Adult Services Scrutiny Committee 7th September 2010

LINk research into Self Directed Support – update on progress

Report prepared on behalf of the Oxfordshire LINk by Margaret Melling (12th August 2010)

1 This report in summary

- 1.1 19 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. The project, sponsored by the Oxfordshire LINk and supported by Oxfordshire County Council, has been carried out by independent consultants Margaret Melling and Helen Grimwade with the assistance of LINk staff.
- 1.2 Difficulties with developing the research sample have meant that the majority of respondents (15 out of 19) 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.
- 1.3 In addition it is recommended that interviews with these respondents are repeated in 2011 to allow the LINk to understand the process of transfer onto SDS.
- 1.4 Respondents in this sample are relatively well distributed by age, gender and geographical location and are representative of a wide range of health conditions.
- 1.5 Findings from this phase of the study will be presented to the Adult Service Scrutiny Committee at the meeting in October 2010.

2 Introduction and research method

- 2.1 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.
- 2.2 As part of this work the LINk commissioned an independent research project, starting in 2010, to understand people's experience of the new system of Self Directed Support and Personal Budgets.
- 2.3 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.
 - o The national evaluation of the Individual Budgets Pilot programme¹ found in 2008 that the feedback from users was affected by the process of <u>changing</u> to the new system rather than reflecting simply on the new system itself.
- 2.4 For these reasons the chosen methodology was in-depth face-to-face discussions (qualitative research) carried out by a trained healthcare professional.
- 2.5 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.
- 2.6 It is recommended that this study is developed into longitudinal research with follow up discussions in 2011 at a time when the respondents have been transferred to SDS.

3 Developing the research sample

- 3.1 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.
- 3.2 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 SDS², based on a feedback from 14 respondents (clients or carers) was published in October 2009 and a follow up report was planned in 2010.
- 3.3 Starting April 2010 OCC gave priority to finding research respondents for this LINk-sponsored research, but by June 2010 only one person had come forward who subsequently became too ill to participate.
- 3.4 This left the LINk research project with no respondents directly provided by Social and Community Services.
- 3.5 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;

¹ Individual Budgets Evaluation Network (IBSEN) on behalf of Dept of Health php.york.ac.uk/inst/spru/pubs/1119/

² Self Directed Support learning exercise evaluation, 15th October 2009, Nick Horn

- Contact with attendees of the "Hearsay!" event (a joint OCC/LINk event);
- Other publicity via the health bus and LINk newsletter.
- 3.6 This effort meant that the research was able to proceed, albeit with fewer SDS clients than we would have liked.

4 Next steps

- 4.1 The full research report including key findings, case studies, views on social care and on SDS is in the process of being prepared and is planned to be available for the October meeting of the Adult Services Scrutiny Committee.
- 4.2 The consultants are planning to attend this meeting to present the key findings and answer any detailed questions on the research.

ANNEX - Profile of respondents

- A.1 In total 19 people in receipt of social care services have participated in this study. Four of the 19 respondents are on Self Directed Support and one other has Direct Payment.
- A.2 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 1 LINk research sample by client's age and gender

| Aged | Female | Male |
|-------------|--------|------|
| 21 to 49 | 5 | 2 |
| 50 to 79 | 3 | 2 |
| 80 and over | 2 | 5 |
| TOTAL | 10 | 9 |

Table 2 Link research sample by district of home location

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

Table 3 LINk research sample by living arrangements

| Living alone | 4 |
|---------------------------------------|---|
| Lives with husband/wife and no others | 6 |
| Lives with family | 8 |
| In residential home or hospital | 1 |

Table 4 Health condition of clients in LINk research sample

Blind and has learning difficulties

Degenerative condition affecting muscles and balance

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 difficulties, epilepsy

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

- A.3 10 of those interviewed were generally positive about their experience of social care and 9 had specific issues that they wished to raise. These will be detailed in the report on findings to be available in October 2010.
- A.4 All respondents are happy to be contacted again by the researchers.