

# **LINK research into Self Directed Support in Oxfordshire**

6th October 2010

## **Oxfordshire**



Your voice on local health and social care

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## 1 Introduction

The Oxfordshire Local Involvement Network (LINK) has a mandate to find out what people like and dislike about local services and to help bring about positive change to health and social care.

As part of this work the LINK commissioned an independent qualitative research project, starting in 2010, to understand people's experience of the new system of Self Directed Support and Personal Budgets in Oxfordshire.

Self Directed Support has been piloted in the Banbury area since December 2008 and, according to the Oxfordshire County Council (OCC) Transforming Adult Care newsletter of August 2010, there are 555 people with a personal budget in Oxfordshire.

### 1.1 Research method

Planning the research method took into account that:

- Gathering information and opinion from social care clients with “critical and substantial” needs (those most likely to be eligible for a PB) **must be carried out with great care and sensitivity.**
- It is important to **understand the circumstances of the client** in some depth as essential background to opinions on the quality of care received.
- **The system of Personal Budgets (PBs) is still very new in Oxfordshire.** It may be that the early recipients of PBs in Oxfordshire - during the pilot trial in the north of the county – have received a “gold plated” service and that feedback will be influenced by the newness of the system.
  - *The national evaluation of the Individual Budgets Pilot programme<sup>1</sup> found in 2008 that the feedback from users was affected by the process of changing to the new system rather than reflecting simply on the new system itself.*

For these reasons the chosen methodology was in-depth face-to-face discussions (qualitative research) carried out by a trained healthcare professional, Helen Grimwade.

- Helen Grimwade has trained and worked as a nurse, health visitor and smoking cessation specialist, the latter role for Oxfordshire Primary Care Trust. Most

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<sup>1</sup> Individual Budgets Evaluation Network (IBSEN) on behalf of Dept of Health [php.york.ac.uk/inst/spru/pubs/1119/](http://php.york.ac.uk/inst/spru/pubs/1119/)

recently Helen led Age Concern Oxfordshire's Community Development team where she delivered projects that included consultation and evaluation working directly one-to-one with older people or within a group setting.

In addition it was decided that the sample would be split between those already on Self Directed Support and those still receiving "traditional" services so that experiences could be compared.

It is planned that this study will be developed into longitudinal research with follow up discussions in 2011 at a time when the respondents have been transferred to SDS.

## **1.2 Developing the research sample**

Despite the early offer of help from Oxfordshire County Council Social and Community Services (Transforming Adult Social Care), the process of developing the research sample – finding people to interview – has not been straight forward.

Oxfordshire County Council (OCC) already had a system of contacting people with Personal Budgets to find out whether they would be willing to be interviewed about their experience. An OCC-sponsored report on SDS<sup>2</sup>, based on a feedback from 7 clients was published in October 2009 and a follow up report was planned in 2010.

Starting April 2010 OCC gave priority to finding research respondents for this new LINK-sponsored research, but by June 2010 only one person had come forward who subsequently became too ill to participate.

This left the LINK research project with no respondents directly provided by Social and Community Services.

In June 2010 an intense effort was made by the LINK to find respondents via:

- Local press and radio including an interview on Radio Oxford;
- Contact with local voluntary groups including Age UK, Carers Centres, OCVA, ORCC, Stroke Association, Headway, Neurological Alliance, Leonard Cheshire, Oxfordshire Unlimited;
- Contact with attendees of the "Hearsay!" event (a joint OCC/LINK event);
- Other publicity via the health bus and LINK newsletter.

This effort meant that the research was able to proceed, albeit with fewer SDS clients than we would have liked.

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<sup>2</sup> Self Directed Support learning exercise evaluation, 15<sup>th</sup> October 2009, Nick Horn

This report is in three main sections plus an annex:

- Section 2 provides a summary introduction with an **overview of the main findings**;
- Section 3 summarises and then provides details of clients' and/or carers **views of Self Directed Support**;
- Section 4 summarises and then provides details of clients' **personal and social networks and their experience of social care**.
- The Annex gives a **profile of the research sample**.

## 2 Summary of findings and recommendations

This section provides a summary of the main findings and the recommendations.

### 2.1 Overview

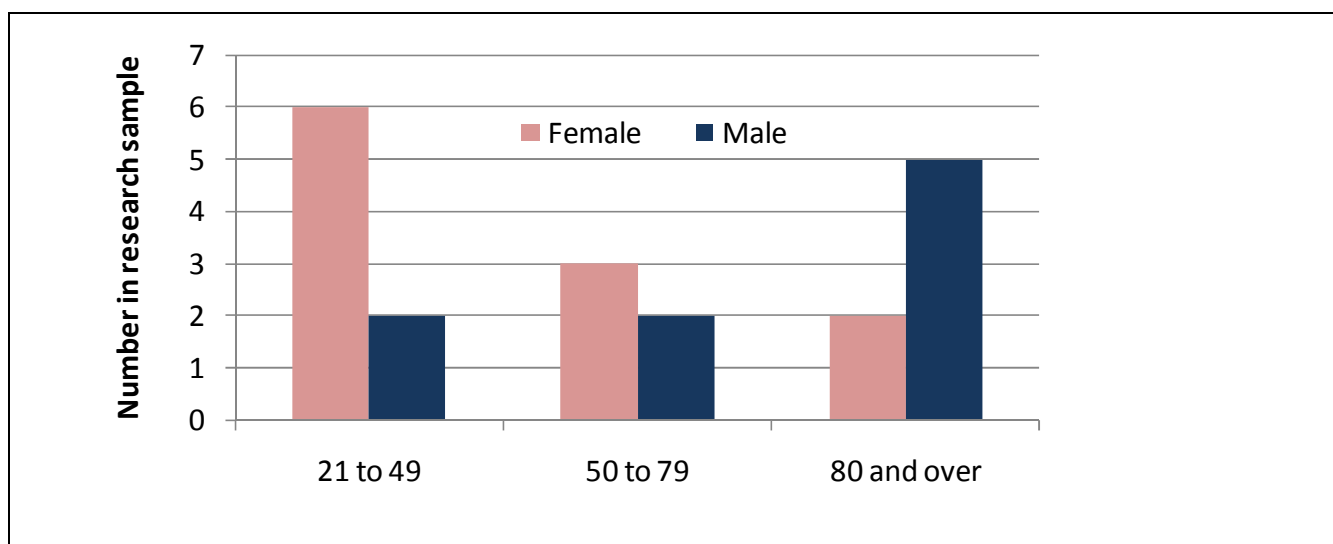
20 recipients of social care services in Oxfordshire have been interviewed in the first phase of a qualitative longitudinal research project looking at experience of Self Directed Support.

Difficulties with developing the research sample have meant that the majority of respondents (16 out of 20) are currently receiving traditional social care services and 4 are receiving SDS. However all clients have provided views on the potential opportunities and issues with the concept of (or reality of) SDS.

It is recommended that interviews with these respondents are repeated in 2011 to allow the LINK to understand the process of transfer onto SDS.

Respondents in this sample are relatively well distributed by age, gender and geographical location and are representative of a wide range of health conditions (see annex for full details). In our view all clients would be categorised as having “critical and substantial” needs.

**Figure 1 LINK research sample by client’s age and gender**



## 2.2 Main findings

### 1. Respondents have highlighted the perceived and actual advantages of Self Directed Support as a system giving more choice, flexibility and an opportunity to meet social needs.

- *Could help to improve client's stimulation and access new opportunities* [client with traditional services]
- *SDS could be an opportunity to develop interests* [client with traditional services]
- *"SDS has been good for providing more options including more flexible and better respite"* [SDS client]
- *SDS is "cutting out the bits in the old system that didn't work [for us] – like the evening carers". Now daughter does the evening shift which means money can be used for things the client enjoys and wants to do* [SDS client]

### 2. A good broker is important in successful delivery of SDS.

- *"Broker was KEY"* [SDS client]
- *A lot of changes at the start (including a change of day centre) but broker supported them throughout.* [SDS client]
- *"Process of setting up was good because of the work of the broker"* [SDS client]
- *Broker seemed to "reduce the time that everything took to arrange"* [SDS client]

### 3. There is experience of (and a fear of) an additional burden of administration on clients and carers.

- *SDS clients need to be able to use a computer – "if [you are] not computer literate then how else would you do this?"* [SDS client]
- *"the paperwork is a CHORE I'd rather not have but can't see how the personalisation element would work if I didn't get involved"* [SDS client]
- *you "do have to think of everything in advance and let everyone know" (taxi, day centre etc) – whereas in the old system there was "one port of call and they cancelled everything"* [SDS client]
- *"They're offloading the bureaucracy onto Carers. I'm 77 and the last thing I want is more paperwork"* [client with traditional services]

- *“Finding new Personal Assistants is very hard”* [client with Direct Payments]

**4. Consistent and personalised communication at every stage is very important.**

- *“Having maximum amount of choice and control is really good. But at the same time it’s good to have advice and support in setting it all up”* [client with Direct Payments]
- *“Wish it wasn’t so hard to find out where to get help from and that the help was proactive”* [client with Direct Payments]
- *“No one explained to me properly what Self Directed meant”* [SDS client]
- *“The lines of communication have been blurred, who does what”* [SDS client]
- *“Would have been nice to have someone come in from OCC amongst all this upheaval and tell me what was happening with the changes. I would have felt more involved in the process”* [client with traditional services]
- *“Rules are so complex”* [client with Direct Payments]

**5. There is a need for properly independent user-led support.**

- *A4E are “more like Social Services” – there has been a blurring of independence. “They [A4E] really don’t know what it’s like.* [client with Direct Payments]

**6. There is the possibility of rural disadvantage.**

- *We are a “bit remote and were asking for 45 mins per day, 3-4 days per week. Couldn’t get anyone to come and help”.* [client with traditional services]



### 3 Views of Self Directed Support

All respondents in the survey were asked for their view of Self Directed Support.

- In the case of those still in receipt of traditional services, respondents were asked first whether they were aware of SDS and were then given some information on the new system (provided to us by Oxfordshire County Council) before being asked for their reaction / opinion.
- In the case of respondents already in receipt of SDS, the discussion focused on the details of the process of being moved to SDS and then how that experience was for the client - "how was it for you".

This section reports on the views of these two groups (non-SDS and SDS) separately.

#### 3.1 Non-SDS respondents

Respondents in this study who were still receiving traditional care services **were generally aware of Self Directed Support** although some were confused about the difference between SDS and Direct Payments.

- It may be that the relatively high level of awareness is influenced by the sample which has mainly been drawn from people already in contact with the LINk (some having attended a LINk/OCC event) and who are, therefore, likely to be more informed than the average.

Direct Payments was mentioned by four of the non-SDS group (two are currently in receipt of DPs, one has given up with DPs and one had heard about it from others). There were clearly some issues with the current Direct Payments system.

- *Used to do Direct Payments. The system" is confusing" and it is "a bit of a minefield" trying to become an employer.*
- *"Finding new Personal Assistants is very hard".*
- *"Others experience of Direct Payments is that it is complicated and slow and you have to write it all down".*

Our assessment of the discussions with non-SDS respondents shows that **most were neutral or positive about the idea of Self Directed Support**.

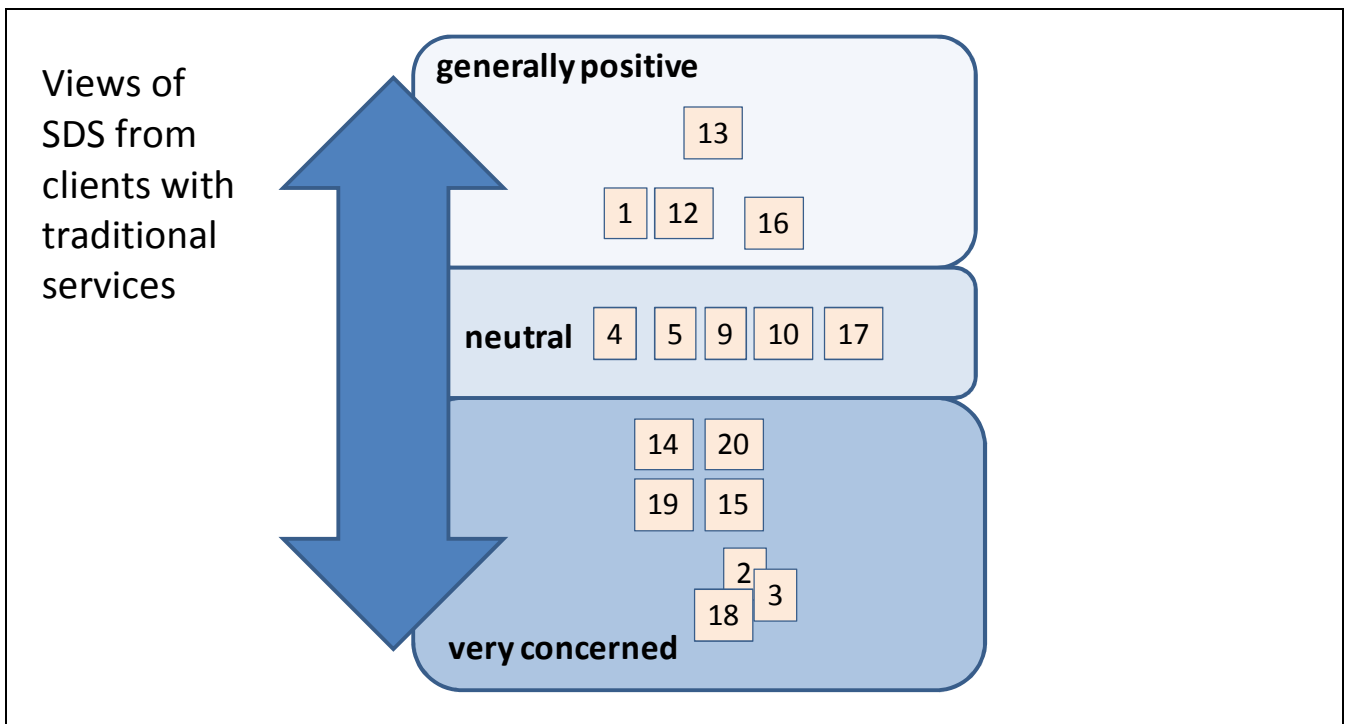
- *"Have heard about SDS but don't know whether it will be any good".*
- *Could help to improve [client's] stimulation and "access new opportunities".*
- *SDS "sounds simple, positive". Like the idea of a broker to help.*

**7 out of 16 however had some concerns.**

- *“Why fix something that isn’t broken”.*
- *“have heard that SDS is complicated”.*
- *“They’re offloading the bureaucracy onto Carers. I’m 77 and the last thing I want is more paperwork”.*
- *“I would rather it would carry on as it is. It works OK”*

The following chart shows how the view of non-SDS respondents’ varied – from generally positive to very concerned (each number is a separate response).

**Figure 2 Non-SDS respondents’ views of Self Directed Support (number = respondent reference)**



Analysis of discussion in section 4 of guide “Awareness of SDS”

We also found some suspicion of the motivation for introducing Self Directed Support and a worry that costs will go up.

- *“is it being brought in to save OCC money?”*
- *“I bet everything would be more expensive if we had to pay”*

**Table 1 Non-SDS respondents' views of SDS – in detail**

Ref	View of Self Directed Support
1	<p><i>Responses provided by main carer (daughter)</i></p> <p>“Sounds like a good idea”</p> <p>Not likely to employ carers</p> <p>Would employ someone to take client out</p> <p>Could help to improve client’s stimulation and access new opportunities</p> <p>Would be happy to manage the financial side</p>
2	<p><i>Responses provided by client</i></p> <p>“a bit worried about SDS”</p> <p>“can’t see it would change [the support] as I would still need an agency to provide all the care components”</p> <p>“SDS might be more flexible but so are my agency”</p> <p>“Why fix something that isn’t broken”</p>
3	<p><i>Responses provided by main carer (mother)</i></p> <p>OCC “keep changing things all the time”.. “a little bit worrying”</p> <p>Would be good to arrange a holiday – maybe that would help – but you would still have to pay for the day centre as well.. so might not be enough money?</p> <p>“I bet everything would be more expensive if we had to pay”</p>
4	<p><i>Responses provided by client and carer (son)</i></p> <p>“would it [SDS] mean more work for my son? [carer]”</p> <p>“is it being brought in to save OCC money?”</p>
5	<p><i>Responses provided by client</i></p> <p>“sounds alright to me”</p> <p>Wouldn’t change anything at the moment, already pays for everything and sorts out payment etc</p>
9	<p><i>Reponses provided by main carer (spouse)</i></p> <p>Client receives Direct Payment which covers a Personal Assistant</p> <p>Wish it wasn’t so hard to find out where to get help from and that the help was proactive</p> <p>Carer feels client is between physical health/NHS and the mentally ill network and that at times they fall down between – with nothing really being achieved</p> <p>Carer suggests that what is needed is:</p>

	<ul style="list-style-type: none"> <li>• Partners assessed as individuals (not as a couple)</li> <li>• A key person for advice and information</li> <li>• Someone available to help carer organise finances and respite etc</li> </ul>
10	<p><i>Reponses provided by main carer (spouse)</i></p> <p>Carer needs more confidence in the services provided for client.</p> <p>Feels “at a loss” with regard to respite.</p> <p>Main issues are the loneliness and expense of things</p>
12	<p><i>Reponses provided by main carer (spouse)</i></p> <p>SDS “sounds fine”</p> <p>Would like a wheelchair (replacement) and a holiday. (Have already got hand rails everywhere)</p>
13	<p><i>Reponses provided by client and main carer (mother)</i></p> <p>SDS sounds good</p> <p>It would be good for the client to be able to get out and about more and become more independent. Client used to attend college and was able to travel independently.</p> <p>SDS could be an opportunity to develop interests.</p>
14	<p><i>Reponses provided by main carer (aunt)</i></p> <p>Main issue is the importance of training for carers and other professionals in the appropriate way to communicate with the client (“not talk over the person”).</p> <p>No strong views about SDS</p>
15	<p><i>Reponses provided by main carer (mother)</i></p> <p>“have heard that SDS is complicated. That you need a broker”</p> <p>Others experience of Direct Payments is that it is complicated and slow and you have to write it all down.</p> <p>Main issue is where client will live in the future – in a flat/house or in a community setting.</p>
16	<p><i>Responses provided by client</i></p> <p>SDS “sounds simple, positive”. Like the idea of a broker to help.</p> <p>But “we’re OK at the moment”</p> <p>Used to do Direct Payments via A4E but couldn’t find anyone to come out to the village and help for the hours needed (45mins per day on 3-4 days per week).</p> <p>Direct Payments system “is confusing” and it is a “bit of a minefield” trying to become an employer</p>

17	<p><i>Responses provided by spouse of main carer</i></p> <p>Have heard about SDS but don't know whether it will be any good.</p> <p>Main (recent) issues are need for a downstairs shower (which OCC are not able to prioritise) and the lack of interpreters (client unable to speak English) at the JR.</p>
18	<p><i>Reponses provided by main carer (spouse)</i></p> <p>Reaction to the idea of SDS: "They're offloading the bureaucracy onto Carers. I'm 77 and the last thing I want is more paperwork".</p> <p>Will have to show where the money has gone. "oh no leave things as they are"</p> <p>"To be honest – once you've been given the money the Care Agencies will put their prices up (that's what I think anyway)"</p>
19	<p><i>Responses provided by daughter</i></p> <p>Opinion of SDS: "I would rather it would carry on as it is. It works OK"</p> <p>Happy with Carer, the company seems good.</p> <p>Can't think that SDS would improve it</p>
20	<p><i>Responses provided by client</i></p> <p>Client receives Direct Payments which covers employment of Personal Assistants.</p> <p>"Not sure of the difference between SDS and Direct Payments".</p> <p>Don't know how Care Managers will get involved.</p> <p>It is a difficult balance – control vs support</p> <p>"Having maximum amount of choice and control is really good. But at the same time it's good to have advice and support in setting it all up." So a good broker would allow as much control as would want.</p> <p>Some people wouldn't be able to take responsibility.</p> <p>With a personal budget perhaps things (eg assessment for wheelchair) will be faster.</p> <p>Finding new PAs is very hard. Took a huge effort to find a new one – could have benefited from more support in that process. But support would need to fit with client's abilities (i.e. NOT 6 interviews in one day)</p>

### 3.2 Respondents already moved to SDS

The small number of respondents (4 out of 20) already on Self Directed Support that we were able to include in this 2010 phase of the research (see introduction) gave mixed feedback on their experience.

Positive comments highlighted **the important role of the broker and the flexibility of Self Directed Support.**

- 👍 *A lot of changes at the start (including a change of day centre) but broker supported them throughout. Broker protected them from “pushy day centre staff” wanting to know how much money the client had to spend from the assessment.*
- 👍 *Broker seemed to reduce the time that everything took to arrange.*
- 👍 *“Some money worries are reduced”.*
- 👍 *“SDS has been good for providing more options including more flexible and better respite”.*
- 👍 *SDS is “cutting out the bits in the old system that didn’t work [for us] – like the evening carers”. Now daughter does the evening shift which means money can be used for things the client enjoys and wants to do.*

Issues included **a lack of communication and the burden of administration.**

- 👎 *“No one explained to me properly what Self Directed meant”*
- 👎 *“The lines of communication have been blurred, who does what”*
- 👎 *lack of clarity about extra respite hours*
- 👎 *SDS clients need to be able to use a computer – “if not computer literate then how else would you do this?”*
- 👎 *“the paperwork is a CHORE I’d rather not have but can’t see how the personalisation element would work if I didn’t get involved”.*
- 👎 *you “do have to think of everything in advance and let everyone know” (taxis, day centre etc) – whereas in the old system there was “one port of call and they cancelled everything”.*

There was also an issue about **lack of information** in the process of setting up care.

- 👎 *Had to find carers personally - was difficult “how can you choose if there is no-one to choose from?”*

**Table 2 SDS respondents' views of SDS – in detail**

Ref	Views of Self Directed Support
6	<p><i>Responses provided by client</i></p> <p>SDS is meeting care needs and improving well-being</p> <p>Relieved that some of the money worries are reduced (was receiving no care before SDS)</p> <p>Has asked OCC to take back the management of SDS finances</p> <p>Concerned that SDS clients need to be able to use a computer</p> <p>Had to find carers personally - was difficult "how can you choose if there is no-one to choose from?"</p>
7	<p><i>Reponses provided by main carer (mother)</i></p> <p>Huge issues with organisation of SDS</p> <p>"No-one explained to me properly what Self Directed meant".</p> <p>Means test process was not good.</p> <p>Real problem for client's family keeping track of "who is doing what".</p> <p>The client contribution was not explained until it was too late and the care had been established. Response was "weren't you told..." hears this a lot from OCC.</p> <p>Broker left and mother had to take over all the organisation of SDS.</p> <p>The lines of communication have been blurred, who does what etc</p> <p>Transport money not being taken out of account. Delay meant money built up in SDS account (8 weeks payment is maximum allowed).</p> <p>SDS has enabled client to go to day centre which client "enjoys a lot" BUT at a cost emotionally to family's wellbeing especially mother.</p>
8	<p><i>Most responses provided by main carer (mother)</i></p> <p>"Broker was KEY"</p> <p>A lot of changes at the start (including a change of day centre) but broker supported them throughout.</p> <p>Broker protected them from "pushy day centre staff" wanting to know how much money the client had to spend from the assessment.</p> <p>No issues with the financial side of SDS</p> <p>However the respite time for carer is taken up with SDS paperwork "the paperwork is a CHORE I'd rather not have but can't see how the personalisation element would work if I didn't get involved".</p>

11	<p><i>Responses provided by client and daughter</i></p> <p>Broker assessed needs and developed support plan.</p> <p>But currently there is lack of clarity about extra respite hours.</p> <p>Finances all sorted by A4E, invoices are sent to A4E who then reimburse.</p> <p>SDS has been good for providing more options including more flexible and better respite – the days needed.</p> <p>Used a PA at the start – worked very well but as they live in a rural village and had to pay travel time it was too expensive. Would “love” to have this again.</p> <p>Broker seemed to reduce the time that everything took to arrange.</p> <p>SDS is “cutting out the bits in the old system that didn’t work [for us] – like the evening carers”.</p> <p>Now daughter does the evening shift which means money can be used for things the client enjoys and wants to do.</p> <p>However you “do have to think of everything in advance and let everyone know” (taxis, day centre etc) – whereas in the old system there was “one port of call and they cancelled everything”.</p>
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## 4 Are care needs met?

Our discussions with respondents – clients and carers – included general background on the client such as the clients’ hobbies and social networks.

This section provides an overview of this aspect of the research – the role of informal carer(s), family members and friends, and the degree to which the client is able to interact with others.

It also includes the client’s (or carers) perspective on the degree to which their care needs are met.

### 4.1 Social contact

Most people in this research have limited social contact outside of their immediate family/carers. This is perhaps unsurprising given that clients in our sample were living with serious and limiting health conditions.

Some people however were able to stay in touch with a wide group of friends despite being in relatively poor health or with limited mobility.

### 4.2 Experience of care

Some clients have experienced difficulties in establishing an appropriate level of care.

- There was an issue with a client finding care in a rural village. *“Difficult to get help if looking for a small number of hours”*;
- *Setting up SDS did not go well.*

Many of the survey respondents mentioned the need for better communication about care - access to information or to help and advice in the process of changing care.

- *[Contact with Social Services] is “never smooth sailing, constantly hanging on the phone trying to get through”.*
- *“Would have been nice to have someone come in from OCC amongst all this upheaval and tell me what was happening with the changes. I would have felt more involved in the process”.*
- *“Rules are so complex”.*

Four out of the seven respondents attending day centres made unprompted positive comments about their centre.

- *“Loves the day centre”*

- Day centre is “really really terrific”
- “Well looked after at day centre”

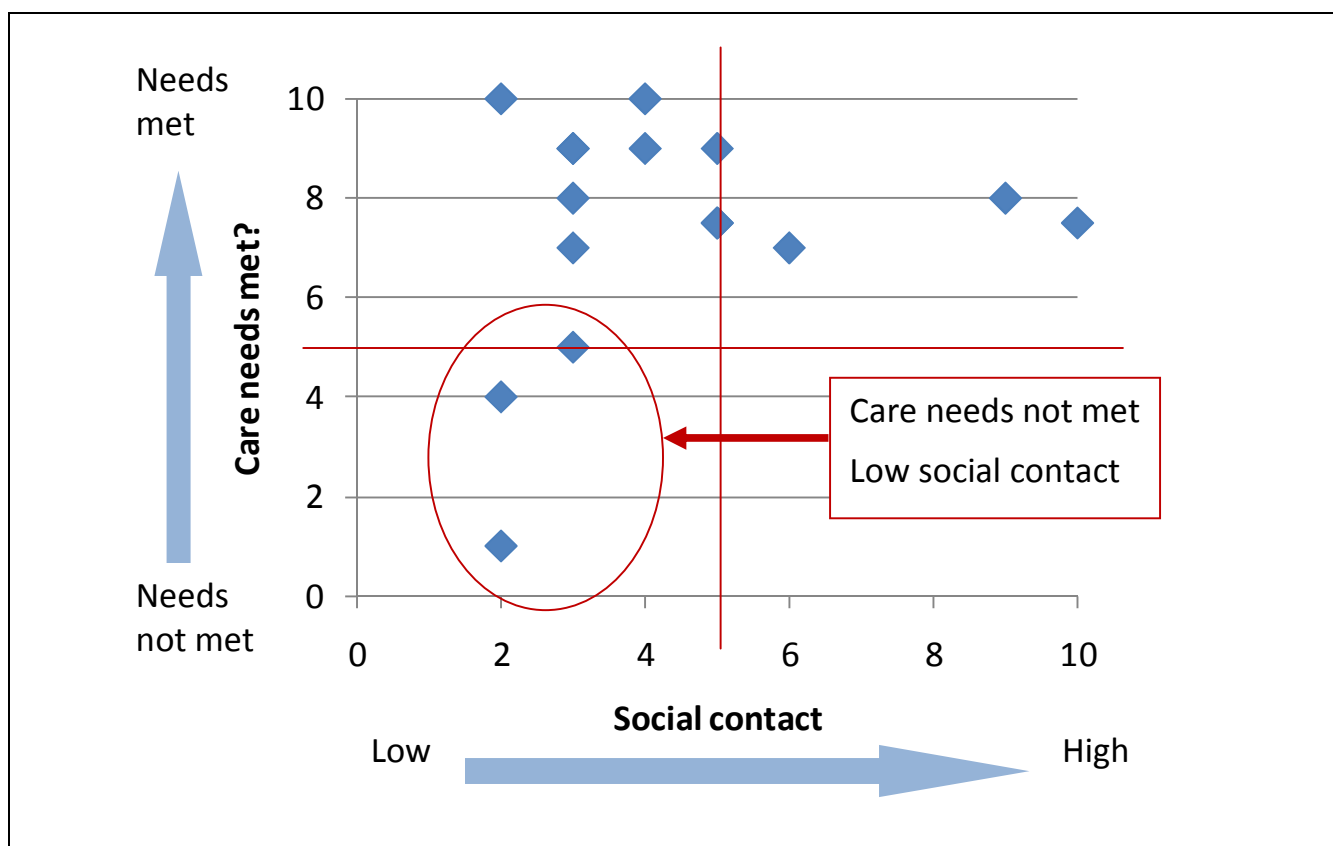
The following chart maps the respondents’ assessment of whether care needs are currently met against our assessment of their current level of social contact.

The chart shows that most people in our survey have low or limited contact with others (5 or below on the horizontal scale) although two in the group are very well connected.

Most rated their care needs as 7 or above (vertical scale) – i.e. their need for personal care is currently mostly or fully met.

However there is a small group (three respondents) with low social contact and where their need for care is (by their own – or their informal carers - assessment) not yet adequate.

Figure 3 Care needs met vs social contact



Analysis of discussion in section 2 of guide “Your personal and social networks”

**Table 3 Personal & social networks and experience of support – in detail**

Ref	Personal and social networks	Experience of support	Care needs met?*
1	<p>Unable to join in activities or conversation</p> <p>Frequent contact with family</p> <p>No connection with community other than health services</p>	<p>Daughter has to make contact with social services and notify if client is admitted to hospital (because of carers allowance).</p> <p>This is “never smooth sailing, constantly hanging on the phone trying to get through”.</p> <p>Confusing information given on whether or not to notify.</p>	7
2	<p>Very sociable and well connected</p> <p>Sees family and friends regularly</p> <p>Is known to shop staff who support the shopping visits</p> <p>Has daily carers</p>	<p>Generally re OCC “they do listen”</p> <p>3 years ago OCC decided to change to a new company providing care. Would have helped if someone had come out to explain the change (had got to know carers really well “bit of a shock”).</p> <p>“Fears were unjustified” the new carers are “very reliable and punctual”</p> <p>“Would have been nice to have someone come in from OCC amongst all this upheaval and tell me what was happening with the changes. I would have felt more involved in the process”.</p>	7.5
3	<p>Main social contact is with mother (main carer)</p> <p>Regular at the local day centre</p>	<p>“Loves the day centre”</p> <p>OCC “keep changing things all the time. A little bit worrying”</p> <p>Happy with the way things are at the moment</p> <p>Does feel that OCC listens</p>	7.5
4	<p>“spends a lot of time sitting”</p> <p>Has daily carers and attends local day centre</p> <p>Some contact with friends and family</p>	<p>Care manager is “very responsive”</p> <p>Lack of choice of care companies. Current company is “becoming bad”.</p> <p>Carers loaded with too many clients.</p> <p>Day centre is “really really terrific”</p> <p>Not warned about increasing cost of incontinence pads</p>	10
5	<p>Has daily carers and visits day centre</p> <p>Has warden on site</p> <p>Able to read</p> <p>Some contact with family</p> <p>Limited connection with other groups</p>	<p>Smooth process from GP to getting OCC round and implementing care package</p> <p>“Good carers”</p> <p>But “sometimes carers don’t come until 11am and that is half the day gone, I have always been an early riser”</p> <p>“Well looked after at day centre”</p>	9

6	<p>Lives with spouse Very limited contact with other family Not able to be part of local groups or local community Carer once a week</p>	<p>Client is on SDS All new to the client as wasn't receiving anything before SDS PB meets care needs and has improved wellbeing of spouse</p>	9
7	<p>Lives with immediate family Attends Day Centre Not able to form relationships in community</p>	<p>Client is on SDS Very poor experience of SDS Setting up SDS did not go well. Main carer is client's mother who worries a lot about the money in the SDS account and feels her wellbeing has suffered as a result. Example of taxis always late but taxi companies only taking instruction from OCC transport "it's horrible, you think something is sorted..."</p>	7.5
8	<p>Main social contacts are immediate family, support worker and day centre</p>	<p>Client is on SDS Mum is main carer, didn't look for personal care but for help with socialising and keeping client occupied. All new as wasn't receiving anything before SDS SDS has meant client is more connected to the wider world – laptop, Day Centre, Support worker "good experience so far"</p>	9
9	<p>Loss of confidence due to illness Client does not like to socialise much Limited social contact</p>	<p>Client on Direct Payments Clients needs have changed over past 2 years but spouse doesn't know how to get this reviewed. Spouse finds it exhausting and wearing keeping track of where you are and who you have had conversations with "I am an intelligent and reasonable person – how do others cope?" Would help if those helping were proactive – "a person who can approach us and tell us what is available instead of me having to go cap in hand to them" Feels client is between Physical Health/NHS network and Mentally Ill network and teams don't communicate so they fall down between both. "Rules are so complex" Spouse very interested to hear about broker system</p>	4

10	<p>Can't join in many activities</p> <p>Some contact with immediate family</p> <p>Has daily carers</p> <p>Attends a day centre</p>	<p>Had bad experience with respite when husband ended up in hospital with dehydration</p> <p>Worst part of arranging care has been having to share finances with OCC – spouse felt “all exposed, we had been such a private family up until then”</p> <p>“there are expenses that people just don't understand when you are looking after someone”</p>	5
11	<p>Social contact limited to main carer (daughter)</p> <p>Attends lunch club in the village</p> <p>Attends day centre</p> <p>Has relief respite carer</p>	<p>Client is on SDS</p> <p>Needs are mainly met</p> <p>Process of setting up was good because of the work of the broker</p> <p>Lacks a key person at OCC who “glues it all together”</p> <p>Issues of sorting transport and training of carers to use hoist (especially when in clients home)</p>	8
12	<p>Unable to get out much</p> <p>Telephone contact with immediate family</p> <p>Able to call neighbour in an emergency</p>	<p>When Social Services came the client was between care home and hospital. According to Carer: “I was so confused I didn't know what was going on. I couldn't think straight”.</p> <p>“Everyone was good. It was all very smooth. Person from Social Services was very very good. I sent a card after saying “thank you”.”</p>	No response
13	<p>Client is sociable but doesn't like crowds or noise</p>	<p>Main support is the provision of the place at the residential home. Is in the process of moving to new home with more independent living,</p> <p>Wants more choice and control particularly over finances and buying food</p> <p>Would be good if client could find things to do personally – not relying on others all the time. Likes to be independent.</p>	No response
14	<p>Not able to join in activities</p>	<p>Big issues with Carers including one carer found to be an illegal immigrant and removed. This upset client and aunt as they had been close to the carer.</p> <p>Transport has always been an issue.</p>	No response
15	<p>Very active and very well supported by family and social groups</p> <p>Main support from immediate family. Other support from Personal Trainer, church, sports and social clubs</p>	<p>“On the whole OCC have been quite good”.</p> <p>Parents have had to be firm about getting client access to activities. Otherwise may have ended up being allocated less.</p> <p>Chose NOT to go onto direct payments. Have heard from others that Direct Payments is complicated and slow – “you have to write it all down”.</p>	No response

16	Don't go out much Sit and watch TV most of the day Doesn't do anything alone	Have the support of spouse most of the time Two hours help per week from OCC Difficult to get help if looking for a small number of hours	7
17	Not able to join in activities	"Carers are a great help but they don't have enough time" As client can no longer go upstairs has to be bathed in the toilet downstairs "very undignified". Have asked OT for shower but told "can't put [client] on the priority list" why not? Trying to contact Care Manager not always easy. Have to leave messages.	1
18	Confined to house	Process of organising carers was fine and did take into account views of client and wife. Problem with respite is that it runs from Wednesday to Wednesday. "I have nothing but good to say about the carers group at Didcot"	10
19	"quite likes own company" "does own garden" Has daily carer Neighbour checks daily	Care was organised via social services at JR – all was fine with this process. Carer lives close by and is the regular Carer unless on holiday. Doesn't attend day centres, daughter thinks "it would do [client] good" won't be persuaded	9
20	Unable to participate in as many activities as would like Has "varied from being housebound to virtually bedbound" A lot of social contact	Has Direct Payment to employ PAs Given "Alternative to Day Care" grant, more flexible than PAs Although it is hard work "Direct Payments works well for me"	8

\*Support needs met? Is from question with a scale of 1 to 10 where 1=Very unhappy, needs not met; 5=needs partly met; 10=Very happy, needs fully met

## ANNEX 1 – Profile of respondents

A total of twenty people in receipt of social care services have participated in this study. Four of the twenty respondents are on Self Directed Support and two others have Direct Payments.

The research sample is relatively well distributed by age, gender and geographical location. Client respondents are representative of a wide range of health conditions (see tables below).

**Table 4 LINK research sample by client’s age and gender**

Aged..	Female	Male
21 to 49	6	2
50 to 79	3	2
80 and over	2	5
<b>TOTAL</b>	<b>11</b>	<b>9</b>

**Table 5 Link research sample by district of home location**

Cherwell	3
Oxford	5
South Oxfordshire	3
Vale of White Horse	5
West Oxfordshire	4

**Table 6 LINK research sample by living arrangements**

Living alone	4
Lives with husband/wife and no others	6
Lives with family	9
In residential home or hospital	1

**Table 7 LINK research sample by ethnicity**

White British	19
Asian or Asian British (Indian)	1

**Table 8 Health condition of clients in LINK research sample**

Blind and has learning disabilities
Degenerative neurological condition
Development Delay, poor spatial awareness, limited language/social skills
Downs Syndrome
Generally in good health. Recently broke a hip
Housebound due to poor health
Has had strokes, poor memory, poor mobility
Learning disabilities, epilepsy
ME
Multiple Sclerosis
Parkinsons and Dementia
Parkinsons and depression/anxiety
Poor mobility
Poor mobility & bad arthritis
Poor mobility, breast cancer
Stroke, dementia
Stroke, prostate cancer
Wheelchair, neurological condition
Wheelchair, progressive heart problems
Wheelchair, stroke

All respondents are happy to be contacted again by the researchers.