’ Which to me, I didn’t even know what a plan was.”
ULO participant

3.2 Information about personal budgets

Information is vital. That is why we regularly asked about the value of what participants may have seen. More than one person mentioned valuable information produced by the LA and the ULO, as was expressed by this satisfied carer:

“RUILS information on self directed support is a brilliant brochure, brilliant. Because they do tell the clients…the ways you can…the imaginative things you can do with your SDS.”
ULO carer
However, for many participants the very process of a personal budget was muddled. The terminology and frequent changes in ‘initiatives’ had led to considerable confusion amongst many participants, who had experienced between them, in no particular order:

- Self-directed support
- In Control pilots
- Individual (or individualised) budgets
- Direct payments
- Personal budgets (or personalised budgets)

This led to a situation where the idea of being in control of one’s own support plan was lost in the fog of misinformation. Ten at least of those in the local authority group appeared not to understand that they had completed a support plan at all, and many had a hazy grasp of what a personal budget was:

“The thing is I was on the individual budget, and now they seem to have stopped that, in general. So now we get an allowance.”
LA participant

Those in the local authority group in particular were frequently confused about the identity or role of the professional they had seen. Sixteen different participants identified the problem of being lost in the sea of visitors. The term ‘support plan’ was not universally used within the local authority group, and it was often very unclear whether a social worker had visited in order to carry out an assessment of needs, or to help with support planning.

Confusion about the fundamental purpose of a personal budget was strongly associated in our data with participants referring to a ‘system’ which had been imposed by the local authority, rather than one which would belong to the service user. For instance, one of the people who heard about self-directed support through her day centre closure felt that personal budgets meant “replacing support with a cheque”. This left service users feeling ‘overwhelmed’ and ‘worried’.
By the time we interviewed them, participants in the ULO group had almost universally reached an understanding that they were taking personal responsibility for their own support; however, that awareness was associated with even greater worry, since the lack of clear information could leave people feeling guilty:

“And you’re worried about it because it’s a lot of money, and then if somebody accuses you of not using it properly – you shouldn’t be doing that - you feel guilty.”
ULO participant

In order to have a firm grasp of what support planning might entail, participants said they need to have a clear route map, which would show how things ‘fitted together’:

“The problems I had were not with (the ULO) at all, because they did their bit perfectly, but the problems that we’ve had have stemmed from social services not really giving us the full picture at the outset. Well in fact the social worker gave us the wrong information, so I was never fully aware how all the bits fitted together.”
ULO participant

The reality is that, however good or bad the written information, this would nearly always need to be backed up by face-to-face explanations from staff who themselves had appropriate training and knowledge. As one participant said, what he really needed was ‘one knowledgeable person’.

“But there’s nothing like first hand somebody telling you about something rather than reading it in a letter. I find even though you get emails and that, not being able to see you have to keep going back and rereading through, because you can’t take it all in at once.”
ULO participant

Support planners were said to be key people, in communicating that information and ‘whole picture’ to the service users they supported. The information and advice offered by user-led organisations was generally experienced as clear and informative. Several people said that they could pick up the phone, and speak to different people in the ULO, who were felt to be ‘on the inside’.
They particularly appreciated the fact that the support planners knew the details of how the personal budget system was supposed to work:

“So everyone up there seemed to know what they were doing. And it’s not like social services - I know they have a lot on their plates - but to be honest, every time I rang up (the ULO) at the time, everybody seemed to know what was going on.”

ULO carer

While recognising the demands on social services staff, several participants commented on the frequent changes, and the need for training about PBs for new care managers.

If full initial information about the personal budget journey was rare, accessible information was even rarer. In Essex, service users themselves had started to get involved in advising on accessible information, and in Richmond, one person in the ULO group had advised about information for visually impaired people. Participants and carers mentioned, between them, the need for computer-based information, pictorial information and video/DVD information.

They commented that this would need to be based on concrete points about people and their lives, rather than focusing on the element of money management. Participants appreciated meetings where information was disseminated, particularly through user networks or organisations:

“They showed us a film of how much more control you had, and how many more areas you could use - because it’s not just for (personal care).”

LA participant

The nineteen participants whose ‘entry route’ had been through their membership and association with a user-led organisation had no problem in understanding the concept of a personal budget. This was not only through written information, but more often because of frequent contact, and the experience of meeting other disabled people who were managing their own lives and support. All the participants who had taken part in public meetings, or were
connected with disabled people’s networks, had gained their knowledge in that way.

3.3 Assessment

Participants in the local authority group were almost universally unclear about the different stages involved in self-assessment, resource allocation and support planning. Generally, they did not even raise the question or use the terminology which would allow them to ask ‘am I being assessed or planning my support?’ The exception, not surprisingly, consisted of those who were already active members of user networks, who were extremely well informed.

As mentioned in 3.1, people had often had grave difficulties in making the first contact with social services, sometimes waiting over a year. Non-responsiveness in the system meant that potential service users felt that they did not deserve the support they were applying for. One person spoke of feeling ‘humiliated’:

“It made me feel like I was begging. Like I was desperate.”
ULO participant

Young people with lifelong impairments, who were at the stage of transition to adult services also had to prove that they were eligible. A parent spoke of her son with learning disabilities and complex needs as being ‘on the border of being accepted’ for adult services, because of his relatively high IQ score. Another parent said that her son had had to wait about eighteen months for an assessment. When it came to adult services, she said, ‘it all fell to pieces’ (ULO carer).

The assessment process was not experienced as a pleasant or self-affirming event. In one case, a young person with potentially challenging needs was being well supported by family and college placement. However, for the purposes of assessing need, it was necessary to step back from the positives so that sufficient resources were allocated. As her carer said ‘you have to put in the worst bits’. Self-assessment can also have its psychological downside for experienced PB users. One very experienced disabled man, who had used direct payments from the mid-
nineties, still found that expressing his level of need could be
depressing, since he had to articulate what he could not do.

A large number of our participants, both in the LA group (N=17) and
in the ULO group (N=23) had a carer who assisted them with
the process of assessment and support planning. It was extremely
hard for those who did not have that support, since they often felt
they had to negotiate a balance between appearing to need help,
and wanting to be independent. This problem was particularly
acute for the five disabled parents in our study, since they felt that
any assessment of their needs may endanger their rights to
maintain custody of their own children:

“I had this great fear that if they walked into my house and said, well obviously she’s not capable of looking after the children. We’re going to take them into care. And then my life will be over really. So I was always very conscious of that.”
ULO participant

It is not just the process of the assessment which has an impact,
but also the outcome. Where enough money had been allocated to
start support planning in earnest, a common theme was that of
surprise and delight at the fact that a particular sum of money had
been allocated. By contrast, where the allocation was insufficient,
the assessment was seen as restricting and disempowering. One
carer who had been forced to give up employment to provide care
for her newly disabled son put this graphically:

“Two years ago our life was completely different. But now it’s completely changed. And it’s ok the 14 hours support for him, but if they gave him more support and more hours I could get a full time job.”
ULO carer

It is very hard in those situations for a support planner to come in
and enable the service user to feel in control of their own plan,
since of course a limited budget restricts choices. For one woman
with physical impairments, pain and emotional distress, for
instance, the support service consisted only of a few hours’
cleaning, when she felt she needed far more personal and
emotional support to manage complex health needs, pain, and
childcare.
One person with an acquired impairment had moved back home with her mother. This had an impact on the mother’s ability to work and earn money, as she had become a full-time carer for her daughter; the money available for a personal budget did not really solve the financial and personal problems for this family, but simply enabled the PB user to have some hours of independent activity outside the home. In these cases, where the allocation was perceived as insufficient, participants tended to feel disempowered, both by the assessment but also by the subsequent support planning.

Clearly, the theoretical model in which assessment is separate from support planning did not entirely match the experience of participants in this study. In fact, the links between one part of the jigsaw and another were very important in the way people experienced support planning. For those in the local authority group, the biggest problem was that there was often no discernible separation at all between the two processes. For those in the ULO group, there could be a disjunction, or clash, between the experience of assessment and support planning.

However, joined-up thinking and team work were occasionally mentioned and appreciated. Some participants in the Southampton ULO group had had a kind of advocacy support from their initial contact with the support planner, who had encouraged them and advised them about the Resource Allocation System (RAS). This was appreciated, particularly by families of people with lifelong impairments, who found it hard to express the extent of their son’s or daughter’s needs. The following comments related to the links between the social services assessor and the support planner:

“She (social worker) has been brilliant as well. Her and (ULO support planner) work together – it works as a combination.”
ULO participant
Chapter 3: summary of main comparison points between LA and ULO groups

- ULO participants had a firmer grip than their LA counterparts on what a support plan was: they were informed about its purpose.

- Those in the ULO group tended to see assessment as clearly separate from the support planning stage. LA participants often remained ill-informed and muddled about what support planning was.
Chapter 4: Experiences of support planning

4.1 Personal practices seen as positive by service users

4.1.1 The ‘genuine’ quality

When discussing what happened during the actual visit(s) from the support planner, one of the most immediately noticeable points was that everyone in the ULO group could recall immediately who the support planner was. That was significant, as the social worker encounters were sometimes reported as confused or unmemorable. A ULO support planner was more likely to be described as a ‘real person’, someone with a name and personal qualities. Similarly, almost everyone in the ULO group commented on the genuine approach taken, as typified in the following comment:

“She was the most ideal person; she understood and you believed her. She wasn’t patronising, she was sincere.”
ULO participant

Particularly by contrast with previous experiences of social services, many of our participants were overwhelmed by the friendly, relaxed and caring attitude expressed by support planners from ULOs. The same participant was relieved by: ‘The novelty of someone that actually wanted to help’. It ought also to be mentioned that people who had experienced LA support planning also sometimes mentioned similar qualities in social workers. This very much depended on the individual qualities of particular people they met, and this will be explored further below.

It is interesting to try and unpick what was meant by this genuine approach. Some of it was undoubtedly to do with the way the interaction was handled. People spoke variously about the support planner being ‘friendly’, and ‘chatting away like we are now’. They also liked it when they felt they had got to know the support
planner as a person, as this could equalise the relationship and prevent the professional distance which so often arises between social care staff and the individual disabled person:

“She went to a great deal of trouble to introduce herself and send out a file so that we had some idea of who she was when she came here. And she’s a very…she’s very light and looks bright and positive. Very helpful. She was very, very reassuring.”
ULO participant

ULO support planners were also said to have been good at remembering details about people’s lives, and taking a genuine interest in their goals and concerns. One participant said that: ‘she knows I’m going to Spain. She will mention that and suddenly it takes on a different colour’.

That ‘different colour’ of the interaction has something to do with loosening the boundaries, and talking in a less professionalised, more personal way. Participants said that this helped them to relax, and to feel that their lives actually mattered. As mentioned in Chapter 2, the goal of many participants had to do with achieving something, becoming ‘who they wanted to be’. By equalising the power balance between support planner and service user, there was more chance to start exploring those more subtle or personal aspects of the support plan.

4.1.2 Listening and respect

Very much related to the sub-theme of ‘genuineness’ was another theme about listening. We included within this theme the idea of respect for the service user’s wishes. People particularly appreciated the support planner not forcing things onto them, but instead, actually following what they wanted.

Again, this theme was very much associated with ULO support planning, and ten of the ULO group said something about what we coded as ‘listening’. For these participants, listening meant that they felt their own views counted for something. The order of events in support planning was significant: first people wanted to
be listened to, on their own terms, and then they wanted advice and suggestions, as this participant put it:

“She didn’t sort of like put anything forward to me, she sort of heard me tell my story and then obviously I asked her questions along the way - I said to her, this is what I want help with if this is possible. I didn’t know anything about it. Obviously that’s what she does every day, so she knew more about it than I did, and I said, this is what I would like help with, is it possible to get help with this? And she said, yeah, yeah that’s fine.”
ULO participant

By contrast, a non-listening attitude was described as a social worker or support planner who had an abrupt manner, and implied that the service user’s requests were not important or justified. The following comment was from someone who had had to explain carefully her own needs to have support in lifting her baby:

“And he just couldn’t…he didn’t understand very well. I mean he allowed me the help, but it was quite abrupt. I don’t want him coming back.”
LA participant

A few participants in the LA group also talked about ‘listening and respect’. That included one person with learning disabilities whose PA said that the service manager had listened to him, and observed over a period of time, that he did not like living in a group home. This quality is therefore absolutely central to distinguishing what mattered to those who had ULO support planning. One participant expressed clearly what respect meant to her, and this was all about equalising the often unequal power balance between professional and service user:

“She treated you with respect, and didn’t look down on you. Because I find people look down on you if you’re disabled in any way. Like you’re lower than them, you know.”
ULO participant
4.1.3 Getting deeper into what you want

One of the themes that emerged as a strong point about support planning was the way in which ULO support planners had helped participants to ‘think beyond’ their initial statement about their needs. Nowhere was this more clearly expressed than in the following quotation:

“With (ULO support planner), they would write down what you said, and then they would pull apart what you said, to get deeper into what you want, and what you’re thinking and what you’re saying. And they would pull out to know what you really do want, rather than a care manager – this is what you say, and this is what they want.”
ULO carer

That type of good practice is clearly important for everyone; however, one of our hypotheses was that it would be even more important to get this right for those who do not already have a strong voice. We can particularly expect those people to be found amongst those with a learning disability (or an additional learning disability), mental health needs and dementia. In fact, of course, it was precisely this group who would find it hard to talk about the fine detail of the interaction retrospectively.

However, with three of the people with a learning disability, carers specifically mentioned the way in which the support planner had ensured that the carer was given suggestions and prompts to think beyond the ‘obvious’. One carer said that she had been encouraged to think about what her son may want support with during holiday periods, as well as his residential college provision. Another carer summed this up, by acknowledging: ‘I know with (my son) I know a lot what’s needed, but not all the time’.

Only one of the people who used mental health services talked about a support planner who had ‘gone deeper’ into what they needed. This was someone in the local authority group. However, her comments clearly showed what would be desperately needed by someone in her situation:
“I am a person, if I talk, I can say everything what I have, and it makes me happier. And by talking – by saying to you, I can know myself…By talking to you, now I understand myself?”

LA participant

People with dementia were naturally quite new to articulating their own needs, and also relied on carers who were generally new to social care. In fact, three of them did mention specifically how ULO support planners had helped them to think of social activities and outings, as well as the obvious ‘personal care’ which they had asked for.

As with the other ‘positive experiences’ of support planning, we scoured the data to see whether they were also happening for people who had local authority support plans. Apart from the one person with mental health needs mentioned above, no-one else mentioned this type of quality. However, it is interesting that the actual skill of enabling someone to ‘go deeper’ is one that one person had experienced outside a ULO, on the Individual Budget pilot in Essex:

“It was only when I went on the individual budget pilot and they started to get you to think about yourself that it’s like…it was a real…actually it made you look at your life. And I knew the outcome was that things were going to be better, but talk about hit rock bottom. I realised that I’d given up on so many things in life.”

LA participant

4.1.4 The individual support planner: do we need an ‘angel’?

In the context of the present project it seems that there was something about the ethos and understanding within a ULO which enabled support planners to adopt a person-centred strategy. It would also seem that local authority care managers were somehow not able to free themselves up in quite the same way, and were perhaps more restricted by the regulations, time constraints or resource worries that dominate their role. However, we also noticed that many of the positive points made about support planning delivered by local authority staff related to the
actual person. In this situation, service users in the local authority group were likely to defend the LA staff, as this woman did:

“Barry is a different kettle of fish, because he’s a different… it’s not their job, but it was given to them. Because they’re very short of social services aren’t they. So Barry is not guilty, because it’s given to him to finish the job.”
LA participant

The advisory group for this study picked out a significant theme in some of our early data from the local authority group. It was remarkable that people spoke gratefully about the ‘good’ professional, who was more than once described as an angel:

“Well this lady came on the 21st of December, and she’s an absolute angel. And she and I coped together.”
LA participant

The occasional angels who worked for the LA generally were said to have similar qualities to those of the ULO support planners. They were described as people who did not stick to the rules, who bridged the professional distance between themselves and the service user, and who sometimes started to act as an ‘ally’ to the service user. One participant in the local authority group, for instance, had known her social worker personally over a period of years, and had kept in touch despite the social worker having changed jobs more than once.

As our advisory group commented, it is not satisfactory to rely on angels, either within social services or within a ULO. One participant in the ULO group summed this up:

“I have faith in (ULO support planner), I just don’t have faith in the system around her. One person can’t change a huge, monolithic factory.”
ULO participant

The types of personal qualities described in this section can of course inform good practice in any of the ‘helping’ professions. However, they will not of themselves transform bad support planning into good. A salutary tale was told by one of the LA participants, who had encountered a social worker who had tried to
overstep the boundary and claim friendship with her. That strategy had dismally failed, as the service user felt demeaned and disrespected, rather than listened to. The social worker in question had also used the same support planning style as was common in the ULO group, by trying to write the support plan in the ‘first person’ as if it reflected the service user’s voice. In fact, this story ended with the service user lodging a complaint against social services, and self-referring to the ULO for her support plan.

4.2 Systemic features of support planning and brokerage

4.2.1 Knowing the indicative budget

In order to make realistic choices about one’s support plan, one of the first principles of self-directed support is that people should know what sum of money is allocated to them. Twenty-nine of the 41 of those who had had support planning from a ULO mentioned that they had been told their indicative budget before writing their plan (as opposed to 14 out of 39 in the LA group).

In one case in the ULO group, the service user was rather frustrated that they had to fill in yet another form (the support plan), after the resource allocation (RAS) form before accessing the money. For most, however, knowing the budget was seen as empowering, since it enabled them to get involved, to calculate the price of their support and to cost out their own plan.

“Yeah, we both - he sat with his pad, I sat with my pad, and we both come up with the same (cost)...so we thought we’ve got to be right because we’ve both got the same figures.”
ULO participant

In the local authority group the majority of people perceived the process as negotiating needs and hours, rather than spending a known sum of money. Two people in the ULO group also said that they thought the support planning discussion was based on ‘their needs’ rather than on spending a sum of money. This was strongly associated with anxiety, since they did not know if they were likely to get the money, and therefore the support, which they needed.
4.2.2 Options about how to spend the budget

Another key element of the personal budget is that a service user should be offered options about how to spend the money in their budget. That can include taking the money as a direct payment; using an agency to supply personal assistants; using a directly provided service – or of course a combination of any of these. The whole point of a personal budget is that it offers choices and puts that decision into the hands of the service user themselves (DH, 2008; DH, 2010).

Thirty people in the ULO group had taken up the option of becoming direct payments employers of their own staff, while only 17 people in the local authority group had taken that step. This is a surprising contrast, since the LA group, it will be recalled, included 13 people who were members of the local direct payments network.

Table 7: Take-up of direct payments by participants

<table>
<thead>
<tr>
<th></th>
<th>Local authority group</th>
<th>User-led group</th>
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</thead>
<tbody>
<tr>
<td>Direct payments employers</td>
<td>17</td>
<td>30</td>
</tr>
<tr>
<td>Percentage of total in group</td>
<td>43%</td>
<td>73%</td>
</tr>
<tr>
<td>Total</td>
<td>39</td>
<td>41</td>
</tr>
</tbody>
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Clearly, something is happening here for those who have ULO support planning, perhaps relating to the way options are explained, and also to the level of confidence engendered in service users. By contrast, those who had LA support planning sometimes perceived the support planner as aiming to limit the spending for each service user, and protect resources, as this carer of an older participant said:

“The council are very keen on the direct payments – I think it saves them money.”
LA carer

Like others, this carer in the LA group felt that she had enough on her plate already since she provided care for her son:

“Rather than me having to employ a group of people, and having to deal with PAYE and all the rest of it: No. I’ve got enough to cope with without having to do that. So we had a chat about it, and we decided that (name of organisation) would probably be the best option, because people are already trained, and they’re already employed by somebody else, I don’t have all this paperwork to keep track of.”

LA carer

However, there was also one report from an older couple in the LA group whose care manager had discouraged them from their desire to directly employ their staff. As they said:

“The most important thing of all is the flexibility. They wanted me to accept social services coming in, and not Beth. And I said ‘I’ll lose her!’”

LA carer

Those in the ULO group regularly reported that they had been given choices about how to use their personal budget, and in the main they felt that ULO support planners had explained those choices well. However, there was also one family in the ULO group who felt they had not been given a choice, and this had impacted on their subsequent dissatisfaction: “what they’ve said to us, that’s what we’ve done”. What is important here is that the service user and their carer feel empowered by being offered the full menu of options.

4.2.3 Models for engaging with disabled people and carers

The central purpose of facilitating a support plan is to enable the service user to take control, and feel a sense of ownership. This sometimes leads to an approach in support planning where it is assumed that the service user can simply carry on and do their planning for themselves. For those in our study who had the
capacity and motivation to assume that responsibility, that type of hands-off approach worked well, as one participant explained:

“I think it’s giving me the information and letting me choose... It’s up to me ... first of all I was sceptical about the whole process, but it’s allowing me to go away and actually read it and read it and read it, and say, does that make sense? Yes, ok. And then actually act on it. That’s the kind of person I am; I like to be analytical and think and pull things to pieces.”

LA participant

However, with those who lacked cognitive capacity, carers often played a key role. In fact, all of those with dementia had a carer involved in their support planning (seven of those lived in the same house as the service user); 14 of the 16 people with learning disabilities had a family carer involved, and of those, 12 lived in the same house as the service user. There were therefore only two participants with a cognitive impairment who did not have family members involved in helping with their plans.

We asked our participants, as well as their carers, how the support planning had been done, and to what extent it included the direct voice of the service user, trying as far as possible to mirror the process of involvement in our interviews. For instance, we would use an accessible version of our questions, with pictures, or a set of large pictures representing different parts of people’s lives, in order to try and speak directly with people with learning disabilities or dementia. In four cases, people with learning disabilities preferred to use felt pens to draw their responses, and then name what they had drawn. Following this type of engagement, we would ask the carer and/or the service user: ‘Did the support planner speak directly with you, like I’ve tried to do?’

The carers in this study all felt that they were the best advocates for their disabled relative, and had had to take on the organisational elements of planning:

“Well we started off with (ULO support planner) saying what did Nicholas want to do, and things. And then once we’d got through that bit, then it was the paperwork bit, and putting the flesh on the bones, and that bit. And that’s where Nicholas sort of bowed out of it.”

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ULO carer

One carer of a person with dementia said that she would want to shield her relative from getting confused with too much information, which they would not be able to understand:

“I only tell her what I think she’ll either deal with, or can cope with. Because otherwise it upsets her because she thinks she’s ignorant and stupid.”
ULO carer

It was clear that for the majority of the people whose main impairment was a learning disability or dementia, in both LA and ULO groups, support planners had had more lengthy and in-depth engagement with carers than with the service user directly. For instance, one carer of a young man with profound and multiple learning disabilities had engaged over a period of time with the support planner, and was very pleased that they had kept in touch, phoned and emailed, exchanging ideas and information about what could be in the support plan. When we tried to ask service users themselves how they felt about that, they were neither aware that their carer had spoken for them, nor were they able to express any particular opinion on that subject.

4.2.4 Person-centred planning

One of the areas in this study, Southampton, did not provide ULO support planning services for those whose primary impairment was a learning disability. Instead, an independent broker was appointed by the local authority, who was skilled at engaging with people with learning disabilities and initiating person-centred planning (PCP) meetings, where the person with learning disabilities was involved, as well as their carer(s).

This model in Southampton accounted for the fact that PCP was reported more commonly in the local authority group (N=6), than in the user-led group (N=2). Eight of the 16 people with learning disabilities in our study spoke about a person-centred planning model, which appeared to work well for all involved, as the following remarks from one carer illustrate:
“This was a positive process which involved lots of people and a series of meetings, which gave everybody time to reflect on the stages.”
LA carer

People reported that PCP provided a way for service users to express what they wanted by using accessible information strategies, by engaging with people in small steps, and surrounding people with familiar, trusted support in order to construct their plans over a period of time. In the interviews, participants with learning disabilities who had a PCP could quite clearly relate to what was in the notes, and carers reported that the PCP notes had helped their relative to show to others what choices they had made. Typically, PCP notes included photographs and large, accessible text. They often focused on people and activities in the lives of those who were referred to as ‘the focus person’.

4.2.5 Separate meetings

Carers of people with learning disabilities occasionally mentioned that the support planner had held a separate meeting with the service user, where the carer was not present:

“Bob went in and had a meeting, and was supported by Rachel. And I didn’t go in with him...because Bob finds it difficult to express what he really wants, and obviously I know him really well, but I didn’t want to put my views in there.”
ULO carer

People said that complex financial details were often handled by the carer. One participant (who in fact had neither dementia nor a learning disability) for instance found that her son was acting as an interpreter between her and the support planner:

Researcher: “When Kylie came, was she easy to understand?”
Service user: “Yes. Easy. Jonathan, Kylie, Jonathan, me. [pointing to her son and herself]
Son: “It was the three of us.”
LA participants
Moreover, engagement with the service user could occur by the support planner simply accompanying him or her during their regular activities. Again, this strategy for engagement was mirrored in two of our interviews, where a person with learning disabilities did not stay in the same room and communicate with the interviewer. However, when invited to go and visit (in one case, a swimming gala, and in the other, a woodland activity centre), there was far more communication and evident enjoyment of the activity in question. During one of these visits, the person with learning disabilities showed the researcher a picture book about his new home, and communicated through Makaton signing that he was happy with it.

4.2.6 Personalising the support planning session

The third model, which was reportedly used both with people with dementia and people with learning disabilities, was to use specific personalisation strategies within the context of the support planning sessions, where both the carer and the service user were typically present. There can be no ‘cookbook approach’ to getting the focus right. However, those who had support plans with help from user-led organisations, or through an independent broker, were enabled to:

- create plans which were written in the first person
- include photographs of key people and places
- discuss the positive aspects of their likes, skills and identity.

When reading through these plans, service users identified with the script, and agreed that the plan did represent their own wishes and goals. Six people mentioned this type of strategy, three in the LA and three in the ULO group. They showed us copies of their support plan, with a personal profile, and statements about the things that were important in their lives. One person, for instance, had a plan recording the fact that she was an active person, used to doing lots of walking, cycling and sport. It was important therefore for her to have a personal assistant who was prepared to accompany her during at least some of these activities. It was the small details which often meant something to the service user, when we read out extracts of support plans in the interviews.
It was also noticeable that user-centred support plans aimed to give a positive picture of the personality and strengths of the individual, rather than the more usual list of deficiencies and needs. Reading out these positive statements to one young man, he responded happily to the description, as indicated in the transcript:

“His gifts and skills are that he’s kind and considerate; opens the door for you - which you did for me, Andrew didn’t you. You were brilliant. Likes to be involved, likes to be useful, wicked sense of humour - as you just said - welcoming, listens to what is going on - which I’ve noticed, because you’re picking up things aren’t you Andrew, from what we’re saying. Has a huge inner light, eyes light up, animated.”
LA participant

The ways in which support planning was tailored to the needs of different groups of people are returned to and discussed in Chapter 8.

4.2.7 Time spent with the support planner

Time was important for the people in this study; on the one hand, several participants praised support planners who did not rush away, but allowed themselves to relax and spend time over discussions prior to completing a support plan. This implied, for many, a genuine interest in their needs and their strengths:

“Then she came here and she saw me about 3 times. I just triggered off something in her and she ended up reading lots of [my] poetry. She wanted to hear some of my adventures in Australia, because I’d lived there for many years.”
ULO participant

Others too appreciated the willingness of the support planner to keep in touch, and to carry out repeated visits to complete the support plan. This feature was certainly not limited to those who had used ULO services; people often had repeated contacts with local authority support planners as well.
What mattered most was not perhaps the actual time spent, but rather that the support planner should take action and do something with the information they had gained. The argument against spending too much time would be that carers and also many of the service users in this study had very busy lives. They did not want to spend time unnecessarily, if that was not productive. Several carers who had used ULO support planners mentioned particularly how useful it was for the support planner to write an initial draft, and then go away and find out further information. At that stage, people had often kept in touch, via email, telephone or mobile:

“So she then came out and did a support plan. And she did it quickly. I did my bits, sent them back into her, we were emailing one another.”
ULO carer

This efficiency and availability was not limited to ULO support planners. People who had seen social workers had also appreciated both repeated visits and, in other circumstances, the efficient way individuals had kept in touch. However, one noticeable difference between the groups was evident here. When contacting a ULO, people often mentioned that the organisation itself was responsive. If the person they were telephoning was not available, then another person could usually answer and provide the help needed. Unfortunately, within the social services system, people had a less positive experience, and that contrast is neatly encapsulated in what one carer in the ULO group said about his past and present experiences of planning:

“When I ring up (the ULO I go, ‘Hello’, and they go, ‘Oh, hello Bob’, and they know me straight away, because of the way that I talk to them and that. They are so friendly down there. Where social services you ring up and it’s all, ‘Sorry, they’re not here, sorry, they’re…’ and it’s so straight-laced. They won’t interact with you.”
ULO carer
4.2.8 Brokerage

There is a delicate line to tread between support planning and ‘brokering’ or putting into action a support plan. However, most of the participants in this study were happy to be offered advice, and for the support planner to come up with suggestions about what was possible. Written information and suggestions needed to be backed up by direct, personal signposting to what was available and possible in the local area. Service users really valued the creative interaction with a support planner who was able to at least offer suggestions:

“It was like a nightmare; where do I start? And she sorted that bit for us. And then she was…maybe write this, or maybe that… And then she looked for support with us, things in the area. She really helped a lot.”
ULO carer

The comment above was from a parent in Essex, where the support planning model was brief and explicitly not concerned with brokerage. Therefore, it is clear that ULO support planners were adapting their strategy to fit individual needs. In Southampton and in Richmond, participants regularly spoke warmly of the advice and suggestions offered by the ULO support planner. There were of course times when the service user may come up with an idea which the support planner could not immediately answer. In those cases, what people appreciated was someone who would listen carefully, go away and take action to find out the information needed.

With people who have large packages of support, it is of course going to take longer to write a meaningful support plan, since there is more money to spend. Five of the 17 people whose weekly budget was over £400 had a lengthy, ongoing contact with their support planner during the support planning process, and another five said they had three visits from their support planner. Particularly for those who were allocated £400 a week or more, some continued contact with the support planner or their organisation was appreciated, and eight out of those 17 ‘high budget’ users were still in touch with the individual support planner, or with the organisation, at their return interview six months later.
Those who had high budgets but had no contact with social services, nor with the ULO, frequently expressed worries about the decisions they had to make. One person in the LA group whose weekly budget amounted to over £1,000 (including ILF money) had grave concerns that his ILF money would stop at the age of 65, and that he would be unable to cope. However, he did not know who to turn to discuss this. By contrast, a family member of a young man who had both physical and learning disabilities was very happy with the continued ‘hand holding’ he experienced through the ULO. With respect to social services, however, it was much harder to get any continuity or response from someone who might know their situation, because of staff turnover.

People whose primary impairment was physical or sensory generally did appreciate the chance simply to take control over their own support. However, others desperately needed a higher level of continued contact, particularly those with cognitive impairments, or those who had a new impairment or condition. The following quotation is from a carer of a young man with a newly acquired sensory condition, who was struggling to adjust to the fact that she had suddenly to give up her work and support her son. The amount of support given seemed inadequate, and there were still many issues to be resolved for this family:

“I mean last October we had so many people here to give us support, and then come December they were all gone. It was every day we had someone from (the ULO) or social services and then all of a sudden no one.”
ULO carer

4.2.9 Organisational efficiency

Service users not only wanted support planners who listened to them, and made them feel good. They also wanted something to happen as a result of the interaction. Some of the most negative comments about past social services support hinged on the fact that things did not actually get done. People realised that social services staff were overworked and unable to respond on an individual basis as they would wish. One person said that it had taken over a month for the social worker even to type up and send
them a copy of the notes of the meeting they had had. By contrast, the ideal support planner, described by one satisfied ULO customer in Southampton, was ‘a mixture of imagination and donkey work’. The way ULO support planners kept in touch and made things happen was, in most cases, very highly praised.

One particular point here was that ULO support planners were felt to know what they were doing. In other words, they understood the system of personal budgets, they were seen as experienced in helping people with support plans, and they could therefore be relied upon. The vast majority of participants in the ULO group spoke about ‘experience’, ‘qualifications’ and ‘understanding the system’. However, it should be noted that this was not necessarily the case for people across all the impairment groups. The numbers are very small, but those with learning disabilities and their carers were not necessarily so impressed by ULO support planning as others were.

It could well be that family carers, who have a lifetime of experience in the service system, are impatient with ULO advice which seems to them to be unhelpful for people with learning disabilities. These matters deserve more investigation.

Of course, what helped most was when the support planner became a familiar face, someone who was known to the service user, and whom they could trust. There were comments both about ULO and LA support planners which related to the value of having a ‘single known person’:

“You really feel she’s fighting your corner. You’re really confident in her. She’s going to do her best for us.”
ULO participant

However, given that support planning only occurs at the start of a personal budget, the continued contact with a particular support planner cannot be assumed. The task is to establish trust and reciprocity in a short period of time, while also taking action and being efficient in explaining the system and making things work. It was precisely this combination of qualities which was highlighted by our participants:
“I must admit I did dread that – with social services, I’d be taken over. But not a bit of that at all. Much higher quality – people who were professional but caring. They weren’t just doing a job of work, and they knew what they were looking for, and they knew you better than you did yourself.”
ULO participant

4.3 Peer support

As we have explored in this chapter, the type of qualities appreciated in ULO support planning related both to personal skills, attitudes and knowledge, but also to the advantages of working within a small, purposeful organisational structure where professional bureaucracy could be minimised. However, it has to be asked whether these qualities are intrinsically linked to the nature of user-led support, which is at the heart of the SAB project. This was a topic for discussion at a meeting with all three SAB project sites in October 2009. People from one user-led organisation in particular talked about the lived experience of the support planner, as a disabled person. She said that there was a ‘deep understanding of lived experience’ within the organisation and that staff there would deliver to service users:

- A deep understanding of how to empower disabled people
- Equalising of power in the relationship between the disabled person and the organisation (very different balance of power from a Local Authority in relationships with people)

Notes of SAB site meeting, Oct 2009.

While not wishing to dispute any of that, another representative from a user-led organisation claimed that the element of lived experience was less important. Instead, he placed the emphasis on the underlying philosophy of the ULO:

“User-led organisations are essentially delivering a social revolution so disabled people have the same opportunities as non-disabled people and won’t settle for “no”. So they create a passion within disabled people to achieve a world that is equitable. Once you have an organisation that models this then people will get that passion”
Notes of SAB site meeting Oct 2009.
The question of peer support was therefore one of the central questions in our interviews with those who had had support from user-led organisations. We asked people about the identity of the person who had visited them for support planning, and also whether they knew anything about the organisation they had come from. Surprisingly, people in the LA group also often had something to say about peer support, largely because 13 people were recruited as members of a user network in Essex (DPUN), and others had experienced an element of peer support through voluntary organisations or through friendship circles or services.

4.3.1 Lived experience leads to understanding

Some fifteen people in the ULO group discussed specifically what peer support meant to them. The theme which dominated these discussions was that of the ‘lived experience’ of the support planner. In fact, when our participants mentioned that element of peer support, they nearly always focused on the actual impairment status of the support planner. Some support planners had had experience as carers, and that also mattered to many participants, who felt that they identified with the support planner. The following comment from a carer of someone with dementia typifies the reactions of others in the ULO group:

“And she’s good because she’d actually had her husband, or partner had had Alzheimer’s, and she’s been through this. So in a sense she’s particularly good because she actually knows. So she said, ‘If I were you, I’d do x, or if I were you I’d do y, or you might find this’ll happen, so you might want to think about…’ So that’s good’.”
ULO carer

The aspect of peer support which appeared to be most important to people was the fact that someone with similar experiences would have good, up-to-date and relevant advice and information. A carer of someone with learning disabilities was spoken of as ‘knowing the game’, and a disabled support planner was seen as someone who had also tackled the barriers that the service user was facing. To some extent, then, the information and advice people sought was matched by a feeling that the support planner
was not an authority figure, someone judging them or caring for them. Instead, having peer support from the support planner meant an equalising of the relationship.

Those in the local authority group, by contrast, often felt that their support planner had failed to empathise or understand them. One person in the ULO group recalled a social worker who could not understand what it meant for her to be in pain:

“It’s trying to explain to people what the problems are, and because they’re not in that position, they don’t really know. It can get frustrating.”
ULO participant

Of course, just because someone worked for the local authority, it did not mean that they were non-disabled. One carer did mention that the person who had helped her with the support plan ‘has a son who has similar problems himself’. Another mentioned that her social services contact had ME, and therefore was not able to make appointments for a long period of time. That was seen as the downside to being supported by a disabled person. However, these comments were outweighed by those about the benefits of being involved in organisations with other disabled people:

“To me what matters is that it’s another disabled person. Yeah, and who understands the system.”
LA participant

Having the lived experience of disability was primarily important to all our service users, then, because of that element of personal knowledge and information.
4.3.2 The disabled person as a role model

Moving beyond the practical value of having insider advice, a related aspect which was mentioned was that of having an inspirational role model. Two people in particular, both in the LA group, spoke about people they had met at a ULO

“My social worker said, you ought to go and meet (leading disabled activist). He’ll tell you about the social model for disability… It turned my life around.”
LA participant

One of our hypotheses was that peer support from a ULO support planner would mean more to people who were not already linked in with disabled people’s organisations and networks, than to those who were. A finding here was that the group of ‘newly’ disabled people tended to speak about disabled support planners in quite a disempowering, and sometimes even patronising, way. One disabled visitor was spoken of as a ‘boy’ (with the proviso that he must have been in his twenties) and three different participants mentioned the actual condition of the person who had visited them for support planning. Clearly, it takes more than one visit to identify in a powerful way with a ULO.

Although the element of peer support was central to the current study, we have therefore to conclude that individual support planning carried out by staff from a ULO is not in itself sufficient to create a sea-change in the thinking and awareness of a disabled person. However, coupled with ongoing contacts, membership and active contributions, individuals did experience greater control and an opening up of their lives through becoming part of a larger collective of disabled people with a mission for change.
Chapter 4: summary of main comparison points between LA and ULO groups

- ULO participants regularly experienced a genuine, empathetic approach from their support planner, and were challenged to think more deeply about their lives. Those in the LA group occasionally talked about similar practices, but attributed this to individual social services staff who stepped outside their role.

- Those in the ULO group felt they were treated as equals, and that support planners who came from a disabled people’s organisation were experts by experience. This generally did not happen at all in the LA group.

- ULOs were experienced as smaller, more efficient and professional in their approach to PBs than social services departments.

- Those in the ULO group were more likely to know their indicative budget before support planning than those in the LA group. They were also more likely to take up the option of direct payments.
Chapter 5: Continuing with the system: what happens after support planning

5.1 Time delays at the validation stage

Once the support plan has been completed and signed off by the service user, there is yet a further stage of the journey which still needs to happen, namely the validation of the support plan by social services. For those who have support planning with local authority support, it might be felt that this stage would run relatively seamlessly.

One concern would be that using the ULO support planning services could delay the validation, since the plan needs to get passed back from ULO to social services for approval. Therefore, the first question we investigate here is whether that hypothesis is borne out in any way within our data, based on the numerical information about time delays which we were able to obtain from service users directly. Not everyone was clear about the time it had taken for various stages to happen, especially if they were talking in retrospect about a support plan from more than a year ago. That was more often the case for the LA than for the ULO group. Therefore, the figures presented in Table 8 are simply averages of those who could give us at least an estimate of how long the various stages took.
Table 8: Time delays in validation of support plans and release of money

<table>
<thead>
<tr>
<th>Time in months</th>
<th>LA Group</th>
<th>ULO group</th>
</tr>
</thead>
<tbody>
<tr>
<td>Time from support plan to validation</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Time in finance department</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Total time</td>
<td>5</td>
<td>7</td>
</tr>
</tbody>
</table>

However ‘rough’ this method of calculation is, there can be no doubt that delays occurred for nearly all service users in this study, both at the validation stage, and subsequently at the stage of actually getting money released from the finance department. Issues about the finance department will be discussed further at the end of this chapter. These delays were of the order of months, both for the local authority and for the ULO groups. The slight difference between the total time taken for the ULO group, as compared with the LA group (amounting to about 2 weeks), was certainly not significant.

5.2 The effect of delays in validation and release of budgets

What effect did these delays have on the service users themselves? In both groups, the theme of ‘waiting’ was frequently mentioned, coupled with the stress that caused, as well as the necessity to put one’s life on hold. During that period of months, there was often no contact with anyone connected with social services. There was a general feeling of disempowerment in what people said about the validation process, much confusion about how validation occurred, and the frustration of having to wait for a result from a system in which they themselves had no say. People reacted to this frustration in different ways. Some were angry, but
others had consoled themselves with the feeling that at least they had taken one step and completed their support plan:

“Well, that’s the future. I don’t know how they…I just feel, at least our feet are in the door. At the moment we are coping.”

LA participant

In reality, a delay of several months in getting started on a support plan could be crucial for new service users. A typical response to this problem in Richmond, and sometimes in Essex, was for the service user and their family to set up the services, and start paying out of their own pocket, trusting that they would be re-funded when the validation and the budget started. For instance, one physically disabled woman in the LA group had a son who was funding her support to some extent. As he explained, she had been granted her ‘basic care’ funding, but was waiting to hear about the validation of funding for her to have a personal assistant and go out on visits outside the home. Clearly, that solution was not available to those who could not afford it. Another woman with physical and mental health needs in the ULO group had waited for months for similar aspects of her support plan to be agreed. In the meantime, she was restricted to her home, and relied on her teenage daughter to provide support for her to go out anywhere at all.

Given the effort and ‘empowerment’ put into producing a support plan, delays in validation did seem to cast a disproportionate shadow over the whole affair, for many of our participants. This was true both for the ULO and the LA participants. However, at least in the ULO group people felt that the ULO support planner was ‘on side’ and was fighting for the service user:

“(ULO support planner) was prodding the social services as well, so that did actually produce...she was very sweet, very nice, very calm.”

ULO participant

In the LA group, by comparison, people often did not use the word ‘validation’ and did not understand what it might entail. Further, some people expressed the view that the validation depended entirely on the luck of the draw, and the individual social worker who had been assigned to them. One of the effects of delays in
validation was to throw people back into a discourse about ‘their money’, and to consider that their own needs were perhaps not so important as those of others, as this woman with physical impairments explained:

“One thing is, at the moment, the situation here, nobody has more money, everybody wants more money. But you ain’t going to get it. If you’re too greedy, you’ll get less money, you know! You’ve got to be realistic in these things.”
LA participant

A related point was that the time delay in obtaining funding for a support plan gave it an unduly important status in people’s lives.

“But there’s no way of re-altering it because it’s there for life.”
LA participant

She had realised, perhaps too late, that she should have thought ahead and put items into her plan which might become necessary later on. That included money for transport, once she could no longer walk with mobility aids. The families of young people who had learning disabilities (or physical plus learning disabilities) more than once stated the obvious point that there was a continuous need for change and updating of their son’s or daughter’s plan. What they needed one year would not be quite the same as the next year. For instance, one young woman was attending a college course when she completed her support plan. However, by the time it was validated, she was back home with her parents, and looking for activities in the local area. It was less than useful to have specified particular needs on the plan, if these were out of date by the time it was implemented.

5.3 Practices across the three sites

Given that the time delays in validation appeared to occur across both the local authority and ULO groups in roughly equal measure, we also examined whether there appeared to be any particular patterns in each of the three areas in our study. Taking the ULO responses first, all three areas included participants who reported delays at the validation stage.
In Southampton, for instance, ULO participants appeared to be unclear about what was happening at the validation stage, but had great trust in the ULO support planner who (it was reported by service users) actually went to the panel and advocated on their behalf. In Richmond ULO group, things seemed to go more smoothly, and more than one person spoke of the efforts of the ULO support planner, who was said to have kept in contact and encouraged social services staff to complete validations:

“And they seem to have woken up social services. Because I get the impression she was on to them about my case.”
ULO participant

The Essex LA group had a fair amount to say about validation. This was possibly of course a reflection of the sample, since it included the people from DPUN (Direct Payments User Network), who had far more access to information about the personal budget process than others. One person, for instance, felt that much depended on the individual social worker, and several people spoke about the specific exclusion of individual items from support plans at validation. Non-eligible items included: hairdressing, petrol, social outings, ‘health’-related activities such as visits to hydrotherapy.

Clearly, matters of local policy are not amenable to change by the efforts of a ULO support planner. Nevertheless, good team work and explanation of cases at an individual level were important practices to foster in all three sites. In Essex there was one positive practice example described, where the ULO support planner had already spoken with the social worker, before taking the plan to panel. How frequently this occurs cannot be known from our data; however, it seemed to be a useful way in this case to ensure that the support plan passed more speedily through validation.

“That was so quick. That was really quick because she (ULO support planner) prepared (the social worker) for it and (social worker) was waiting for it - and that’s what I was worrying about… but (the social worker) looked at it, she said, no, all that you’ve got down there I totally agree with it all. She says, I don’t think we’re being unreasonable. And she said, I’m
really going to fight for this. And it went straight to panel, she come back and she said, all been approved.”
ULO carer

As we have seen, rather than slowing things down, the involvement of a ULO support planner could act as a catalyst. If independent support planners are deployed, then team work and collaboration at the validation stage would appear to be essential for a speedy outcome.

5.4 The role of the finance department

The role of the finance department emerged as a significant factor in the delays and disempowerment experienced by people in this study. Not everyone was aware of the actual point at which their plan was validated – i.e. when their plan went to panel and was agreed. Therefore, the precise amount of the delay that could be attributed to the finance department was only apparent to a minority of participants. Nevertheless, some interesting themes emerged.

The first one has to be ‘muddle’. For instance, one person with a physical impairment in the ULO group in Southampton explained that her budget had actually been paid into the wrong account. Others had also been faced with some unfortunate treatment from staff in the finance department. This man with a visual impairment explained:

“We get nasty letters sometimes from the finance department ….asking for this or asking for that. And one day we got - it was about four or five pages of columns of figures that they wanted for SDS and they sent that to Mark and assumed he could see. And I’ve heard this moan from so many people with visual impairment, that they know they can’t see - why send them pages of tiny writing?”
ULO carer

It seemed that staff in the finance department simply had not been trained to be aware of the purpose and ethos of a personal budget. Service users were left feeling that they had to defend their own right to the money, and that finance departments were begrudging
them that right. Some had support from their social worker in sorting out such problems, and others from the ULO. However, it would seem to be quite wasteful for any staff involved to have to spend time and energy, like one social worker, who was said to be;

‘Pulling her hair out, and screaming and shouting at the administration and financial departments to sort this out’.  
LA participant

The overriding message from PB users in this study was that the system, including both validation and release of the budget, should be streamlined, and many echoed the following view:

“They agree it, it goes back to the social worker - I don’t know - goes back to the finance board for them to agree. Well if one board agrees it at the council, why does it have to go all the way round the houses…why can’t they just bang, do it.”  
LA participant

Chapter 5: summary of main comparison points between ULO and LA groups

• Although both ULO and LA participants experienced long delays at the validation stage, and in the release of their budget, those in the ULO group were more likely than the LA group to be well informed and to feel that the ULO support planner was fighting their corner. By contrast, those in the LA group often did not know what ‘validation’ meant.
Chapter 6: Putting the budget into action

6.1 Views about the benefits of a personal budget

Both in the ULO and in the LA group, having a PB was a liberating experience for many people, who expressed frustration that they had not had one sooner.

“Yeah, it is a very, very strong thing there... because that is the difference between the two [before and after support planning]. I mean when I first told my mum about this (the PB), she said, if only you’d known this. You could have had all this previous.”
ULO participant

ULO support planning in particular seemed to be linked with a greater sense of control and freedom. For some people, like the speaker above, the arrival of the PB proved a life changing experience. Within six months that participant was not only controlling her support and managing her budget, but also confident that she would be able to review her own support needs and develop future plans without support. Participants mentioned a number of aspects of the choice and control that having a PB gave them, these included being able to pay family members, rather than having an outsider coming in, and gift style payments, which enabled a better sense of control. Having the money helped to combat depression, and so improved mental health and well being increased by social contact. An overall theme in both groups related to being able to be part of ordinary life, and feeling ‘normal’.

“I'll be able to...yeah, I thought while the weather’s nice. I mean I went out a couple of months ago on a really nice day when my mum was down, and we went along the quay. And it was just so nice. I felt normal. I know I wasn’t walking, but it was just nice to go out and move. And it be me doing it, not having...it’s annoying having people push you.”
LA participant
The flexibility and responsiveness of PBs was one of the most frequently mentioned themes, particularly by those in the ULO group. Flexibility meant that the budget could be spent when needed, for instance in one case an elderly person going out when the weather gets better or they were feeling stronger, or in another case when their carer was ill and needed others to help more. This was particularly important for people with fluctuating levels of pain, fatigue and mobility:

“With the personal budget I don’t have to have 3 hours a day; I can have more hours and then either add them onto next week, or take them off, or I can change it to the way I want.”
ULO participant

One important aspect of this flexibility was the ability to plan for emergencies or high stress periods in life, putting aside money without the fear of having it clawed back. The following quote reflected the fusion of the ordinary (planning for school holidays) and the extraordinary (emergency admissions to hospital) that could be part of disabled people’s lives, and which people said the PB could give them the flexibility to manage.

“If the boys wanted to be booked into a summer scheme over the holidays, or the Easter holidays, there’d be some money held back each month that I could think, right, I’ve got a little pot, if I go into hospital for a week that’s going to pay for (my PA) to sleep 5 nights of the week.”
ULO participant

Support could mean many things, not just hands-on professional carers. One person in this study, for instance, had decided that she would use part of her direct payment to buy a tea-maker for her own bedroom. That meant that, if a PA was absent or sick, she could still make her own hot drink without leaving her room. Another person’s support plan had included binoculars for bird watching, which enabled him to take part and win prizes in a national competition. These creative examples helped people to feel that their PB had given them real benefits in life, and were not necessarily expensive when compared with PA wages. Other examples we heard included spending the money to buy equipment to get in and out of the bath, have washing done by a
friend, go on holiday, get the computer fixed or travel to see a friend or relative. As one person said, quoting her support planner

“She said, it’s to make your life better and if going up to see your son would really cheer you up, so be it.”
ULO participant

Unlike many previous forms of social care, a personal budget was often seen as a way of becoming more active as a citizen. This felt important to participants in both the local authority and the ULO groups, as it was quite unlike previous types of care, where people felt demeaned, passive or having to ‘beg for support’. This aspiration had been realised within the ULO group in particular, by people using their PB to support them in volunteering roles including work with peer groups, teaching, audio describing and advice giving and others were acquiring skills and experience which might enable them to undertake paid work in the future. Some participants in the local authority group would have benefited, if they had been enabled to use personal assistants to support voluntary work. For one person voluntary service-user involvement in social work training had turned into paid work, at a rate which recognised the value of her live experience and bolstered her self esteem.

“That’s brilliant though, that you’re really offering something like that of your experience. So it makes you feel, yes, I do matter.”
LA participant

Participants in the ULO group were far more likely than those in the LA group to express their own identity as someone who values autonomy and independence:

“Don’t tell me what to do. Ask me, advise me, but don’t tell me what to do! My mum and dad learnt that very early in my life!”
ULO participant

A competing theme here was that of gratitude. Participants in the LA group were far more likely to be left with feelings of guilt than those in the ULO group, talking about having been ‘lucky’ to get their budget. Some people in both groups did express the idea that they felt ‘beholden’ to the local authority for their personal budget,
and several people mentioned that funding was being reduced, and how relieved they felt to have negotiated their PB. However, the LA group included the thirteen people in Essex who were part of the direct payments users network, and they too had made the strong link between having the money, being an employer, and taking control of one’s life:

“And for me to be in control of my money - which I like. And Gerry does the payment. So we’re employers - so that part we like.”
LA participant

6.2 Employing personal assistants

As mentioned in 4.2, participants in the ULO group were more likely to be direct payments employers than those in the local authority group (30 participants in ULOs, 17 participants in LAs). This was an extremely important aspect of the experience of personal budgets.

It is a difficult thing to have a paid helper or carer come into your home, and several participants mentioned that ‘they didn’t like people coming in and out’ (ULO participant). Some also discussed how hard it was to accept that you need help:

“I like being in control. I like to be able to do bits and pieces I need to do how I like to do them. To let go of that in any sense is horrendous. But now I have it’s so…I feel like I could sort of like bounce. You know what I mean? It’s so weird. I’ll get used to it but at the moment it’s still just really new for me.”
ULO participant

This woman, like many others in the study, wanted PAs who were sensitive, friendly and who stepped back when not needed. However, these were not necessarily seen as ‘professional’ skills. At least ten participants in the ULO group had employed PAs who were already familiar to them as friends (N=6) or relatives (N=4). However, only one person in the LA group had employed a friend. This seems to indicate that ULO support planners were more likely than a social worker to help participants express what was
important to them, and to step outside the framework of qualifications and experience. Although a few people in both groups talked about the need for PA training once employed, far more important, for most people, was the fact that they felt relaxed and comfortable with the person who came into their home.

Even for those who chose their PA through a more conventional route, there was a strong theme of friendship and familiarity. Participants almost universally wanted a PA with whom they felt comfortable and relaxed. That did not mean necessarily sharing their lives as one would with a friend. Nevertheless, PAs frequently were said to provide social company, as well as support:

“She can come here and even if I just have a cup of tea and talk to me and do nothing for the two hours, just talk to me. That’s OK, because it’s what I want.”
ULO participant

An equally important theme was that of longevity and sustainability. The local authority group, it will be recalled, included nine participants who were already direct payments users. Some had employed personal assistants for as long as fourteen years, since the Direct Payments Act was first passed. It was remarkable how many of these had kept long-term PAs who had stayed with them over the years. Even those with more recently acquired impairments had often employed a PA who had then become something like a family friend. One of the participants was happy to have helped the family of her PA, and another mentioned specifically the reciprocity of the relationship, speaking of it as an ‘intra-relationship’. Her PA was also a mother, and so both understood each other’s needs if there was an emergency with children.

The other dominant theme about PAs was flexibility. This related both to flexibility of hours, but also to the way in which PAs could be deployed to do what the service user needed at that point, including provision of transport, social company, going on outings or shopping. By employing your own PA, participants said they had that control to decide things on the spur of the moment, and to ask a PA to step in. There were frequent comments about flexibility, both in the ULO group and also amongst those in the LA group who had been longer term DP users.
“There are times when I get on the scooter and go round the village - I did that the other day, we went round the co-op, Jan walked with me then we went round...it was really, really nice... But then I might do that and then not feel up to doing anything else for the rest of the day. So it’s balancing what you want to do.”
LA participant

Leaving aside for the moment those nine longer-term DP employers, of the 13 who were part of a network, those in the LA group who had chosen a direct payment were far more likely than the ULO group to mention problems in finding staff. They had sometimes worried about availability, felt that they had been extremely lucky in finding anyone at all, and also had experienced some problems in interviewing and choosing their staff. By contrast, those matters were often eased within the ULO group. Two participants had had direct recommendations of personal assistants (PAs) via their ULO support planner, and PA registers had been used more often, where the ULO was mentioned as a source of ideas and ‘matching’ of PA and customer. These ULO services are of course available to anyone in the area. However, through having ULO support planning, it seemed that service users were encouraged to ‘have a go’ at interviewing a PA with the support they needed.

“I do trust her. From the moment she sat here and I interviewed her, I knew within 2 minutes that she was going to be the absolute perfect person. I’m always a person who makes a decision - I either like somebody or I don’t - very quickly.”
ULO participant

Finally, it should be mentioned that PAs were also very important for people who had a learning disability as their main impairment. These people included amongst them six who employed PAs, and for all of them, this was with parental support. The main themes of friendliness, informality and flexibility were even more important to this group; in addition, PAs often needed to learn the subtle skills about motivating and advising their employer, without taking control. From the evidence of this study, parents and family members were well aware of these issues, and maintained roles
as managers of their son’s or daughter’s services. However, their comments indicated that there is still a long way to go in providing support to people with learning disabilities to be effective employers in their own right.

6.3 Using agencies or organisations

24 participants in this study used their personal budget exclusively to buy in services from an agency or an organisation (13 in the local authority group, and 11 in the ULO group). The choice to use an agency was often made explicitly because of the fear of taking on the responsibilities of being an employer. Additionally, there were three direct payments employers who also spent part of their budget to fund additional support from an organisation or agency. The services that were bought through organisations could range from one-one support from organisations dedicated to services for people with learning disabilities, to cleaning services, or agency home care. Service users who had agency or organisational support, wanted support planners to recommend agencies which could offer:

- Consistency (having one known person, whether that was a cleaner for a physically disabled person, or a PA for a person with learning disabilities);
- Managers that were available and helpful in case of problems;
- At least a degree of personal choice over the actual staff who were allocated.

Since there are distinct issues arising for different groups of participants, we will divide this section into a) people with primary physical or sensory impairments; b) people with learning disabilities.

People with physical or sensory impairments

We had plenty of evidence from both ULO and LA groups that they had been advised of possible agencies and organisations by their support planner. In particular, ULO participants mentioned the support planner getting on the phone, during the visit to the service
user, to contact agencies and find out comparable hourly rates. Particularly within the ULO group there was still, in other words, a sense of choice and control about deciding which agency to go for:

“She got all the printouts about different agencies, she brings all of that when she comes. And she was sorting it through with me to see which one would suit me, which one is expensive, which one is more expensive, and which one is reasonable. She did all of that with me, everything.” ULO participant

Many of the direct payments employers themselves had past experience of using agency support, or indeed one-one carers supplied directly by the local authority. Without exception, they described the benefits of having PA support which was under their own control, and listed the disadvantages associated with agency care, which included inflexibility, agencies which insisted on hours to suit their staff (rather than the client), lack of personal involvement by the carer, and indeed lack of consistency. The carer who turned up could be unexpected or unfamiliar.

On the whole, the tales we had of current agency or organisational support did not match that bleak picture. Indeed, the agencies or organisations used by people in this study appeared to have developed at least some person-centred practices. For instance, this included the opportunity to choose and engage with a particular carer or personal assistant, as well as the attempt to meet exactly the hours required by the individual client. One participant with physical impairments, in the local authority group, could not have anyone in the house who had been smoking, or had been in a smoke filled atmosphere. That was a medical necessity, as it triggered her asthma. The agency from whom she obtained cleaning and personal care support needed to find a carer who met her requirements. The service user had had to insist on this, which required some interaction with the agency. However, because of her personal budget, she was able to bank extra money which she accumulated when her personal carer was not available:

“I want to stick to one carer. So I phoned up (social worker) again, and I said ‘If stick to one carer and that carer’s not
available, am I allowed (to say no) - is that going to cause hassle?’ Because now I keep my money…”
LA participant

Participants with physical impairments, who sometimes required support with housework, and/or personal care, wanted to have people in the house who were pleasant, understanding and friendly. More than one person spoke of the social value of having a cleaner who arrived at predictable times and could provide company as well as practical support. For them, it was important that they felt they could get to know the person who was sent from the agency.

People with learning disabilities

When a family carer was involved in managing the budget, organisations and agencies were often chosen because of the perceived benefits in management. Those arguments tended to outweigh the problems that might occur through lack of choice. Nine people whose primary impairment was a learning disability bought in services from a specialist organisation. In one area, the choice of organisation was dominated by one major provider, and, according to parents’ accounts, the way in which one-one support was delivered was by deploying staff who were still contracted mainly to work in a group home. This meant that they could not guarantee each service user would be allocated one particular personal assistant, and one of these parents acknowledged this was not ideal. However, as she said at the first interview, they were able to change things if there were problems:

“There was one person she didn’t get on with, and we told the person who organises Annie’s care that it didn’t work out, so we’ve never had them again.”
LA carer

An advantage of buying in support from an organisation, discussed by several of these parents, was that their son or daughter could join in group activities provided by that organisation with greater ease. For instance, one person went on a holiday project, and others used the group home facility for short breaks. This was not unpopular with the people with learning disabilities themselves, as
far as we could ascertain. It enabled them sometimes to have a social life and meet up with friends.

However, on the second visit to some of these families, things did not appear quite so rosy. The family mentioned above had found that the support was sometimes provided on the organisation’s own terms, rather than based on her daughter’s needs. They also were aware of the high hourly rate being paid to the organisation, and the fact that they would be able to make the budget go further if they managed it themselves. Another family had also chosen to pay an organisation for PA support; in fact they bought in from one large national provider, and another smaller specialist provider. However, on the second visit they mentioned several problems that had arisen. For instance, support workers were charging the service user for their travel time, as they were sometimes working with other clients at a distance. This also resulted in support workers sometimes arriving late, which posed a distinct problem for one service user, whose impairment meant that she needed routine. Another person described support workers who arrived on foot, rather than by car. This meant that the parent was still involved in providing transport, if her son wanted to go out with his support worker.

Not everyone with a learning disability lived with a family carer. In fact, there were two participants who had previously been living in group homes, and had chosen over a period of time, to move out of their home and try a more independent lifestyle. What was most notable for both of them was the important role played by the manager of the organisation running their group home; it was that manager who had in effect provided support planning. In both cases, as far as we could ascertain, that had included a series of person-centred meetings to include the service–user in decisions, support to find a new place to live, and choices offered to the service user about continuing with staff that she or he knew and trusted. While this seemed to work well in one instance, there were also dangers of providing support planning which was bolted on to the organisation. The second service user in this situation was lonely and depressed, relying still on telephone contact with her former staff.

Skills and attitudes of PAs were vital, particularly for those with mental health needs, learning disabilities or dementia.
Communication issues may mean it takes longer to get to know the service user, and there were more subtle issues which the support worker had to get right. These included understanding particular syndrome-related needs, as well as the personal preferences and style of communication of a young person with autism or the memory problems and inconsistencies of an older man with dementia. Support planners needed to be aware of organisations which could supply different types of specialist support, and where they had managed this (e.g. in Southampton), participants were very satisfied.

6.4 Service users managing their own budget

Having a personal budget and/or a direct payment is not like coming into an inheritance. A personal budget is public money, which the service user is responsible for managing. That is certainly how all our participants experienced it, and this woman with a physical impairment spoke for many:

“Although it’s allocated to me, at the end of the day it’s not my money, is it. And if I do it wrong, they could take it away. So that’s why I want to do everything by the book and to the letter.”
LA participant

In this section we will summarise the evidence we had about how people felt about being managers of personal budgets, whether or not they had taken the money as a direct payment. The vast majority of disabled people who managed their own budget were those with physical or sensory impairments, although our sample also included a small number of people whose primary impairment was a mental health need. Of those, three were managing without the assistance of a carer. Given that our sample for the local authority group included 13 people who were members of a direct payments users network, we were clearly biased towards individuals who would stand a chance of being successful direct payments employers. However, as we shall see, even they experienced considerable difficulties, as well as successes.

Several service users explained that they already had a skill base around finance and management, on which they could build. At its
best, a personal budget gave them the opportunity to re-awaken past skills and to prove their capability in management tasks. This gave some service users a sense of pride and control. For instance, one woman said: ‘I am very fussy with my money, my account looks healthy’. Some of those who were direct payments employers took some pride in their skills:

“It is very complicated. But if you are used to working with technology and used to working – because I’m actually a qualified book keeper. And I also do my own books as well for it. So not only do you have to do the payroll you also have to do the books as well.”
LA participant

Those who had long experience of direct payments had worked out systems which suited them. However, this included them relying on the services of particular personal assistants, who (in addition to providing personal support) took on the role of monitoring and recording financial matters. Arguably, there could be a conflict of interest there, and a personal trusting relationship was vital to the success of such arrangements. One longer-term direct payments user also had a dedicated accountant, whom she paid out of her budget.

In taking on a direct payment, disabled people said that they were breaking away from paternalistic services which were provided by local authorities. A frequent experience in the past was that of powerlessness, and many people looked back at the time when they did not have the choices they needed, and had to fight for services that suited them. The opportunity to have control over a budget, arguably, should reduce that need to continue fighting for support. On the whole it did, and service users talked about the ‘freedom’ and control, which were vitally important in their lives.

6.5 Carers’ responsibilities in managing the budget

Exactly half of the 80 participants did not manage their budget or direct payment themselves, but had family carers who took on that role, and so many of the points about management are about the views and experiences of those carers. Table 9 shows how many
participants in this study had personal budgets which were managed by carers.

Table 9: Family carers’ involvement in managing budgets

<table>
<thead>
<tr>
<th></th>
<th>Total numbers</th>
<th>Carers managing budget</th>
<th>Managing budget independently</th>
</tr>
</thead>
<tbody>
<tr>
<td>LA group: direct payments employers</td>
<td>17</td>
<td>6</td>
<td>11</td>
</tr>
<tr>
<td>LA group: using agencies or directly provided care only</td>
<td>19</td>
<td>10</td>
<td>9</td>
</tr>
<tr>
<td>LA group: aids and adaptations only</td>
<td>2</td>
<td>1</td>
<td>NR</td>
</tr>
<tr>
<td>ULO group: direct payments employers</td>
<td>30</td>
<td>15</td>
<td>15</td>
</tr>
<tr>
<td>ULO group: using agencies or directly provided care only</td>
<td>11</td>
<td>8</td>
<td>3</td>
</tr>
<tr>
<td>ULO group: non take-up of PB</td>
<td>1</td>
<td>0</td>
<td>NR</td>
</tr>
<tr>
<td>Totals</td>
<td>80</td>
<td>40</td>
<td>38</td>
</tr>
</tbody>
</table>

From the service user’s point of view, the shift towards personalised services often brought the locus of control closer to home, but particularly for those with cognitive impairments or mental health needs, it also brought the family carer into sharper focus. The relationship of trust with a family carer was explicitly mentioned by several service users, including a young woman with physical and learning disabilities, an older woman who relied on her son, and a man with dementia whose wife managed his budget. One older man with a physical and communication impairment trusted his daughter with his money, even though he did not understand at all how the personal budget was worked out:
“No. Hopeless, money… money… pension… deal… shopping… carers, carer.”
Daughter: “OK. My dad has trouble understanding what aspects he has to pay for himself, out of his funds that he has coming in, like pension credit and stuff, versus what is being paid for out of the personal budget area.”
LA participants

As the wife of a man with dementia explained:

“For Bertie there's gain, whereas for me it's probably not, because I'm still struggling with the paperwork.”
ULO carer

Family members of younger people with learning disabilities were often aware of the dominance of their own views and contribution, through their budget management. In these cases particularly, managing a budget was not just about keeping receipts and logging expenditure. It was far more about brokering a whole service for their relative, and included for instance:

- interacting with social services departments and finance departments
- employing and selecting staff
- finding activities which their relative might enjoy
- finding options for new living arrangements.

Particularly for those managing large packages of care, these duties looked very much like service management. For instance, taking responsibility for personal assistants was one of the key management functions which parents sometimes fulfilled, if their relative had opted to take their personal budget as a direct payment. Some of the service users in these cases had had advocates, as mentioned in Chapter 2, and this was one of the ways in which family members could ensure that their relative at least had some kind of independent voice in what was happening.

Some carers were long-term organisers of their relative’s services, while others were expected suddenly to learn a whole new set of skills. Many of them said that they were building on skills in their present or past job (for instance, bookkeeping skills, financial management skills). However, bringing those skills together with
the necessity to keep the service user ‘in control’ is a very subtle and sensitive task. Many of them faced this challenge with great resilience. One mother, for instance, who had a son with profound learning disabilities, was keen for him to become more independent of her as he approached adulthood. To that end, she made sure that his personal assistants could relate to him well, listen to what he wanted, and work as a team to ensure that he had time away from his mother. Other carers in similar situations were also keen to have others involved in the management and decision making, including circles of support and trusts.

Nevertheless, the vast majority of the family carers in this study were not only taking on the management of a personal budget, but were also still involved in the actual delivery of care to their relative. Not all carers were ‘naturals’ at managing the financial aspects of the budget, as this mother said:

“I’m a nightmare with the paperwork, I’ll tell you. I never used to be. But I’ve just...as I’ve said; the last two or three years, everything and anything can keep going wrong, it has.”
ULO carer

Moreover, several carers said that they had not had a choice in taking on this level of responsibility. They knew that, if they wanted their relative to have freedom of choice, that they would have to manage that process:

“I think I got the impression if I didn’t have the budget [that social services would do it]. Because I do work for two days - and I want to keep in the work place to keep my foot in the real world. And I’d be quite happy for her to go to a day centre for two days, but there is no day centre.”
ULO carer

6.6 Brokerage and service provision

While a personal budget is intended to give choice and control to the service user, it can only do that within the confines of the opportunities available. It is not necessarily the role of the support planner to engage with the detail of how the personal budget is going to be spent – particularly at the level of individual choices of
activities. As we have seen, those with physical impairments on the whole were happy to have flexibility within their plan.

For some of our participants, however, “mainstream” activities were only partly meeting their needs. A personal budget is intended to give the opportunity to choose more traditional services, as well as PA support, and various service users in the local authority and the ULO groups mentioned group or congregate services which they valued. These included, for instance:

- A charitable organisation that provides educational, vocational and therapeutic services to physically and sensory impaired adults and their carers
- A provider service primarily aimed at people with learning disabilities, who want to work with animals and horticulture.
- A drop-in café club for people with dementia and their carers, provided by a voluntary organisation

In order to construct a meaningful support plan, people of course needed information and advice, to know that such activities existed. Both in the ULO and in the LA group, some participants did mention that they had received such advice initially. However, those in the LA group tended subsequently to lose contact with their support planner, while those in the ULO group often spoke of getting continued advice and guidance. Particularly for people with learning disabilities in both groups, much of the value of having a support plan was about having the flexibility to access a range of activities, work training (two people), education (four people), and leisure related projects or clubs (five people).

Problems could arise here for our participants, however, not only due to lack of information about what was available. An arguably greater, fundamental problem lay in the closure of specialised services, due to individualised support. This represented a real threat, as one carer expressed eloquently:

“That’s what makes me so cross. They’re very happy to give you money, but there’s nothing to buy with it, because there are no services. And my view is, it’s very easy for the government to give you money, but they don’t have any responsibility for any services.”
ULO carer
Enabling PB users to choose group services means reorganisation in the provider sector, which was certainly beyond the remit of the support planners in this study. However, the issue of service closure did affect different groups of participants. For instance, although we had very few participants with mental health support needs, as mentioned earlier the study included two people in the LA group who had previously enjoyed using a day centre, which became earmarked for closure.

The group of young people with learning disabilities who were (broadly speaking) making the transition to adulthood mostly expressed satisfaction with the arrangements that had been made for them. However, it should be remembered that the majority of these young people were still living at home. One parent, for instance, had researched various options for living arrangements for her daughter on returning from college. However, on the second visit, we found that none of those had been found to be suitable. While the service user therefore said that she was ‘happy’ to be back home, the parents had had to take on renewed and increased responsibilities in organising her support plan and her life.

At the second interview stage, one of these 13 young people had moved out from his parents’ home into supported living accommodation nearby. This had been done with the support of his parents primarily, but also a circle of support and a person-centred planning process. The researcher was enabled, through his father, to meet up with the service user on this second visit, and it was quite clear that he was both excited, settled and happy with his new home. He had a photo communication book relating to the new environment and support staff, which he used to talk about what he preferred, and was happily engaged in a new daytime activity which engaged his energies. The parents themselves were still very involved in organising this young person’s support plan; they also felt quite bereft and lonely themselves, with his departure. However, the process had clearly been managed so that this move could occur with full parental support. Another young woman had also recently moved into her own rented flat, and was one of those supported by the same organisation providing her former group home. Both these young people provided reminders that support planning must take into
account the wider context, and the provision of support which can change and adapt to be sensitive to the developing needs of the service user. One parent had experienced precisely that type of support from the ULO support planner in Southampton, but was currently not assigned a social worker to take on that role. She spoke for many in describing exactly what was needed:

“(ULO support planner) used to come up with ideas; ‘Well why not this, why not that…?’ - ‘Oh yeah, good, good.’ Because you actually need somebody to come up with a few ideas. It got us thinking a bit more. I mean the next big question is housing, and that sort of thing. But even if he came up with an idea that we laughed at, and said, ‘You must be joking,’ at least it made us think, well actually, maybe that might happen (in the future).”
ULO carer

6.7 Support to manage the budget

Another very general complaint about the outcomes of a personal budget related to the feeling of insecurity and worry generated by anxieties over what could be bought. Some items which participants wanted on their personal budget had been definitely excluded, especially with the argument that health services were provided by the NHS. However, travel and petrol money, hairdressing appointments, and payments for PAs’ entrance fees were all mentioned as items which people worried about. Generally speaking, there were no particular sources of advice on these issues to participants from social services departments themselves. Therefore, several participants in the ULO group continued to turn to the ULO for such advice, and those in the Essex DPUN network gave each other support to work through these issues.

One of the most frequent words used, in connection with managing personal budgets, was ‘stress’. This was true for both service users themselves, and for carers who were managing the budget. For some carers of older people who were recently disabled, their lives had been turned over. In some cases, the relative who now had dementia was in fact the one who had always managed the finances in the family. In taking on budget management, then,
some of these carers were stepping into brand new roles in life, in addition to managing the changed relationship with their relative. Even for those who were coping relatively well, there could be a massive amount of extra work, and people spoke about being ‘overwhelmed’:

“I've got a folder this size with all these bits and pieces in it. Not to mention what’s on the computer, and I’m not very computer literate.”
ULO carer

The technical problems faced by carers and service users who were managing direct payments included muddles with payslips, not having kept the correct accounts, and confusion over who paid for ‘directly allocated’ services. Those who were carers of people with lifelong impairments were perhaps used to this level of back-up work. However, they too feared the increased responsibility, and several had chosen not to take up the responsibility of a direct payment, precisely for that reason.

Four particular types of stress for service users themselves should also be mentioned in this section. One was the stress of relying in ILF funds, as has been mentioned before. The second stress related to the pooling of personal budgets, which had happened with a group of people with mental health needs. The person who took on the management of that arrangement felt a great sense of responsibility and worry, since he had to be aware of the budget arrangements relating to all the other service users in the scheme. A third very frequent concern related to worries about what expenditure was allowable within the budget. Finally, the difficulties mentioned by service users themselves included, naturally, the effects of their own impairment. Many people have conditions which fluctuate, as this man described:

“If I’m having a bad day, sometimes looking down, or looking at a piece of paper makes me feel really bogged down by it.”
LA participant

In these situations, continued support is absolutely vital, and participants spoke about the support they received from user-led organisations, as well as from networks or organisations of disabled people, and from voluntary organisations. These types of
continued support deserve further exploration, but from the hints we had in this study, what people appreciated was a sense of camaraderie with other disabled people facing similar problems, and a ready source of advice in case of problems. By contrast, unfortunately, those who had no such contacts said that they were reliant on fruitless phone calls to social services departments, were sometimes passed on to finance departments, who had no knowledge of the case, and had to re-explain their issues each time they called and spoke to a new social worker. The following comment from a woman with a physical impairment in Southampton sums up the needs of many:

“Now I just speak to (ULO support planner) because he’s sort of at the centre of it all, dealing with people who have disabilities he is like the core person to speak to. Or anybody from (the ULO), but he is sort of like the spokesperson for me personally. So he would be the go-to person.”
ULO participant

Chapter 6: summary of comparison points between ULO and LA groups

- People using ULO support planning were more likely to employ friends or family, and to adopt a flexible approach to their support plan. By contrast, those in the LA group sometimes talked about the difficulties of finding PAs, and were also more likely to feel constricted by their support plan.

- People in the ULO group appreciated being able to go back to the ULO to ask for advice on managing their budget, and also liked ongoing trouble-shooting. By contrast, those in the LA group were often left without any social services contact.
Chapter 7: Independent living outcomes

In Chapter 2 we presented a brief picture of our sample of participants, including what they said about who they were, and who they had been. They also told us about their goals, and what was important in their lives. In this chapter we explore independent living outcomes for these participants and ask whether ULO SAB services helped.

7.1 Achieving greater choice and control in different areas of life: how did ULO support planning help?

We used two measures with participants during the study:

1) As part of each interview we asked participants to score their satisfaction with levels of choice and control in their lives, taking nine areas of daily living, and one overall category of independent living. At the first interview we asked participants to score their satisfaction before and after their support plan came into place, using a Likert scale of 1 to 5 for each area of life (see Appendix D). Later, at the second interview, we asked participants to score the same areas again in relation to their current situation.

2) At the second interview, six months later we also recorded the reflections of participants on whether they were going forward (or not) in relation to those goals, outlined at the first interview.

While recognising that this is a relatively crude measure of satisfaction with choice and control, this enabled us to gain a picture both of any initial change in satisfaction as the support plan came into place, and to see if there had been any changes as the support plan ‘settled down’. Therefore, the changes in scores were often more useful than the absolute score, and in much of the analysis, we aggregated the scores over 3, in order to identify ‘positive’ views. In completing the scale, we were also able to ask
participants to talk about the reasons for their response, and to explore the issues that faced them. These comments are discussed in the following paragraphs, while the numerical tables on which they are based are presented in Appendix D.

7.1.1 How far does my support plan enable me to exercise choice and control at home?

The ability to purchase personal care, and to have choices about who comes and when was highly valued. As is apparent from Table 10 (App D), there were no differences at all here between the ULO and the local authority group. Generally, there was a strong tendency to rate personal budgets highly in relation to their impact on home life.

However, the reasons for these responses were mixed, and seemed to depend on the local authority in relation to practical aids and equipment. Several people were using their PB to purchase equipment to aid their mobility and independence in the home, so circumventing the rationing of equipment and grants, although others were still struggling for the lack of basic equipment. Having carers in the home could, arguably, decrease the feeling of autonomy within one’s home life. However, PAs were also felt to increase the chance to do things for oneself. Two people employed carers who were culturally appropriate for their needs, one in the LA and one in the ULO group.

7.1.2 How far does my support plan enable me to exercise choice and control in relation to work and income?

Compared with choice and control within the home, fewer people felt totally satisfied that their personal budget (PB) gave them choices about work. However, there was still an even spread over the ULO and local authority groups here, and the most popular score at the first interview was still a ‘5’ (Table 11, App D). Unlike with home life, though, high ratings were not necessarily attributed to the PB. At the second interview, only ten people said their opportunities to work had increased, and for fifteen it had decreased (Table 21, App D).
Because we had such a diverse sample in this study, our participants included those who had been forced to retire from careers they valued, as well as young people who were still waiting to get onto the job ladder. In discussing their choice and control about employment, a common theme nevertheless related to achievement and contribution. Employment was not just seen as a source of income. Sometimes the PB made it possible to volunteer, which bolstered self esteem. Occasionally it also was used for support to work. For instance, one young man was carrying out a voluntary work placement in car repair, another training in farm work. Both valued these opportunities highly. Older people in the sample also felt that the opportunity to make a contribution was important, and many in both ULO and LA groups had got involved in supporting other disabled people in different ways.

However, financial issues were important for several participants, and a personal budget was often appreciated because of the increased ability to ‘pay one’s way’. We heard the difference access to funding made to participants, although this differed across the sample, at least partly in relation to their levels of funding and previous situation (there appeared to us to be a considerable disparity between people as to who got what sort of things funded and to what level). Many people still emphasised that money was very tight.

7.1.3 How far does my support plan enable me to exercise choice and control about relationships and social life?

The chance to meet and keep friends and relations was vital, and on the whole, in both groups, people felt that their personal budget enabled them to have a better social life. 47 out of 70 respondents gave this aspect of their life a score above the ‘mid’ range of 3, at the first interview, indicating that the support plan would improve (or had improved) their social life (Table 12, App D). This was at least partly because a large number of participants in both groups were more isolated in their lives than they would have liked, and craved human contact. Having a personal assistant, as was
mentioned in Chapter 6, was often seen as a way of having regular social contact in the home, and therefore a richer social life.

The majority of our participants had family members, as well as friends, who were acting as informal carers to them. One of the important issues for them was to free some of these people from their caring role, so that they could enjoy a relationship on a more ordinary footing. For instance, one young woman with a physical impairment had previously relied heavily on her mother to come and help out in her flat. Once she had a PB, however, she could employ personal assistants directly, and explained, ‘(my mum) can now just be a mum’ (ULO participant). Others said very similar things about partners, children and grandchildren. One couple mentioned that the husband had had a carer’s assessment and been given funding to go on holiday with a friend. Both husband and wife were delighted about this, although mentioning that they’d felt guilty asking (LA participant).

We heard frequent stories of funding being used to travel to see relatives and friends. The choice to be able to keep in touch with old friends, and the possibility of arranging activities and socialising with new friends, was extremely important to everyone. However, many were also limited by their impairment, in ways that did restrict their social life. For instance, more than one couple where a partner had dementia explained that socialising had become more restricted, since the person with dementia found it impossible to keep up with the conversation. Some of the barriers people faced were complex, and included lack of transport and accessibility issues, as this woman with a physical impairment explained:

“When I had the car, and I had my live-in carer, she used to put me in the car, and I used to drive to the friends, the friends used to meet me out there and take me in, you know. The friends have to help me. Some of them aren’t in the position – I haven’t been to my brother’s house for five years, he’s got a very high step to go in. Before I could stand up and take that step, now I can’t. And he’s not in the position to push me up the step.”
LA participant
7.1.4 How far does my support plan enable me to exercise choice and control about taking part in society?

The slight trend for ULO participants to score higher rates is reversed here (Table 13, App D). However, it must be recalled that 13 of our participants in Essex were recruited via the DPUN network, and so were by definition taking part already in social and political activity.

Being part of their community requires disabled people to be able to get out of their homes and into wider society, and some of the barriers they faced were described in Chapter 2. Participants told us they had used funding to enable them to join classes and social groups, and PAs became companions for many people. One young person with a learning disability in the local authority group illustrated this, explaining that going out to the pub with his PA had acted as a ‘starter’, enabling him to meet and make ‘real’ friends there. That means that he now no longer needs to go with the PA, but can simply go and meet his friends like anyone else.

The topic of participation linked strongly with that of employment. As mentioned above, a large number of participants were active in their voluntary contributions to society, and in particular to the world of disability. For instance, one man had become an advisor to the BBC on audio-description, and several were acting as service-user trainers. A problem faced by many of our participants related to funding being withdrawn from voluntary activities, which then became threatened. That included DPUN as well as educational activities.

7.1.5 How far does my support plan enable me to exercise choice and control in getting to where I want to go?

The scores for ‘transport’ are slightly lower than some of the other areas (home life, relationships), indicating that the problems faced in transport were perhaps greater. In fact, 45 out of 67 responses gave ‘transport’ a score above 3 at the first interview (Table 14, App D), showing that they felt their support plan was helping them
in this area. Eleven people also shifted their scores upwards in the second interview (Table 24, App D).

Accessible public transport was extremely important to many participants. However, even in areas where some of the transport was accessible, the problems were not always resolved. In Essex, we were told of one area where the accessible bus only went to Tesco, and about railway stations, where there is no-one to assist a disabled passenger. Travel nearly always required a degree of pre-planning which took away much of the ‘choice’ if not the ‘control’.

Those with physical impairments who did not use wheelchairs sometimes had the greatest problems, and needed door-to-door transport, so that they could get to their destination independently. For many of those, satisfaction was expressed at the PB freeing them of struggles to use public transport, in some cases through being able to fund use of a taxi or running a car, or helped to use public transport with PAs. Having money to spend on taxis was also mentioned as important, since it took the guilt out of asking family and friends for lifts.

Those without physical impairments also had transport issues, which their PB had sometimes helped with. One person with a mental health need for instance, had a lump sum in her direct payment which paid for a car. That, as she said, was a life-saver for her, and had transformed what she could do in her life. People with learning disabilities also needed transport, usually because of the safety issues associated with using public transport unaided. However, where a PA could assist by providing transport, this actually freed up parents, one of whose many tasks was often as ‘chauffeur’. Notably, not a single participant in this study mentioned transport training as part of their PB package.

7.1.6 How far does my support plan enable me to exercise choice and control about my leisure?

People painted a similar picture on ‘leisure’ as on relationships and participation. 43 out of 62 participants gave this aspect of life a score above 3, showing that the support plan on the whole was helping people pursue leisure activities (Table 15, App D). Fifteen
people shifted their score up at the second interview, although 13 shifted it downwards (Table 25, App D).

Leisure might sound like an extra, but in this study, people spoke wistfully of the things “I used to do when I was me”, and many of these things were the more creative aspects of their personalities. We heard satisfaction expressed by those people who had been able to use their funding to support their own creativity, whether that was sporting, practical, artistic or intellectual:

“(With my PA), I can go to the gym because it helps my condition, and it also maintains that independence; then people know who I am, what I’m doing, where I’m off to.” LA participant

‘Leisure’ was one of the main items on the agenda for many of the people with learning disabilities, and linked strongly with socialising and development of skills. For instance, it is hard to know whether a visit to a forest centre is to do with learning new skills or socialising with friends. Quite often, it implied both. Personal budgets had therefore really helped some of the younger people to build up their interests and social life at the same time.

7.1.7 How far does my support plan enable me to exercise choice and control over my health?

Personal budgets were not felt to make such a difference to health issues. About half of those who answered this question gave their score on ‘health’ as higher than 3 at the first interview (Table 16, App D). However, 18 had decreased their score at the second interview, compared with 16 who had increased (Table 26, App D). We heard about struggles with NHS systems, and both good and bad relationships with a range of health professionals. There seemed to be nothing that the PB could do to improve these. Sometimes it was very hard for participants to rate their ‘choice and control’ about health matters, since their experience was coloured by an actual deterioration in their health. This was challenging, and with more than one participant, we explored what health means within a model of independent living. Not everyone wanted total responsibility:
“I can’t go and see my GP, because every time I see my GP they say, well I can’t give you antibiotics, we know they don’t work…So I end up feeling that it’s very much my responsibility. I’m too much involved in it when really I just want someone to tell me what to take and let them do the work.”
LA participant

Another issue which affected feelings of choice and control was the problem relating to restrictions on PBs being used for health therapies. Where participants were able to use their PB to fund therapies (e.g. chiropractor, hydrotherapy) they generally reported improvements in feeling in control of their health. We were also told frequently about the benefits to mental health and well being that came from a more general sense of being more in control of their lives.

7.1.8 How far does my support plan enable me to exercise choice and control by feeling safe?

The question about safety and security gave a similar picture to that about health. Approximately half of those answering this question said that the PB did make them safe (i.e. a score above 3). However, on the whole, people were less likely to give a ‘top score’ to their feelings about safety, than about some other aspects of their life. (Table 17, App D).

For many participants ‘security’ related strongly to the nature of their local neighbourhood, and possible problems with crime or harassment. We had a report of a burglary, a mugging, and two reports of harassment by neighbours, all of which made participants feel very unsafe. However, a PB did help here on some occasions, since it could fund PAs to be present in the home on a regular basis. Therefore, the most significant aspect of security affected by the PB was people’s sense of safety in the own homes, followed by feeling more secure on the street because accompanied by a carer or able to pay for transport.

For people with dementia, as well as those with a learning disability, there were often safety issues associated with going out, negotiating traffic, or crossing roads. In these cases as well, having
a PA to accompany trips out was an invaluable way of increasing people’s sense of security:

“I’ve got to know the area that I’m in, where I’ve got to go to, and from A to B. So before I even set foot in the bus I need to have that firmly in my mind. But I also would have to invite someone to go over it with me. Because unless I know…for instance my great fear when I get on a bus is I don’t remember to get off at the right stop.”
ULO participant

An unexpected example of an improvement in security was the use of contingency funding in one young adult’s budget (LA group) to purchase extra short break time when her parents could not get back from their holiday due to the volcanic ash cloud.

7.1.9 How far does my support plan enable me to exercise choice and control over learning new things?

Further education and learning opportunities were important to people across our sample, and most people were reasonably happy that the PB gave them good chances to pursue educational opportunities which they wished for (Table 18, App D). A large number of those in the local authority group in Essex were attending a Further Education provider for disabled people, and used their PB to enable them to get to the college. Twenty people said that their educational opportunities were improved by their PB.

However, for younger people still at FE college, personal budgets were generally not being used to supply support, which was funded through the Learning and Skills Council. However, some young adults living in a rural area used PBs to cover the costs of transport to colleges and similar settings, with at least one person using the funding to enable him to socialise with college friends after hours. This was extremely important to him, and was a large reason for increases in his feelings of choice and control once his PB had been set up, giving him:

“The ability to go places, to see things, to get new experiences, to grow as a person, to become more able to
support myself, to be taught how to manage my own bank accounts, to be taught how to do tax returns, to be taught how to cope with all of these things.”
ULO participant

The majority of comments about choice and control in this area came from older people. Several people included attended classes as part of their support plans, and at least three participants wanted to have basic training in computer skills, which would in fact help them to manage their personal budget. In two cases, this training had not been forthcoming, even at the second interview. It would seem that there is a great opportunity here to ensure that a PB could deliver greater choice and control by enabling better management of the budget.

7.1.10 How far does my support plan enable me to exercise choice and control in my life generally?

The central question about choice and control related to what we have termed ‘independent living’. In general, we introduced this question by asking something like: ‘So looking at it over all, do you feel you have got the choice and control you want in your own life?’ This question was the most likely to produce a high rating with participants in both groups, 44 of whom gave expressed satisfaction with the choice and control given to them with their support plan (Table 19, App D). Ten of those in the ULO group increased their satisfaction rating at the second interview, as opposed to six in the LA group (Table 29, App D).

Satisfied participants spoke of a general improvement in their sense of independence, including for two people the pleasure in being able to ‘give back’ to their PAs through taking on a mentoring role. Another mentioned the way her funding package generally, and her PA support specifically, offered her 'help to move on and not mourn the person I was' (ULO participant), and yet another that the company of his PAs had helped him to pull himself out of depression and self neglect (ULO participant).

Within the ULO group, people said that the personal budget was a way of enabling them to feel that they were not relying on favours or on charity:
“It’s the fact that I’ve now got a bit of independence, and like I said before, I’m not relying on everyone to give me favours, and handouts. I can actually turn round and say, ‘cheers for doing that, you know, and there’s some money, or whatever.’”

ULO participant

As we explore in the next sections, there is some evidence that this sense of control and appreciation of one’s rights may have had some effect on the eventual choice and control that people in the ULO group were able to exercise in their lives.

7.2 Six months later

We now consider the experiences of our research participants six months after their first interview. Return interviews were conducted with each of the participants to determine:

- whether there had been any changes in people’s experience of their support plan
- the time taken for implementation of their support plan (where this had not yet been implemented at the time of first interview)
- experiences of choice and control, in order to see if these have changed at all, as the support plan ‘settles down’
- any continuing contact with the support planner or broker
- any continuing needs for support planning, advocacy or brokerage.

We planned to re-interview all 80 participants in the research, however only 70 people were available to be interviewed, this was due to a combination of people falling acutely ill, dying or moving from the area, plus a small number being unavailable due to other changes in their lives. Considering the groups of people sampled for the research this is not an unusual drop out rate. We were able to interview 33 people in the ULO group, and 37 people in the local authority group.
7.2.1 How did the satisfaction scores fare?

At the second interview we reapplied the satisfaction scoring measure with participants (see Appendix D, Tables 20-29). One of the most noticeable effects was that all the scores tended to shift down one point. Participants were not shown their previous scores until after they had responded at the second interview, and so this was not a way for them simply to say ‘things were not as good as I’d expected’. Nevertheless, in effect, these slightly depressed scores may well represent the fact that initial enthusiasm for a PB tended to fade slightly after the reality of putting it into action came into play.

There is little relevant one can say about most of these results at a group level as the shifts are relatively balanced between those for whom their satisfaction increased, those for whom it decreased, or remained the same, other than to note that (relatively) satisfaction with employment and income and in relation to security increased, and it decreased in relation to transport. However, as Table 29 (App D) shows, in relation to overall 'choice and control', those in the ULO group were more likely to give themselves a higher score (10 increased their ratings) than those in the LA group (6 increased their ratings).

7.3 What people said: Have I gone forwards in achieving my goal?

In the second interview we also asked participants to summarise for us whether they had gone forwards in achieving their goal(s), or backwards, or whether they felt that things had stayed the same for them. As can be seen from Table 21, the scores were generally more positive in the ULO group (A=63 per cent) than the local authority group (A=36 per cent of those interviewed). Not everyone answered this question, and so the total figures and percentages are less than the numbers of those taking part in Stage 2 interviews.
Table 21: Participants reporting on progress towards their goal

<table>
<thead>
<tr>
<th></th>
<th>A – have gone forwards</th>
<th>B – have gone backwards</th>
<th>C – have stayed the same</th>
</tr>
</thead>
<tbody>
<tr>
<td>ULO group</td>
<td>19 which is 63%</td>
<td>8 which is 27%</td>
<td>3 which is 10%</td>
</tr>
<tr>
<td>LA group</td>
<td>14 which is 36%</td>
<td>10 which is 28%</td>
<td>12 which is 33%</td>
</tr>
</tbody>
</table>

For some people the effect of wider life changes overtook any outcomes of support planning. These included deterioration in their impairment, necessitating admission to residential care (2 people in ULO group) or a reduction in mobility; substantial loss of sight, including the effects of the lack of support available to an older person losing their sight (no mobility training, advice about her home and how to manage) (one person in ULO group); and the results of surgery to improve their mobility (one person in LA group). For these people the question was relatively meaningless.

A: Going forwards

ULO support planning was not only appreciated by our participants because of the actual process. More clearly even than the scales on ‘choice and control’, the above table demonstrates the clear tendency for that choice and control to persist after six months. In other words, ULO support plans were more likely to be successful than those carried out by local authorities.

People gave a variety of reasons for this shift, which included increased independence, reducing the pressure on family carers (three people), maintaining physical and mental health (two people), and enabling individuals to fulfil their roles as parents and partners (two people):
“So much better: with the help of this money, I don’t have to rely on my partner all the time. I have three different carers now.”

“It opens up a completely new world, its all about having the choice, being independent, being able to do what you want when you want.”

“It’s made such a difference; I’d spent a year on the sofa.”

ULO participants

One person explained that things were still going forwards, even if some of her support plan was not yet in place because she was taking it at her own pace, ‘One or two things have stopped … Its me, overloaded my brain, me on a go slow’ (ULO participant). She went on to add that she felt able to draw up her own support plan in the future, obviously feeling empowered by the process with her ULO support planner to both pace and plan.

For some the shift was more radical; one man in the LA group told the interviewer that things had improved; he now has carers coming in, people he likes to see. Compared with last year, when his birthday was a wash-out, he was looking forward to hosting his own party, and several of his support workers were planning to come. Another in the ULO group explained that he had been contemplating suicide before the support plan was put in place. ‘If I hadn’t got this I wouldn’t be here, I was on the verge’.

B: Going backwards

In both ULO and local authority groups, however, there was a smaller number of people who felt that their lives had gone backwards, six months after their first interview. Much of this was to do with impairment related factors which were largely outside the scope of personal budgets. Of the 18 people reporting things going backwards, 8 were due to deteriorating health or increased frailty. This could lead to depression, and consequent lack of energy for social contact, as one person explained, ‘the will goes’ (ULO participant).
In four instances people commented that the effects were aggravated by an appropriate service, such as physiotherapy or day care, not being available, or by absent support and guidance (ULO carer), or vital equipment breaking down, causing one person to be forced to sleep in her wheelchair or on the sofa (LA group).

One woman, with a deteriorating neurological condition causing her to have severe problems with her speech, had been forced into residential care because she was wandering at night, and the social services reassessment refused her a rise in funding to enable her to have support at night time. This was particularly inappropriate as the residential home was occupied by much older people, and her communication needs were not being met (ULO participant).

C: Staying the same

Some issues were not amenable to improvement, including neighbour troubles, unpredictable health, and missing equipment and adaptations. These tended to give rise to a ‘much the same’ response, and were scored as C.

Participants also tended to score as C when their experience was a mixed one, eg health is worse but PAs were working well (three people), or support is going well but a larger budget is needed (LA participant). We also heard concerns about the future, particularly fear of cuts, in both groups. The relative unavailability of (re)assessment by social services posed a problem for many.

7.4 Changes in the wider world

Asking people to make an assessment of their overall condition provoked a large number of additional comments relating to anxiety about the future, the vast majority of which related to the prevailing economic situation and funding cuts in the public sector.

Of the 70 people interviewed for a second time, nearly a third (N=24) expressed anxieties about financial matters, largely caused by fears of cuts, social services procedures and a lack of
information about what they could spend their DP on, delays in being paid, issues relating to contingency and flexibility. These financial anxieties, whether caused by local practices or anticipation regarding national government changes, had a considerable impact on disabled people and their carers.

We were also aware that, although the situation may have improved for the service user, sometimes there was less improvement for their carer. Anxieties about the future and the availability of appropriate services was a common theme for carers of younger people with learning disabilities (ULO carer), and those caring for people with rapidly deteriorating conditions such as dementia (ULO carer). Some of their points are summarised in the ‘Final Messages’ in 8.3 of this report.

### 7.5 The link between support planning and life outcomes

To be confident that ULO support planning was of assistance to disabled service users, we were interested to look for evidence of the link between support planning and outcomes. In other words, did those who expressed the greatest improvements in satisfaction about their lives also have particularly good experiences of support planning? Conversely, did those who expressed the least satisfaction in terms of their lives experience support planning which was not helpful? There are no absolute answers to this type of question to be found in a qualitative study. However, our data was sufficient to allow us to dig more deeply into some of these connections, and we were particularly interested to unpick the types of factors in support planning connected both with the ‘most happy’ and the ‘least happy’ groups.

In order to identify the most and least satisfied, we looked at two measures. One was the improvement ratings in ‘independent living outcomes (expressed as choice and control)’ between the score at the first and second interview, and the other was the service user’s own response to the question ‘Have things got better or worse for you since we last met?’. These two scores often did not tally, for various reasons. These certainly include the vagaries of interview questions, and self-assessment rating scores, as well as the complications caused by health deteriorations, and the
discrepancy between a person’s physical health and their ability to be in control. Nevertheless, in order to identify the most satisfied customers, we only took those whose scores tallied, on the grounds that we could be most confident that they were happy with the outcomes in their lives. We also matched up those who had depressed scores in independent living outcomes, as well as a self-assessed ‘worse’. This process resulted in identifying eight ‘most satisfied’ customers (six of whom were in the ULO group) and five least satisfied customers (three of whom were in the ULO group).

Table 22: The most and least satisfied customers

<table>
<thead>
<tr>
<th>Independent living outcomes</th>
<th>Customers from the ULO group</th>
<th>Customers from the LA group</th>
</tr>
</thead>
<tbody>
<tr>
<td>Most satisfied</td>
<td>6</td>
<td>2</td>
</tr>
<tr>
<td>Least satisfied</td>
<td>3</td>
<td>2</td>
</tr>
</tbody>
</table>

7.5.1 What mattered most about support planning for the most satisfied customers?

In order to look back at what our satisfied customers had said about support planning, we examined all their responses about positive and negative aspects of their experiences of the process of support planning. The first and most obvious theme that emerged was the importance of having good information. Nearly all of these eight people had mentioned receiving information about personal budgets early on, so that they understood clearly what choices and rights they had. One person had obtained their information from disabled people’s network meetings, another had seen a film about individual budgets at the start of the Individual Budgets (IB) pilot, and a third had seen a DVD at the ULO. There was a strong connection between having good information and hearing this information from disabled people.

“I got introduced to somebody (from the ULO). And he said did I know about the support you could get through them to get carers. And I didn’t know anything about it, so he sent me
all the information through and we’ve talked about various ways that I could get funding and help and that. So he was quite good in following it through and helping me in every step up until now.”
ULO participant

From what people said, it seemed that this first information link was vital in enabling a disabled person to see what they could achieve. By having a) clear written information about a personal budget; b) the living example of disabled people who had independent lifestyles, people set off towards a personal budget with a degree of self-confidence. A clear sense of direction possibly helped this group more than anything to achieve greater choice and control as personal budget users.

Some people in this ‘most satisfied’ group had valued their support planning process, precisely because of the contrast with previous bad experiences with social services. These included the difficulty of accessing social services, the long waits to hear back from social workers, and the feeling of being ignored. Another person in this group had also had bad experiences in trying to apply for an education grant, and so there was a sense of relief when a support planner arrived who was prepared to listen. In fact, our ‘most satisfied’ customers included one participant who had been so dissatisfied with a local authority support plan, that he had complained and self-referred to the ULO. The points he particularly emphasised as positive about ULO support planning were the fact that it was provided by disabled people, who really were ‘experts by experience’. It was because they had that experience for themselves that they knew what it was all about. There was clearly a degree of trust here, and in fact this service user only needed one visit from a ULO support planner, who ‘actually listened in a professional way’ and gave good advice about how to cost out and add up the hours he needed.

Another important point mentioned by several people in this ‘satisfied’ group was the informality and friendliness of the encounter with a ULO support planner. For the two in the local authority group, they had similar things to say about an independent broker and about a social worker who had adopted a person-centred strategy. They spoke about the support planner coming in and having a conversation, involving carers where
relevant, and showing what we have described in Chapter 4 as a ‘genuine approach’: ‘She wanted to help, sincerely’ (ULO participant). Again, several of the group were able to contrast this style of support with the ‘abrupt’ or distanced approach from social services.

For some of the group, it was important that information was received in accessible formats. Two people in the LA group had learning disabilities; one had had a series of person-centred planning meetings with a circle of support he felt in charge of. He could select and invite who came to the meetings. The other person had an accessible plan which she kept in her own room, and which expressed in her own words what type of support she wanted. Both were still able to understand and recall what was in their plans, and felt happy that they had achieved some of the things that mattered to them. In one case, the high satisfaction scores were due largely to the fact that the service user had established a new personal relationship.

Underpinning all of this was the idea of control. Put simply, people who had control over the process were more likely to achieve control in their life outcomes. That sense of control was partly obtained through having good, clear information, and also by modelling their own lives on those of other people who could demonstrate what independent living really means. The skills of the individual support planner were important in all this, and it was evident that the process of support planning could entail meeting new disabled people, and being treated as an equal. However, it was that deeper understanding of independent living which was absolutely necessary for people to really carry on making choices in their lives.

7.5.2 What were the barriers for the least satisfied customers?

Using a similar process, we identified those who had depressed scores when rating their independent living outcomes on the second interview, as well as a self-assessed rating of ‘worse’. This was a smaller group, and it was not quite so clear what may have led to their bad experiences. As we mentioned above, life may well have dealt people a blow, in terms of health, relationships or
circumstances. These factors could easily lead to people feeling their choice and control had decreased.

However, again one of the obvious themes about support planning emerging for this group related to information. In their case, the points they made about support planning were about confusing or misleading information. One person with mental health needs, for instance, had not been given any choice about direct payments. She said:

“I enquired about whether the SDS [self-directed support] money would be taxable, and I still haven’t got an answer to that”
LA participant

If accessible information led to happy customers, one of the people in the ‘dissatisfied’ group was an older woman who had lost most of her sight. When asked about her support plan, neither she nor her daughter were really aware of what a support plan was. They did have documentation from social services, which the daughter had had to read to her mother, but the print was small and the text dense. Finally, one of the young people with learning disabilities in our sample fell into the ‘dissatisfied’ group, since his situation had deteriorated rapidly between the first and second interviews. Having been excluded from day activities because of health problems, no other support had been offered. Although the family had a budget, they were not feeling empowered to spend it in a meaningful way with their son. Looking back at what this family spoke about in support planning, it appeared that they had been pushed from one scheme to another:

“It was a bit of a mix up; we had a person from social services come out, fill in our form, and they must have been some system that was in place before, very similar. So we were on track to do that and then we didn’t hear anything and I kept ringing and it turned out that that was obsolete and they were bringing in this new system.”
ULO carer

The account above gave very much the feeling that the disabled person and their carers felt like pawns in someone else’s game. Again, it is a self-evident point, but in order to maintain choice and
control in the face of adversity, it was helpful to have planned for your own support in a way that engendered a sense of being in control. Long waits, frequent changes of system, and sudden changes could detract from that sense of control.

Chapter 7: summary of main comparison points between ULO and LA groups

- Those who were most satisfied with the choice and control in their lives, after a period of six months, were more likely to have had ULO support planning.
- Those who had LA support planning were more likely to be muddled about their PB, and to experience frustration about their situation.
Chapter 8: Conclusions and recommendations

8.1 What worked best for whom? Individualised support planning

Personal budgets aim to deliver a personalised, individual service, and are based on the premise that each person is different. Group solutions will not work, if disabled people are to exert some control and choice within their own life. It follows therefore that support planning as well must be individually tailored to meet the requirements of each person; a 'one size fits all' model is not only going to be insufficient, but it also runs counter to the spirit of personal budgets. This report has demonstrated broadly the advantages of ULOs leading support planning, when compared with local authorities. However, many of the helpful features of that service were not unique to ULOs. It is not enough, therefore, to simply conclude that ULO support planning is in some way 'better'. This section examines in more detail what our data show about the precise features which work best for service users in different situations.

In order to investigate this question, and having coded each interview transcript as described above, we created a casebook in NVivo, where we could also tag each individual interview against a number of classifications. In other words, the classifications represent our hunches about what might differentiate our sample. We discussed these features with support planners themselves at one of the three-site meetings, and the list in Appendix B is based on their ideas as well as our own.

We also classified all participants according to whether they had had ULO led or local authority support planning, and according to their area. In addition, we classified them, where known, for the approximate number of visits the support planner had made during the initial support planning. In that way, we could combine features to query the data in specific ways, and we could also run off one classification against another, for example to check how many support planning visits specific groups experienced, or to see how
many people with specific impairments also had carers involved. However, the main point of analysing the data in this way was to explore the factors in support planning which were important for different groups of people: what worked best for whom?

8.1.2 Experience of disability

Our first hypothesis was that the experience of disability would matter. Those who have been disabled for many years, or indeed have a lifelong impairment, may appreciate different features in support planning from those who are newly disabled.

What we found was that people new to their impairment had greater difficulties than others in using a support planning service. They did not necessarily see themselves as users of social services, and so particularly highlighted to us the way in which support planners had enabled them to see their own needs as valid. One of this group of people said:

“I have difficulty trying to explain things that I need. Because if I don’t do it, I don’t need it. It’s as simple as that.”
ULO participant

Eleven of the thirty people who were classified as having a ‘new impairment’ had seen their support planner three or more times, and they really appreciated the time and effort put in. They mentioned specifically the fact that support planners had listened to them, and had not re-worded things. One person said that, had the support planner not been there, she (the service user) would have just said ‘forget it. We’d have bunged it in the bin’. It is true that the majority of this group (19) did not have a lengthy or prolonged support planning process.

The most common finding was that people remembered the support planner coming about twice, and keeping in touch by telephone or email in many cases. Successful support planning with people who are newly disabled is perhaps not just about time spent, but particularly about helping people to think about possibilities they may not have considered before. One person said:
“I think that was the biggest thing I learnt really; ‘oh, I didn’t know you could do this, I didn’t know they would pay for that, you know’”
ULO participant

In other words, people who were newly disabled appreciated a relatively proactive style of support planning. One person, for instance, mentioned that she did not know what might be available, and felt the need for advice:

“She just sat and listened to me really, she didn’t really say anything... they just sat and listened to my life and said, well this is what social services can offer you. And that’s what it was.” ULO participant

What about those who had the longest experience, that is, a lifelong impairment? The vast majority of this group were people with learning disabilities (N=18), although some also had a physical impairment and had used services for both groups. These people, more than any others, were experienced users both of social services, health and other specialist services. Thirteen of the people with learning disabilities were young people in transition to adulthood, and so their main experience of services had been at school or college.

This group, more than any other, was likely to have the active involvement of a family carer (N=16) and carers were frequently conscious of the contrast between support planning services in 2011 and their previous experiences with social services. One of the features that was most appreciated in support planning was the encouragement to think more creatively and to look beyond the obvious needs they had. Carers told us that previously they had only thought about congregate services, day centres, special schools or specialist support. One carer of a young man with profound and multiple learning disabilities said:

“They sit and help you sort out what the needs are – and write it out for you, emailing me all the time: ‘what do you think about this, what do you think about that? You know? And what about that? I know with my son a lot of what’s needed, but not all the time.”
ULO carer
In helping someone with a lifelong impairment to plan for support, it was vital that support planners again took enough time and care, to draw on the expertise and knowledge of service users and carers, but also to challenge their service-led expectations of the system, and to enable them to think about ordinary life solutions. Service users with lifelong impairments, of course, were also the most likely to be people with learning disabilities who had basic skills needs, and difficulties in understanding and communicating their needs. Therefore they are also discussed below under those headings.

8.1.3 Basic skills needs

It cannot be assumed that personal budget users can all understand and communicate via print. Almost half of our participants (N=37) had problems in accessing text. Of those, fourteen had basic literacy and communication needs as part of a general learning disability. However, the other 23 included people who had visual impairments, those with dementia who could not retain information, people who had literacy problems or dyslexia and older people who did not have the physical capacity to read or write.

Specific practices in support planning which were mentioned as positive features by people across this group of 37 were:

- The use of pictures in support planning (photos of the service user and others in their lives could be incorporated into the plan);
- Personal contact was important, not simply a piece of paper;
- Repeated visits were often necessary, in order to get to know the support planner;
- Information needed by the service user needed to be ‘headlined’ (i.e. delivered in a clear and salient way);
- People could make choices best when they had some direct, concrete experience – e.g. visits to see bathroom adaptations;
- It was important to write exactly what was said, rather than to embellish it;
However, it was also important to help the individual look beyond what they said. Some people would always say ‘yes’ to any suggestion.

Within this group of people with basic skills needs, those with learning disabilities had particularly benefited from person-centred planning (PCP), as was explored in Chapter 4 (4.1.4). Specific practices mentioned and appreciated included pictorial information, advocacy and concrete information strategies. People with learning disabilities appreciated familiarity with those who helped them to plan. One young man, as mentioned, described how he chose the people who came to his PCP meeting, and another was able to refer to the accessible notes from a PCP meeting to communicate her needs to the researcher. When the carers were asked whether the person with learning disabilities had been ‘in control’ of his or her plan, one explained that their son or daughter had ‘provided some input’ (ULO carer) - rather than actually taking control. From the support planner’s point of view, then, it was important to take the time with this group either to set up systems for PCP, or to work with circles of support which were already in existence for people with learning disabilities.

By contrast, those who had problems with accessing text for reasons other than a learning disability often did not have their needs met specifically in any way. Several mentioned specifically that a family carer did everything for them, and they trusted that person implicitly. However, many did not have any means of accessing their own support plan for themselves. People with visual impairments needed support plans to be produced in media other than print, and several people with dementia or those with physical and cognitive impairments would have also benefited from independent advocacy, as well as accessible information.

8.1.4 Carers’ involvement

The majority of those in the group of thirty-seven mentioned above (with basic skills needs) benefited immensely from the involvement of a family carer. In all, 40 out of 80 had a ‘live-in’ family carer involved in their support planning and management of their budget, in this sample of 80, and 11 others had more distant carers who were nevertheless heavily involved. Although this study was not
set up to consider carers’ own needs directly, nevertheless the discussion often hinged on the carer’s comments and points of view, as well as those of the service user.

One of the vital aspects of support planning mentioned by carers (and by people who had family carers) was the ability of the support planner to get the right balance between involving the carer, and focusing on the service user. Several carers of people with learning disabilities mentioned that they were aware they had dominated the support planning process, and two said that their son or daughter had had independent advocacy as well. Nevertheless, parents in this situation were experts on their own relative’s needs, and they did want naturally to be heard and to influence the process of support planning. It has to be said that the success of most of the support plans depended heavily on the input of the carer, not only as a support planner and advocate, but also as a major part of the care package. In other words, most of these people with learning disabilities would have needed far higher levels of support without factoring in the parents’ contribution.

Family members caring for a person with dementia were in similar situations, as were those whose relative had a newly acquired impairment (e.g. visual impairment, or stroke). All these families vastly appreciated the sensitivity of a support planner who really understood the situation, and several in the ULO group specifically mentioned the value of meeting a support planner who had lived experience as a carer themselves.

Nevertheless, across the whole group of people with carers, specific strategies were often mentioned as positive ways to ensure that service users themselves had a voice. These included:

- Spending time to observe what the service user likes, especially for those who could not express themselves in words (LA carer)
- Using pictures and making lists of likes and dislikes (LA carers)
- Service user having a separate meeting from the carer (ULO carer)
• Asking concrete questions, including about the people in someone’s life. Many had enjoyed making relationship maps as part of their support plan. (LA participant)
• Describing in the support plan the positive things about a person, and not just focusing on their needs (LA carer)
• Basing conversation on known topics – things that the service user can talk about (ULO carer).

Only a small number of people with basic skills needs (N=6) of any kind did not have a family carer involved in their support plan. Those people found it even more important to have consistency, to get to know the support planner personally, and to have sufficient time for support planning. However, not all this group would need any kind of ‘special treatment’ if they had accessible information. For instance, one person with a visual impairment had been given a support plan with visual diagrams on it, which even his PA had difficulty in reading aloud to him. Time and effort would perhaps be better spent in ensuring that people with a visual impairment could access training and support to use computers and spreadsheets.

8.1.5 Linked in with other disabled people

The point of this research study was to look at the effect of ULO led support planning; however, a larger related issue concerned peer networks, and also the membership and other activities of a ULO. Nineteen participants who were members of user organisations mentioned how important they had been for them. For instance, because of the sharing and support they received through their networks, these people were far more likely to take control of their support at a personal level:

“I get a pot of money for my 45 hours. How I spend the money then is up to me.”
LA participant

As we explored in Chapter 3, user-led organisations were often a prime source of information. However, people sometimes specifically spoke about the value of role modelling, by meeting other strong disabled people (LA and ULO participants), and they appreciated the fact that they were among people who knew and understood about PBs (ULO carer). They were also more likely to
use other services provided by ULOs, including PA finder services, and peer support meetings. The value of peer support cannot be overestimated:

“I got talking to other people that I knew that were on personal budgets, and they said, ‘Oh, you can do it how you like; you can write reports, you can do pictures, you can do anything you want’. And I thought, right. I’m more of the report person.”
LA participant

There was also a strong theme amongst those who were involved in user organisations of offering something back, and being able to contribute their knowledge and experience of personal budgets to other disabled people. They were quite literally ‘linked in’. What these people valued more was the ability to work out any problems with each other:

“There’s still bits that we’re quite unclear on, but I’ve got a friend - I think she’s going to take part in this as well - and her and I, we swap notes ever such a lot, and we’re always picking each other’s brains and running things by one another. But her and I are very sort of tuned in on it, so we’re...we like to say that we like to be as if we’re one step ahead of them.”
LA participant

Developing, supporting and funding peer networks could make support planning a far more straightforward task.

8.1.6 Primary impairment group

One of the most noticeable features in this study sample was that people often had more than one impairment. Nevertheless, the usual way of classifying disabled service users is by their primary impairment. This has long been the basis for allocating people to specific social services teams, which has resulted in one set of services for people with learning disabilities, for instance, and another set for people with physical impairments. This final section will consider what mattered most, from the point of view of people from the four ‘main’ impairment groups.
Mental health needs

Although there were only six people whose primary impairment was coded as mental health needs, there were at least ten more who had a mental health need in addition to a physical impairment. Participants in the current study who fell under ‘mental health services had poor experiences of support planning to describe. These included the enforced closure of group services which they had valued, coupled with extremely confused and poor information about direct payments. People were left disempowered and muddled. However, two others who had contact with a ULO were both very happy with the personalised services they had. They particularly appreciated the advice and encouragement they received from the support planner:

“This is what (ULO support planner) only said to me yesterday, she said, ‘the more we get to see each other, and the more we talk, the more things will come out that you might be… could do with help more, that you haven’t thought of before’, which is true, actually, because we don’t always think of things straight away.”
ULO participant

Further research is needed to see what styles of support planning would be most important to this group. However, enabling ULOs to provide services to people with mental health needs may be a very productive way forwards.

People with dementia

Fourteen people in this study had a primary impairment of dementia. Five of the carers involved with this group spoke positively about the role of voluntary organisations in giving specialist advice. That included the RNIB, in assessing and advising on aids and adaptations in the home. They had also found the Alzheimer’s Society a valuable source of information and signposting.
Another important aspect of support planning for those with dementia related to the time spent. People generally wanted their carer involved in support planning, but also appreciated time to be included themselves, on their own terms. Sometimes this entailed using photographs to talk about the past, and at other times it included talking with the person with dementia separately (perhaps while their carer was making a cup of tea). Many could only manage short bursts of concentration, and carers said that it was important to know what the person with dementia responded to. For instance, one man in the local authority group responded well to relaxing music, but the care manager had not even attempted to communicate directly with him. Far better practices were reported from the ULO group. One carer reported how a social worker had failed to communicate on her father’s terms. It was absolutely necessary to go from what he wanted to say, rather than to tell him things he could not understand:

“And that lady wasn’t going to be the best for my dad. She would have been alright if I spoke to her, because I could deal with her. But my dad couldn’t and I couldn’t say anything because my dad was sitting there. He’d go, I can speak up for myself. But he don’t. Years ago he would, but he don’t now.”
ULO carer

In this case, the ULO support planner took a far more successful tack, in looking at old photos, and enabling her father to speak about what he wanted to.

People with physical or sensory impairments

The 49 people with physical or sensory impairments in this sample included the vast majority of people who spoke for themselves about the benefits of a PB, and about how they valued choice and control in their lives. For many of this group, peer support was important, and people spoke about membership of disabled people’s networks, as well as membership of the actual ULOs included in the study. Two people spoke explicitly about role-modelling in that regard, and how useful it had been to them to meet other disabled people who were managing their own lives.
“It was an eye-opener, because I didn’t know what I could achieve - not quite by myself, but through not…achieve through working with other disabled people, and not just able-bodied people. It was good to meet them and see what their problems were and how they coped with it.”
ULO participant

An important part of support planning for this group was almost always to do with flexibility. They mostly did not want anyone to ‘hold their hand’ during support planning, but were happy to be given good information, and then to write their own support plans. That was particularly so for those who had longer experience of their disability. Being newly disabled, as we have mentioned above, was significant. People in that situation included some with deteriorating conditions, and their need for time and support was paramount.

People with learning disabilities

Finally, points about support planning for people with learning disabilities have been raised throughout this report. Those who had experienced a person-centred planning process were most likely to have been actively involved in their own support plan. That included the ability to involve people they knew and trusted, while giving them time to explore options and to have a voice in the process of planning.

However, not all those with learning disabilities did have that option. Support planners needed many skills, including the ability to use accessible information, time to listen directly to the person themselves, and the skill to talk with carers, while also foregrounding the voice of the person with learning disabilities. It has to be said that people with learning disabilities themselves said that they liked people they knew and trusted, in order to be able to communicate their own wishes. At times, those who were part of service provider organisations had clearly fulfilled that role. However, there needs to be more exploration of how to provide independent support planning for this group, which is both user-centred, and allows for the changes and continued needs people will have to update their plan and move on in life.
8.2 Conclusions and summary

The research discussed in this report was part of a specific initiative (the SAB project) to move one single element of the personal budget process out of social services and into user-led organisations. At the outset, it seemed to the research team that this was just one detail, not necessarily a major structural shift in delivering personal budgets. However, as this report demonstrates, the significance of support planning is far greater than at first assumed. In fact, support planning was experienced as the central hub of a personal budget, the point at which a service user was offered the chance to really take control and to plan what is best for them. Support planning was both affected by, and affects, all the other elements of personal budgets, and that is why we have included some comments from participants about the whole journey. Each part of it was connected, and without good independent support planning, it would seem that a personal budget had problems in delivering positive independent living outcomes for participants.

The comparative design of this study was set up in the hope of being able to match experiences of participants more exactly; in the event, that was only partially successful. On the whole the results in the local authority group were skewed towards the positive and empowering end of the continuum, because of the inclusion of the DPUN group in Essex, and also those with learning disabilities in Southampton who had the services of an independent broker. Therefore, the points which have actually emerged about the positive values of ULO support planning are relatively trustworthy. In summary:

- ULO support planning offered service users comprehensive, creative information about personal budgets.

- Support planners from ULOs were backed up by organisations which were responsive to service users, who adopted an open approach to enquiries, and who were friendly and helpful.
• ULO support planning was more likely to give people the confidence to become direct payments employers, and to be creative in employing friends.

• ULO support planning was seen as person-centred. This included the relatively informal style of the support planners, the fact that they appeared genuinely to care, and the style in which they were able to take time to get behind what people said they wanted.

• Peer support was important, in that some disabled service users recognised that the support planner had experience as a disabled person, and was more likely to understand and empathise with them.

• ULO support planning was professional and efficient.

• Those who have had ULO-led support plans are more likely to value choice and control in their lives, and the effects of that choice and control were still visible after six months of their personal budget.

The points listed above are relevant to everyone. All the groups of participants in this study appreciated a person-centred, genuine, yet professional approach. However, as explored in the earlier part of this chapter, a one-size fits all model did not work for everyone. To some extent, ULOs were able to adapt to different groups of individuals. Drawing on the data from both the local authority and the ULO groups, a tentative framework is offered to conclude this report. Broadly speaking, there appeared to be three types of support planning, ‘Hands Off, Hand Over, and Hand in Hand’, which are probably best viewed as a continuum (see Figure 1).

The three different sites in this project adopted slightly varying models (see Appendix C). For instance, in Essex there was a relatively ‘hands off’ approach, based on a strong tradition of disabled people’s voice and control, with many experienced direct payments and individual budget users. However, the frequent changes in terminology in the personal budget system were sometimes experienced as confusing. Communication and team work between the local authority and user led organisations were
praised. This included both the ULO in this project (ecdp) and the direct payments users network (DPUN).

Different models operated in Richmond, with some ‘hands off’ and some more ‘hands on’ contact taking place with service users. On the whole, this was experienced in a positive way, as differentiated and sensitive to individuals’ needs. As in Essex, instances of team work and collaboration between the ULO and LA were appreciated.

Participants in Southampton particularly appreciated the ongoing support from the ULO, which helped people to problem solve and to increase their feelings of control and independence over time. As elsewhere, social services systems were often felt to be relatively unresponsive. However, people with learning disabilities and their families were satisfied with the person-centred support received by an independent brokerage arrangement. This was a relatively ‘hand in hand’ model, with service users benefiting from ongoing person-centred planning.

The service users in this study were all at different starting points, in terms of what they really needed from support planning. Their starting points, as we have seen, were affected by their impairment, but also by the length of their experience of disability, their existing ‘peer support’, the presence or absence of a carer, and by their own communication skills. The point of good support planning, to some extent, will be to enable people to move up this continuum and become more independent.

Figure 1: The ‘Hands’ Framework

Model 1. HANDS OFF
- Give good information to the service user about their rights and the system
- Tell them their indicative budget
- Trust them to write their own plan – a) with carer; b) without carer

Model 2. HAND OVER
• Help service user ‘see beyond’ their lack of expectations; give suggestions and help people to meet other disabled service users who have PBs.
• Give information on what’s available
• Write plan together – or maybe support planner goes away and drafts it, then takes back to service user.
• with carer; b) without carer
• Stay in touch if needed (e.g. by email or phone); meetings for service users generally.

Model 3. HAND IN HAND
• Work with others who know the person well – e.g. through a person-centred planning process.
• Take time to get to know the individual, communicate on his terms. Find out what he really likes.
• Give information on what’s available + broker NEW opportunities where things do not exist.
• Make sure things are presented in a way that is accessible to the service user
• Ensure that strategies are put in place to foreground the voice of the service user
• Write plan together with service user and those around him/her. Take it back a) with carer; b) without carer.
• Ensure there are structures to keep in touch, with a key person who can react and respond to changes, and to continued needs.

8.3 Final messages from participants

At the conclusion of the second interviews, participants were asked if they had any final message for the research. We conclude this report with a brief summary of those important messages.

People generally felt they had experienced many different systems of care management and resource allocation, with different terminology attached. There was a strong message about taking the time and energy now to ‘get this right’, and to ensure clarity for service users. Service users were very generally very happy with a
system which allowed them more choice and control. They felt PBs were a more 'human' system, and particularly appreciated the ULO role in reducing the bureaucracy involved. For instance, the ‘final message’ from one service user was:

“The ULO helps you sort it out, and then they step back. You feel in control, and you don’t feel that you have to keep going down to them with your begging bowl.”
ULO participant

Despite this positive message, some of the service users, and several carers, had a strong message about differentiation. They felt that people were all different, and that support planning should take account of these differences. ‘Choice and control’ maybe the ultimate goal, but it will be approached differently by someone with a physical impairment, in contrast with someone with a learning disability. There were also strong views from many service users and carers about the need for actual services. It was felt that personal budgets were only useful if there were services to buy. Therefore, a priority must lie within the development of the provider sector.

Family carers regularly performed a core role in supporting their disabled family member. It was clear in many cases that the PB system would not work without them. For family carers, there was a strong message that support planning needs to recognise and support their vital role. In particular, gaining and keeping paid employment outside the family was an important need for them, but one that is difficult to achieve. Nevertheless there was also a strong feeling that all disabled people have a right to the benefits of a personal budget. Those who have the highest needs, and their carers, felt strongly that they should not be excluded.

A common message was about the need for better information, both to ‘advertise’ the PB system to potential service users, and also to explain clearly what the steps in a personal budget are. Support plans were felt to be most useful when they were flexible. Service users were worried about the implication that their plans would be ‘set in stone’, and wanted to have the right to reflect on and change the details of their support plan on a regular basis at reviews. Training and support for all those involved in the PB system was felt to be vital. In particular, social services staff were
felt to need better training, and service users said they were in a good position to help provide that.

The second set of interviews was carried out at a time of financial constraint, after the Government’s comprehensive spending review. There were many worries that PBs would be cut, that people with high levels of need would be ‘re-allocated’ to continuing health care funding, and in some cases, service users felt that their own choice and control would be threatened by cuts to services. Support from peers in user-led organisations, or networks of disabled people, was felt to be a vital part of the system.

Service users said that they felt worried about threatened budget cuts, which would affect the ability of user networks to continue to function and provide them with support. The overwhelming message from this research, then, was that user-led support does work, and that service users and their families appreciate good support to be in control of their lives. Having come this far, they were anxious to spread the good practice, and to ensure that one system for personal budgets is funded, with all disabled people involved and well informed.

References


Appendix A: Topic Guide

As a topic guide, the following notes are intended to guide in-depth qualitative interviews, which will probe participants’ experience. As such, the guide is not a questionnaire and nor will questions necessarily be asked in strict order nor in the same format. Rather, the interviewer aims to follow up what is important for participants. The topic guide ensures that certain areas are covered and information collected on key items of importance to the project.

1. The purpose of these interviews is to find out the extent to which people currently experience independent living outcomes in their everyday lives:

   a) choice and control over various aspects of their life
   b) choice and control over their support services in particular
   c) satisfaction in relation to what they want to do in their own lives (i.e. achievement of the life they want)
   d) achieving a sense of positive identity

2. The interview will also probe the extent to which people’s experience has changed. All participants will have either a) recently seen a care manager; b) recently seen a peer-supporter in the SAB services. The interview will attempt to look at how things were before this intervention, and how they are now.

3. Finally, the interview will attempt to pinpoint ways in which support services (SAB services or traditional services) have helped; the efficiency and timeliness of their help; what people have particularly liked; the outcomes from particular contacts with support services; the ways in which they have been supported to be in control of their own services or what got in the way of this.

We aim to be relaxed and get to know people as much as possible. With some people, we will have had a pre-meeting before the interview. However, the interview may become very long if participants relax into it. We will therefore ensure that a) we propose breaks at regular intervals; b) we vary the activities and ways of presenting questions to people (see the tools attached).
1. Getting to know you

- Introductions and ‘Your Life, Your Choice’ project (looking at leaflet and information sent).
- Checking again on consent to put audio recorder on.

Personal details
- We will then make sure we have the basic details correct for the person we are talking to:
  - Name, age
  - BME group (if appropriate)
  - Living situation: on own, or with someone (including whether there is someone identified as an informal carer)
  - What type of place do you live
  - Address and contact details

Goals and aspirations
- We aim to start with something positive, which focuses on what people want in life:
  - Can we start by you saying a bit about your own goals in life, and what is really important to you?

2. What is your life like now?

- Can we talk through a typical day/ a week? What are the things that you do on a day-to-day basis?
- What are the high points, things you feel good about?
- Any particular highlight in your life right now?
- What are the issues for you, things that cause you problems?
- Any particular problem in your life right now?
- Are there particular things you’d like to do, but don’t do now?
3. Support services

We want to ask people about how support services impinge on their lives, but first of all to make sure we get clear exactly how much support they receive, and what is in their care plan. It will be very useful to find out if the services have changed at all since their last review or assessment, and whether they are satisfied with that.

Overview of support services
- What kind of support do you receive? For instance:
  o Support in the home (hours of PA time)
  o Day activities (how many days/ hours)?
  o Short breaks (how often, how long)?
  o Anything else (including equipment and/or adaptations)?

Specifics of support plan and services received
- At what points have you had contact with support services, social services, anyone else?
- Do you have a support or a care plan? Do you have a person centred plan?
- What is in your support plan? (We will try to be specific, and if possible see the plan)
- Has your support plan changed at all (in terms of the services and equipment/adaptations you get now)?
- Do you know how your support plan is funded? For example do you receive direct payments?
- How do you feel about the support services you get now? (including equipment and adaptations)
- What is working well?
- Do you have enough support/ too much/ not enough?

We will finish this section by saying that we will go into more depth about this later on.
4. The process of organising support and services

We will try to clarify first what ‘Support, Advocacy and Brokerage’ might mean, especially for people in the ‘target’ group.

You may have seen the words ‘support, advocacy and brokerage’ on our information leaflet. Did those words mean anything to you? (We will explain that the words are all to do with giving people support to manage their own assessment and care planning).

First, we want to probe whether the style of meeting (and the identity of the person supporting) was helpful or not:

- You have recently had an assessment or a review of your care/support plan. Did you get some support to help you do this?
- Who have you seen recently from social services/ from the (ULO)?
- How did this person compare with other people who have done assessment, support planning or reviews with you?
- If there was a difference, what made that difference?
- How did you get in contact with them?
- How long did it take for you to get an appointment?
- What did you want to get out of the meeting?
- In what ways did you feel this meeting was useful to you?
- Where was the meeting? How long was it?
- Were there any problems with the meeting?
- What happened afterwards?

We then want to make sure about whether people felt they were in control of the process of organising their own support. We will go through the stages of self-directed support (with or without picture-diagram), to check whether:

- Do you know how much your support services cost? At what stage did you find this out?
- Did you feel you had a chance to make your own plan for support services? Did you get good support to do this? Were you in control of this?
• Was it easy to get your plan agreed? Did you feel you had the final say, or were other people telling you what you needed? Were you in control of this?

• Were you offered a direct payment? Did you decide to go for one or not? If yes, did you feel in control of managing the money? Did you get good support or advice about how to manage this money? Did you have any choice in how you spend it?

• Were you offered any other options for managing your support services (e.g. broker, 3rd party arrangement, trust, provider)? Did you understand and feel in control of this choice?

• Were you able to make choices about how to design your own support services and/or about what equipment/adaptations you have? Did you feel in control of this?

• You’ve already told us about how it feels now in your own life and what you do. But social services probably comes back to review what you are doing from time to time? Has this happened to you? If so, did you feel that this worked well, and were you in control?

We also want to probe whether the process of SAB (or care management) was sensitive to specific needs of people – including those from BME groups, or from particular impairment groups.

• What kind of support really helps you to think about your own needs?
• Have you been offered any extra support?
• Was the service sensitive to your particular needs? (e.g. was accessible information offered? MH needs? BME?)
• Are there any specific ways in which professionals can be more sensitive to your needs?
• Did these things happen in your recent (meeting) – when you saw (X)?
5. Choice and control in your everyday life

This is the central part of the interview. Starting with the things people have said were important in their lives, explore further the following areas (these areas were taken from the areas advised by disabled people from the ODI Experiences and Expectations study). Prompt questions are included under each ‘area’:

- **Home life**
  Are you always able to make your own decisions at home?

- **Employment, income and voluntary work**
  Are you doing a job or voluntary work or other kind of activity that you enjoy, and where you feel you achieve something and make a contribution? What was your previous job? Do you have a pension?

- **Personal relationships and social life**
  Do you have friends and close family members or other people around you? Is it easy for you to participate in your family life and see the people you want to see?

- **Participation and community involvement**
  What things are you involved with in the local area, or in your wider community? Are you a member of any local groups?

- **Environment and transport**
  Do you make your own decisions about going out, or travelling locally – or further afield? Are you in control of when and how you travel?

- **Leisure**
  Do you feel that you follow up your own interests, and that you have hobbies or activities that you have chosen for yourself? When was the last time you had a holiday?

- **Health and security**
  Are you given the chance to make decisions about your own health, or to tell people when you need support in relation to health issues?
  Do you feel safe where you live, and when you go outside?
• Education and lifelong learning
If you are on any courses, or following up any learning opportunities, do you feel that you have choices about what you learn, and how you learn? Do you feel you get the support you need to participate in learning opportunities?

• Independent living and wellbeing
In general, then, do you feel that you have choice and control over your own life? Do you feel that you are in control of the support services that you have?

Visual method of recording ‘choice and control’ in these different areas of life:

Where appropriate, and if participants want to, we will use a visual method of recording ‘choice and control’. In each of the above areas, put key points on post-it notes, and use a ‘dartboard’ sheet to place the post-it notes according to whether the participant feels they have control (most control in the centre of the dartboard).
(Prompt on each topic with a ‘who decides’ question: for instance: ‘If you want to go and have an evening out, who decides about this and do you feel you can make your own choice?’)

Explore barriers, and any problems people face – e.g. discrimination, costs, harassment, lack of access.

6. Before and after

In this section, we want to collect some ‘measurable’ data about people’s levels of satisfaction (before and after their recent review/assessment/care planning). We also want to probe whether they feel better about themselves, and how they see themselves. We will use a 1-5 scale (see Tools attached) to rate people’s responses, having explained to them that the scale means:

5: Over the moon
4: Pleased
3: OK
2: Some concerns
1: Negative
We will go through the areas we have talked about in Question 4, to rate satisfaction separately for each area. In each case, we will try to probe for more detail, alongside the ‘score’ given:

- Has it always been this way?
- What has got better (and reasons for this)?
- What has got worse (and reasons for this)?

At the end of this, we will ask about how people see themselves, and whether this self-perception has changed at all.

- How do you feel about yourself and your own life?
- Have your feelings about yourself changed at all?

7. **Future aspirations and expectations**

Getting toward the end of the interview, we want to make sure people have had a chance to say what their goals in life really are. Sometimes people are more able to say this when they have relaxed and gone through all the rest of the questions. So, we will ask:

- In the future, what do you want from your life? (some probing, to go through the areas of importance, and the different aspects of life).
- What do you feel will help you get there?
- What are the risks or threats that you see?

8. **Summary about getting support to be in control of your own life and services**

We will conclude by returning to the theme that people are trying to change things, so that people are more in control of their own lives and services. We will then ask people to sum up their own experience by saying:

- What was it (if anything) about your contact with the ULO/LA that has helped you most to be in control of your own services and support? Tell us one thing that really stands out for you.
• What was it (if anything) about your contact with the ULO/LA which you most found got in the way of you being in control of your own services and support? Tell us one thing that really stands out for you.

We hope that things work out for you, and that we can come back in about 6 months time, to see how you are getting on. Conclude by making arrangements to keep in touch, send information about how the project is going. Offer to send back transcript of interview. Thank people, and give a token of our thanks.
Appendix B: Classification of interviews

Experience of disability
- New condition
- Became disabled (over 5 years ago)
- Lifelong disability (started in childhood)

Experience of services
- Uses or has used congregate services
- No experience of any social services
- Has used individualised services before

Carer involvement
- Family carer involved living in same home
- Family carer involved, but not live-in
- No carer involvement

Size of support package
- Over £400 per week
- Between £301-400
- Between £201-300
- Between £101-200
- Between £50-100
- Under £50

Basic skills needs
- General basic skills needs (e.g. cannot read text)
- Specific basic skills needs (e.g. dyslexia, or memory loss, or specific access needs)
- No basic skills needs

Learning disability
- Learning disability: main impairment
- Learning disability in addition to other impairment
- No learning disability

Mental Health needs
- Mental health needs: main impairment
- Mental health needs in addition to other impairment
• No mental health needs

Physical and/or sensory impairment
• Physical and or sensory: main impairment
• Physical impairment in addition to other impairment
• No physical or sensory impairment

Dementia
• Dementia: main impairment
• No dementia

Family carer
• Family carer in house
• Family carer involved, but not live-in
• No family carer
• Young carer involved
Appendix C: Specific experiences of participants in each of the three sites

This study did not recruit evenly over the three sites, and the practices of ULO support planning were in any case planned differently in each area. This final summary thus in no way represents an evaluation of practice. Nearly all the points made throughout this report about ‘good’ and ‘bad’ support planning were made across the board by people in different areas. This appendix simply offers some comments that relate to specific differences between sites.

Essex

- Essex is an area where disabled people’s organisations have a long history. One of the first areas to take up and promote direct payments in the 1990’s, Essex has also taken part in several initiatives since then, including for instance the Individual Budget Pilot in 2006-7.

- The sense of continuity and support from user-led organisations came over strongly in Essex, both from the LA and from the ULO group. People often highlighted how much peer support had meant to them. Essex Coalition of Disabled People and subsequently also other organisations such as the direct payments users network, were singled out. There is a strong tradition of disabled people having their own voice, and that shone out in their attitudes towards personal budgets and support planning:

“It was the bi-monthly meeting which...in the morning they have a closed session. Where you can talk about anything between yourselves, without social services hearing what you’re saying. Anything like that.”
LA participant

- Some participants mentioned that there was a good link between social services and ECDP. Social services were said to have referred people to ECDP, and several of the
DPUN participants praised the practice of senior social services staff speaking at service user meetings, in order to give them information.

“I was trying for months to get through to social services, from the beginning. And when I was at a meeting with Essex coalition of disabled people, or DUNP, there was a lady from Essex social services, quite high up, and she said to me, have you asked for a complaints form”
LA participant

- In the local authority group, at least four individual social workers were highly praised. However, there were also comments about the need for social worker training and many participants in both groups had had great difficulty in contacting social services, or in getting a response. People particularly complained about the practice of being ‘banked’, and not having a contact point in social services

“If I didn’t need any assistance for a certain amount of time they would put me on the...they would take me off their books until I re-asked for something, then they would put me back on. And then for some reason they would either leave due to illness, or going to different parts of the county, or...And in the end me and my parents and family just dealt with things our way.”
ULO participant

- There were many experienced direct payments users in the sample in Essex. Nevertheless, more than one person commented on the frequent changes in the system, and also in terminology:

“I’ve had three different systems in three years, and the titles of people who’ve come out to assess me.”
LA participant

- The model of support planning adopted in Essex was very much at the ‘hands off’ end of the continuum suggested in Chapter 8 of this report. People with physical or sensory impairments generally appreciated that model, and found
ULO support planners extremely helpful, experienced in disability issues, and strong role models.

- Families of young people with learning disabilities also identified with a ULO support planner who was a family carer herself. They felt that she had the right 'lived experience' to advise them.

**Richmond**

- Participants in Richmond particularly appreciated the very personalised approach taken by support planners. Many people specifically mentioned how the ULO support planner had taken time, and had genuinely wanted to get to know them. Several people also liked the way in which the support planner sent out information to introduce herself:

  "*She went to a great deal of trouble to introduce herself and send out a file so that we had some idea of who she was when she came here.*"

  ULO participant

- Richmond had a model in ULO support planning where the services were provided by contracted-out organisations, as mentioned in the SAB Report. This made it harder perhaps for some service users to make any connection between the ULO and the support planner who had visited them. People also sometimes said that confusion and lack of communication could occur (ULO carer).

- A good point about the different organisations involved was that support planning appeared to be sensitively differentiated for different service users. For instance, carers of people with dementia praised the amount of care, time and attention spent by the support planner.

- There was also good practice reported, where a ULO support planner joined in a person-centred planning process for people with learning disabilities. However, as elsewhere, people with learning disabilities received inadequate ongoing support, and the system relied unduly on family carers.
• The information leaflet about personal budgets produced by Richmond Social Services and RUILS was highly praised:

“RUILS information on self directed support is a brilliant brochure, brilliant. Because they do tell the clients, or whatever you want to call them, the ways you can…the imaginative things you can do with your SDS.”
ULO participant

• Some people in the local authority group were ‘out of the loop’ with personal budgets, and appeared to have very poor advice. That particularly included people with mental health needs. However, this was undoubtedly not just true of Richmond, but was simply a result of the way people were recruited to the research with greater speed and openness in Richmond than elsewhere.

• In general, ULO support planning was experienced as efficient, respectful and active. People appreciated the fact that the ULO support planner(s) were prepared to engage with social services on their behalf.

• Richmond included some self-funders, who had had a good service from the ULO, and were extremely well informed.

• Some service users, particularly in the later interviews, were appreciating the chance to get involved in supporting others through peer networks instigated by RUILS.

“Went to a first meeting last week there. They want more of us to talk about it, you know, what it means to us, being independent.”
ULO participant

Southampton

• Amongst service users in Southampton, there was a fantastic level of commitment and respect for the ULO support planner involved in the SAB project, who was said to
be efficient, available, supportive, and creative: “a mixture of imagination and donkey work.” (ULO carer)

- One of the points particularly appreciated was the active listening of the ULO support planner: “With (ULO support planner) they would write down what you said, and then they would pull apart what you said, to get deeper into what you want, and What you’re thinking and what you’re saying. And they would pull out to know what you really do want, rather than a care manager – this is what you say, and this is what they want.” (ULO carer)

- In Southampton, the ULO also has a long history, and is seen as a very strong organisation. As elsewhere, the ULO was important as a structure, and people appreciated being able to get continued advice and guidance from SCIL.

- Again, as elsewhere a problem for many people was that social services systems were inaccessible. Service users rang up social services, only to find that they had been 'banked'.

- The finance department was considered to be a particular problem in Southampton. Several ULO group participants had had issues in having to wait for funding to be released, and also various muddles, and disrespectful communications from the finance department.

- The Southampton SAB model did not officially include people with learning disabilities (although some had more than one impairment, and were using learning disability services). Instead, people with learning disabilities had support plans through an independent broker, who was also highly regarded by the families and by the service users involved. They particularly liked the fact that she knew the system, and could recommend particular services.
Appendix D: Satisfaction ratings on choice and control in different aspects of life, after the support plan

Scale used to rate satisfaction with choice and control in areas of daily living was 1 - 5.

5 is the ‘high point’ where participants felt totally happy that they were in control of that aspect of their life, 3 is the mid point, and 1 is very dissatisfied.

The participants were asked about these aspects of their lives:

- Home life
- Employment / income
- Relationships
- Participation
- Transport / environment
- Leisure
- Health
- Security
- Education
- Independent living
1st Interview ratings

Table 10: Home life
Interview 1: How far does my support plan enable me to exercise choice and control at home?

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Table 11: Employment and income
Interview 1: How far does my support plan enable me to exercise choice and control in relation to work and income?

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### Table 12: Relationships
Interview 1: How far does my support plan enable me to exercise choice and control about relationships and social life?

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### Table 13: Participation
Interview 1: How far does my support plan enable me to exercise choice and control about taking part in society?

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### Table 14: Transport and environment
Interview 1: How far does my support plan enable me to exercise choice and control in getting to where I want to go?

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### Table 15: Leisure
Interview 1: How far does my support plan enable me to exercise choice and control about my leisure?

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### Table 16: Health
Interview 1: How far does my support plan enable me to exercise choice and control over my health?

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### Table 17: Security
Interview 1: How far does my support plan enable me to exercise choice and control by feeling safe?

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### Table 18: Education
Interview 1: How far does my support plan enable me to exercise choice and control over learning new things?

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### Table 19: Independent Living
Interview 1: How far does my support plan enable me to exercise choice and control in my life generally?

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Changes in rating aspects of life between first and second interview.
Table 20: Home life
Interview 2: How far does my support plan enable me to exercise choice and control at home?

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**Table 21: Employment**

Interview 2: How far does my support plan enable me to exercise choice and control in relation to work and income?

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Table 22: Relationship and social life
Interview 2: How far does my support plan enable me to exercise choice and control about relationships and social life?

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### Table 23: Participation

Interview 2: How far does my support plan enable me to exercise choice and control about taking part in society?

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### Table 24: Transport

**Interview 2:** How far does my support plan enable me to exercise choice and control in getting to where I want to go?

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Table 25: Leisure
Interview 2: How far does my support plan enable me to exercise choice and control about my leisure?

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Table 26: Health
Interview 2: How far does my support plan enable me to exercise choice and control over my health?

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Table 27: Security
Interview 2: How far does my support plan enable me to exercise choice and control by feeling safe?

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Table 28: Education
Interview 2: How far does my support plan enable me to exercise choice and control over learning new things?

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Table 29: Independent living
Interview 2: How far does my support plan enable me to exercise choice and control in my life generally?

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