
Professor Chris Hatton, John Waters, Simon Duffy, Jonathan Senker, Nic Crosby, Carl Poll, Andrew Tyson, John O’Brien, David Towell

Edited by Carl Poll and Simon Duffy

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Foreword

in Control is at the cutting edge of Public Service reform in this country.

Its innovative and ground-breaking work has been a major factor in ensuring that Self-Directed Support and Personal Budgets are now at the heart of a radical social care transformation programme which will begin this April in every local authority area.

People, irrespective of their age, disability or illness have a right to exercise maximum control over their own lives. in Control has demonstrated that this approach to the relationship between support services, individuals and families leads to better outcomes which are affordable and result in high levels of user satisfaction.

A just society requires all citizens to have the chance to pursue their aspirations, make the most of their talent and have a decent quality of life. By challenging traditional ways of working and conventional wisdom, in Control has moved ‘People Power’ from the margins to the mainstream of the debate about the need for a new adult support and care system in our country.

Ivan Lewis MP
Parliamentary Under Secretary of State for Care Services
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Introduction

A report on in Control’s Second Phase 2005-2007. This report looks back on the last two years of in Control’s work.

In 2003, in Control began work on the development of a new model for social care. The model evolved in a circular process of testing, learning, revising and testing again – at first with six local authorities, and later with many more.

in Control’s earlier work is analysed in A report on in Control’s first phase 2003-2005. This report can be downloaded from in Control’s library: www.in-control.org.uk – search for document number 0128 (or 0129 for a summary).

The present report continues the story. Some things have remained the same, for example, in Control’s operating system which, as John O’Brien and David Towell write in Chapter 7, mediates ‘between Government policy and citizen experience’. Some things have changed. Over 100 local authorities are now in Control members and are implementing Self-Directed Support. People from all ‘social care groups’ are directing their own support. In Putting People First, the government has announced a major transformation of the social care system based on Personal Budgets.

This report appears when about 3,500 people direct their own support. The government’s commitment to change means that many thousands more will soon be offered more control.

in Control hopes that this report will assist the creation of a new system in which everyone who needs support will have genuine power and control.

The report is in two parts:

Part One is an evaluation by Professor Chris Hatton of Lancaster University and John Waters.

Part Two contains seven chapters in which different authors reflect on the lessons offered by in Control’s work in important subject areas: Self-Directed Support – a universal system; economics; support planning and brokerage; children and young people; community; commissioning and provision; and in Control’s role.

For more information about in Control: www.in-control.org.uk
in Control’s Principles

These are the principles that underpin Self-Directed Support and all of in Control’s work. The test of systems and processes claiming to be part of Self-Directed Support is: do they embody these principles? Would an individual make the statements below each principle?

1. Right to Independent Living

If someone has an impairment which means they need help to fulfil their role as a citizen, then they should get the help they need.

‘I can get the support I need to be an independent citizen.’

2. Right to a Personal Budget

If someone needs on-going paid help as part of their life they should be able to decide how the money that pays for that help is used.

‘I know how much money I can use for my support.’

3. Right to Self-Determination

If someone needs help to make decisions then decision-making should be made as close to the person as possible, reflecting the person’s own interests and preferences.

‘I have the authority, support or representation to make my own decisions.’

4. Right to Accessibility

The system of rules within which people have to work must be clear and open in order to maximise the ability of the disabled person to take control of their own support.

‘I can understand the rules and systems and am able to get help easily.’
5. Right to Flexible Funding

When someone is using their Personal Budget they should be free to spend their funds in the way that makes best sense to them, without unnecessary restrictions.

‘I can use my money flexibly and creatively.’

6. Accountability Principle

The disabled person and the government both have a responsibility to each other to explain their decisions and to share what they have learnt.

‘I should tell people how I used my money and anything I’ve learnt.’

7. Capacity Principle

Disabled people, their families and their communities must not be assumed to be incapable of managing their own support, learning skills and making a contribution.

‘Give me enough help, but not too much; I’ve got something to contribute too.’

This statement is a distillation of In Control’s Ethical Values, a more detailed account of the values that underpin the whole of our work. Ethical Values can be found at http://in-control.org.uk/how/localAuthorities.php#values
Evaluation


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Professor Chris Hatton and John Waters
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Background

The social care system in the United Kingdom is about to undergo radical change. Central government has declared its intention to oversee large-scale reform. Local authorities which are responsible for meeting the community care needs of older and disabled people will be required to offer each individual eligible for support their own Personal Budget. This simple but far-reaching innovation is a marked departure from the way in which the current system is organised.

For this vision to become reality, local authorities will need to organise themselves very differently from the way they do at present. They will need new approaches in all areas of their activity including assessment, care planning, commissioning and service delivery.

For the local citizen, it is hoped that the introduction of Personal Budgets will allow a shift from the current situation – in which people who use services are often passive recipients of care – to one in which individuals and their families can design and control truly individual support packages. The Department of Health’s stated intention is to ‘reform the social care system to put choice, independence and dignity right at the heart of service delivery’.

in Control and Self-Directed Support

The concept of a Personal Budget was conceived and developed by in Control, as part of a new operating system for social care designed with the specific intention of promoting active citizenship. This new operating system is referred to as Self-Directed Support.

in Control was set up as a social enterprise by a number of partners, including the Department of Health, in 2003. Its primary focus was to explore ways in which the current system of social care might be reformed, in particular to develop a pragmatic and universal model of Self-Directed Support to progress the personalisation of social care services. in Control’s learning to date and an in-depth description of Self-Directed Support are available on the in Control website www.in-control.org.uk.

in Control’s initial work was carried out between 2003 and 2005 in six local authorities across England. This initial phase of work was confined to people with learning disabilities and has been reported elsewhere, including in a small-scale evaluation of the impact of Self-Directed Support on the lives of the people using it. The success of the work contributed to a number of developments in national policy, including the promotion of Personal Budgets within government policy documents.

Following this first phase, in Control opened up a membership programme for local authorities and embarked upon a second phase of work which began to identify ways of ensuring that its model was sufficiently flexible to work for all social care groups.

This report presents a snapshot evaluation of some of in Control’s Phase Two work. It is important to emphasise that this evaluation is not the result of a large-scale formal research project investigating the effectiveness of Self-Directed Support compared with the prevailing system of social care. Instead, like the evaluation of Phase One, it is part of an ongoing collaboration that attempts to develop low-cost methods for routinely monitoring Self-Directed Support as it develops.
Important components of this approach are that:

- The evaluation methods should be low-cost (including the cost of evaluation measures, the cost of collecting information and the cost of analysing the information).
- The questions being asked in the evaluation should be recognised as important by every group involved in the evaluation.
- The evaluation methods should impose a minimal burden in terms of time on the people being asked to provide information.
- The information provided should be analysed and reported in ways that can be used by the groups of people taking part and others interested in Self-Directed Support.
- Evaluation methods developed using this process should be freely available for use by others.

In this spirit, the project reported here was taken forward as an information-gathering exercise, seeking the views of people (or those close to them) who have gone through the Self-Directed Support process.

**Aims**

The project aimed to shed light on the early experiences of people taking control of Personal Budgets. It was hoped that the project would help shed some light on the following questions:

- Do people in the early stages of using Self-Directed Support think it has made a difference to their lives?
- Do people using Self-Directed Support know what a Personal Budget is for and what outcomes they should be aiming for?
- What support do people have to plan their lives and does the type of support used make a difference?
- Are there differences across social care groups, or according to age, gender or ethnicity?
- Are people spending money differently when they have control of their own budget?

**What we did**

In total we obtained information from 196 people who had been using Self-Directed Support.

**How we found people**

In Control maintains close working links with local authority managers who are implementing Self-Directed Support. These authorities report regularly the number of people they have supported to take control of a Personal Budget. This intelligence made it possible to readily identify areas of the country where people had taken control of a Personal Budget and to reach them in order to ask about their experiences of Self-Directed Support. All local authorities who had reported allocating Personal Budgets were invited to take part in the work.
For the purposes of the project, a person receiving support was deemed to have a Personal Budget if their local authority identified that the person or their advocate knew:

- the amount of money available to them to meet their needs and the outcomes to be achieved with the money and...
- that the person or their advocate had been given control over the money to the extent that they could spend the money on things, in ways and at times that were right for them.

In local authority areas where there were small numbers of people using Personal Budgets (less than 20), everyone was offered the opportunity to take part in the project. In local authority areas with larger numbers of people using Personal Budgets, the local authority identified a target number of participants and invited people at random to take part, continuing to invite participation until the target number had been reached or everyone had been invited to contribute to the project.

**What we asked them**

196 interviews with people using Self-Directed Support (sometimes with help from others close to the person) were conducted using a standard questionnaire.

In the interview, each participant was asked to report what difference, if any, having a Personal Budget had made in various aspects of their life. In each of the areas below, participants were asked to make a judgment as to whether things had improved, stayed the same, or got worse since the start of their Self-Directed Support, in respect of:

- health and well-being
- relationships
- quality of life
- opportunities to take part in or contribute to their community
- choice and control over the important things
- feeling of security at home
- personal dignity in support
- economic well-being
- life as a whole.

Interviews were carried out by both local authority staff and by independent staff recruited specifically to work on the project. Interviews were held both in person and over the telephone. All the interviews were completed between June 2007 and August 2007. Participants were informed that the information they supplied would be used to improve understanding of how Self-Directed Support is working, and all offered consent to information from the interview being used in this way.

**What we did with the information**

All the information was coded numerically into databases (Excel and SPSS) and statistically analysed by the first author. We hope that descriptive statistics (typically, numbers of participants or percentages) are clear in their meaning throughout the report.

Sometimes, we wanted to investigate if there were differences between groups (for example, are there differences in outcomes across social care groups?) or if there were associations between
people’s responses to different questions (for example, if a person reports an improvement in one area of their life are they also likely to report improvements in other areas of their life?). To investigate these types of questions we used relatively conservative non-parametric statistical tests. These tests all investigate the probability that the pattern of results we got occurred by chance – if the probability is low (less than 1 in 20; written as p<0.05) then we have assumed that the pattern of results we obtained is non-random and reflects something meaningful. The meaning of each statistical test is stated clearly in the text of the report, with each relevant test statistic reported as a footnote. Where the number of participants in a particular group was too small (typically less than 10 people; for example participants with sensory impairments) we did not use statistical tests.

Who took part?

In total, we had information on 196 adults in England who were then using Self-Directed Support although, because we didn’t get complete information for everyone, the numbers do not always add up to 196. This section briefly describes who provided us with information for this report.

Local authorities

These 196 people were living in seventeen local authorities across England. Because local authorities are at different stages in their implementation of Self-Directed Support, the number of people included in this report varied hugely across local authorities, from 1 person in one authority to 76 people in another authority (7 local authorities contributed information for 10 or more people – see the graph below). Because the number of people in many local authorities was small, we cannot compare local authorities in this report.

Social care groups

People in this project were identified as being from a wide range of social care groups (see the graph below). Over half the group was people with learning disabilities (58%), and there were
also enough people with physical disabilities (20%) and older people (13%) for us to do more analyses throughout the report.

![Figure 2](image-url)  
**Figure 2** Number of people by social care group

**Age, gender, ethnicity**  
As the graph below shows, people from a wide age range (18-95 years old) were using Self-Directed Support. On average, people with learning disabilities were younger (average age 30) than people with physical disabilities (average age 51), who in turn were younger than older people (average age 78)\(^7\).

![Figure 3](image-url)  
**Figure 3** Age across social care groups
Overall, there were slightly more men (54%) than women (46%). However, there were clear differences between social care groups, with more men than women in the groups of people with learning disabilities and more women than men in the group of older people.

As would be expected from general population data, White people formed the vast majority (89%), with smaller numbers of people across the broadly defined Census categories of Asian (8%) and Black (4%). Across the whole sample, there are too few people from ethnic groups other than White to look at possible differences across social care groups.

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**Figure 4** Number of men and women

![Number of men and women](image)

**Figure 5** Who answered the questions?

![Who answered the questions?](image)
Who answered the questions?
In the questionnaire, we asked people to record whether they had mainly answered the questions themselves; whether they had answered the questions themselves with help; or whether someone else had answered the questions on their behalf. For the whole group, the way the questions were answered was fairly evenly split. However, there were big differences across social care groups. Among the people with learning disabilities, only 4% of people answered the questions themselves and for 59% of people the questions were answered by someone else. In contrast, most people with physical disabilities and older people answered the questions themselves, with relatively few questions being answered by someone else (see Figure 5).

Self-Directed Support
In the questionnaire, we asked for some basic information on the Self-Directed Support people were using – this section briefly describes some aspects of the Self-Directed Support process.

Before Self-Directed Support
Overall, most people (70%) were using some form of social care support before taking up Self-Directed Support. Older people were less likely to have had social care support before directing their own support than people with learning disabilities and people with physical disabilities.

Figure 6 People using social care before

Time since start of Self-Directed Support
Overall, most people had been using Self-Directed Support for less than six months (64%), with smaller but substantial numbers using Self-Directed Support for longer periods. People with learning disabilities were more likely than people with physical disabilities and older people to have been using Self-Directed Support for longer than 6 months.
Help to plan Self-Directed Support

Almost everyone (96% of people) had received help to plan how they spent their budget.

Almost half of the people had help from family and/or friends (46%), with similar numbers receiving help from family and/or friends across social care groups\(^{12}\). Fewer people had help from a person paid specifically for the purpose (18%), with almost all of this support being used by people with learning disabilities and almost none of this support being used by people with physical disabilities or older people\(^{13}\). Overall, most people had help from a social worker (71%), with people with learning disabilities less likely to use this source of help than people with physical disabilities and older people\(^{14}\) (see graph below).

![Figure 7](image_url) How long using Self-Directed Support?

![Figure 8](image_url) Source of support for planning
Overall almost two-thirds of people (65%) had help with Self-Directed Support from one of the sources of support mentioned above, with just over a third (35%) having support from more than one source. People with learning disabilities were more likely to have help from more than one source of support than people with physical disabilities.

The Self-Directed Support process

Overall, almost everyone reported that they felt they had control over how their Personal Budget was spent (97%) and a vast majority felt they understood what they were supposed to be achieving with their Personal Budget (91%).

Most people (82%) also reported that they had changed how money for their support was spent, with no differences across social care groups or according to the length of time they had been using Self-Directed Support.

Costs

Cost information for people’s social care support before and after the introduction of Self-Directed Support was only provided for 35 people (24 of whom were people with learning disabilities) and the accuracy of this cost information has not been verified. For these reasons cost information is not used in this report.

Outcomes

In the questionnaire, we asked people 8 questions about whether various aspects of their lives had got worse, stayed the same or improved since starting to use Self-Directed Support. People scored generally consistently across the questions (for example, if a person reported improvement in one area they were more likely to report improvements in other areas); but with enough variation to suggest that the different questions were tapping into different aspects of people’s lives.

General health and well-being

Overall, almost half of people reported improvements in general health and well-being since starting Self-Directed Support (47%), with a similar number reporting no change (48%) and a minority of people (5%) reporting that their general health had got worse since starting Self-Directed Support.

Overall, people were more likely to report improvements in their general health and well-being if:

◆ they had been using Self-Directed Support for over a year rather than for a shorter length of time
◆ people had support from family and/or friends to plan their Self-Directed Support
◆ people had support to plan from a wider range of sources.

Within the group of people with physical disabilities, women were more likely to report improvements in their general health and well-being compared with men.
Within the group of older people, younger members were more likely to report improvements in their general health and well-being\textsuperscript{23}.

\begin{figure}[h]
\centering
\includegraphics[width=0.5\textwidth]{general_health_wellbeing.png}
\caption{General health and well-being}
\end{figure}

\textbf{Spending time with people you like}

Overall, a majority of people reported improvements in the time spent with people they liked since starting Self-Directed Support (55%), with a substantial number reporting no change (42%) and a minority reporting that things had got worse since starting Self-Directed Support (3%).

\begin{figure}[h]
\centering
\includegraphics[width=0.5\textwidth]{spending_time_like.png}
\caption{Spending time with people you like}
\end{figure}

Overall, people were more likely to report improvements in time spent with people they liked if they:

\begin{itemize}
  \item had support from their family and/or friends to plan their Self-Directed Support\textsuperscript{24}
\end{itemize}
◆ did not have support from a social worker to plan their Self-Directed Support\textsuperscript{25}.

Within the group of people with physical disabilities, people were more likely to report improvements in time spent with people they liked if they:

◆ were women rather than men\textsuperscript{26}
◆ were younger rather than older\textsuperscript{27}
◆ had support from their family and/or friends to plan their Self-Directed Support\textsuperscript{28}
◆ did have support from a social worker to plan their Self-Directed Support\textsuperscript{29}.

Quality of life

Overall, a large majority of people reported improvements in their quality of life since starting Self-Directed Support (76%), with a minority reporting no change (23%) and a small minority reporting that things had got worse since starting Self-Directed Support (1%).

Within the group of people with learning disabilities, people were more likely to report improvements in quality of life if they had not been using social care services before starting Self-Directed Support\textsuperscript{30}.

Within the group of older people, people were more likely to report improvements in their quality of life if they had been supported in their Self-Directed Support planning by a social worker\textsuperscript{31}.

Taking part in and contributing to the community

Overall, a majority of people reported improvements in the extent to which they took part in and contributed to their communities since starting Self-Directed Support (64%), with a substantial minority reporting no change (34%) and a small minority reporting that things had got worse since starting Self-Directed Support (2%).

\begin{figure}
\centering
\includegraphics[width=\textwidth]{quality_of_life}
\caption{Quality of life}
\end{figure}
People with learning disabilities and people with physical disabilities were more likely than older people to report improvements in taking part in/contributing to the community.

Within the group of people with physical disabilities, people were more likely to report improvements in taking part in/contributing to the community if they were:

- women rather than men
- younger rather than older
- supported to plan their Self-Directed Support by a social worker.

**Choice and control**

Overall, a majority of people reported improvements in the choice and control they had over their lives since starting Self-Directed Support (72%), with a minority reporting no change (27%) and a small minority reporting that things had got worse since starting Self-Directed Support (1%).
People with learning disabilities and people with physical disabilities were more likely than older people to report improvements in choice and control since starting Self-Directed Support\textsuperscript{36}.

Within the group of people with learning disabilities, people were more likely to report improvements in choice and control if they were supported in their planning by a greater range of people\textsuperscript{37}.

Within the group of older people, people were more likely to report improvements in choice and control if they were supported to plan by a social worker\textsuperscript{38}.

**Feeling safe and secure at home**

Overall, a minority of people reported improvements in their feelings of safety and security at home since starting Self-Directed Support (29\%), with a majority reporting no change (70\%) and a small minority reporting that things had got worse since starting Self-Directed Support (1\%).

![Figure 14 Safe and secure at home](image)

People from White ethnic groups were more likely to report improvements in feeling safe and secure at home than people from other ethnic groups\textsuperscript{39}.

**Personal dignity**

Overall, a majority of people reported improvements in their personal dignity since starting Self-Directed Support (59\%), with a substantial number reporting no change (41\%) and no-one reporting that things had got worse since starting Self-Directed Support.

There were no differences in people's ratings of improvements in personal dignity across the group as a whole.

Within the group of people with learning disabilities, older people were more likely to report improvements in personal dignity compared to younger people\textsuperscript{40}. 
Within the group of people with physical disabilities, women were more likely than men to report improvements in personal dignity.

Within the group of older people, people were more likely to report improvements in personal dignity if they were supported to plan by a social worker.

**Economic well-being**

Overall, a substantial minority of people reported improvements in their economic well-being since starting Self-Directed Support (36%), with a majority reporting no change (59%) and a minority of people (5%) reporting that their economic well-being had got worse since starting Self-Directed Support.

Overall, people were more likely to report improvements in their economic well-being if they had been using Self-Directed Support for a longer period of time (over a year).
People with learning disabilities and people with physical disabilities were more likely than older people to report improvements in and economic well-being.\(^{14}\)

Within the group of people with learning disabilities, people were more likely to report improvements in economic well-being if they had not previously been using social care services.\(^{15}\)

**Conclusions**

This report has summarised the findings of a snapshot in time, concerning almost 200 people across 17 local authorities mostly in the early stages of implementing Self-Directed Support. It was not resourced or designed to be a full-scale, comprehensive evaluation of Self-Directed Support. Instead, it was designed as an example of the type of low-cost, low-impact monitoring that could take place routinely throughout services supporting Self-Directed Support. This of course means that there are limitations as to how the information can be interpreted. For example:

- Although the sample of 196 people is relatively large at this point in the implementation of Self-Directed Support in England, it is not a complete or necessarily representative sample of people using Self-Directed Support in England.
- The information collection was heavily weighted towards a small number of local authorities and the social care group of people with learning disabilities, which may have had an impact on the findings.
- The questionnaire used was designed to address important outcome domains in terms of current policy but has not been comprehensively tested in terms of its reliability or validity.
- Information collection was handled through local authorities and the impact of their information collection processes on the information collected is unknown.
- We did not have information on costs from enough people to use cost information in any of the analyses.

Despite these limitations, some useful messages can be drawn from the project.

**The first set of messages concerns the implementation of Self-Directed Support:**

- The big variation in numbers of people across local authorities and the fact that most participants had been using Self-Directed Support for less than 6 months suggests that Self-Directed Support is at an early stage of implementation in England but well-progressed in some areas.
- The high numbers of people with learning disabilities in this project possibly reflects the historical origins of Self-Directed Support in working with people with learning disabilities, although the range of social care groups represented suggests that this is broadening out over time.
- In terms of age, gender and ethnicity, the people in this project were broadly similar to their relevant social care populations, although we obviously don’t have information for this project on support needs and other important dimensions of people’s lives to know whether the implementation of Self-Directed Support is leaving out any obvious groups.
Even at this early stage of implementation, the take-up of Self-Directed Support is not confined to people already within the social care system.

People using Self-Directed Support generally report that its essential characteristics are present, in that the vast majority of people report that they feel in control of the process, they understand what Self-Directed Support is for and they are changing the way they spend their money as a result.

The second set of messages concerns the impact of Self-Directed Support on the participants:

- Very small numbers of participants reported things getting worse since the introduction of Self-Directed Support, in any of the 8 areas of life we asked about.
- Across the whole group of almost 200 people, majorities reported improvements since taking up Self-Directed Support in spending time with people they liked; their quality of life; taking part in and contributing to their local community; choice and control over their lives; and personal dignity – all areas of life where Self-Directed Support would aim to have an impact.
- In the areas of general health and well-being, safety and security at home and economic well-being, more people reported no change than improvements since taking up Self-Directed Support. These are areas of life where Self-Directed Support would not aim to have a direct impact in the short term. For two of these outcomes, general health and well-being and economic well-being, people who had been using Self-Directed Support for longer (over a year) were more likely to report improvements, suggesting that Self-Directed Support may require a longer period for improvements in these areas to be apparent.
- The support that people had with planning their Self-Directed Support – whether from family and friends, social workers or a wider range of people – was associated with largely positive outcomes. However, in general, Self-Directed Support may be more effective if family and friends, rather than social workers alone, are involved in the Self-Directed Support process.
- For some outcomes, people with learning disabilities and people with physical disabilities were more likely to report improvements than older people, although the small numbers of people involved make it difficult to know why this might be. Relevant issues might be that older people were less likely to have been using social care support before the introduction of Self-Directed Support; and they had also, on average, been using Self-Directed Support for a shorter period of time.

In summary, for this group of almost 200 people, the findings are encouraging. Local authorities seem to be implementing the essential features of Self-Directed Support with an increasingly wide range of people; and most people report improvements across a wide variety of life domains since taking up Self-Directed Support. Clearly we will need more information to track both the longer-term impact of Self-Directed Support on people’s lives across the range of people using social care and the impact of implementing Self-Directed Support on a wider scale.
NOTES


7 K-W chi-square=85.5, df=2, p=0.001

8 Chi-square=11.27, df=2, p=0.004

9 Chi-square=83.3, df=2, p<0.001

10 Chi-square=8.00, df=2, p=0.018

11 K-W chi-square=11.93, df=2, p=0.003

12 Chi-square=5.27, df=2, p=0.072

13 Chi-square=13.17, df=2, p=0.001

14 Chi-square=7.14, df=2, p=0.028

15 Chi-square=6.81, df=2, p=0.033

16 Chi-square=1.20, df=2, p=0.55

17 Chi-square=0.49, df=2, p=0.78

18 Average correlation between outcome questions Kendall’s tau=0.32; range 0.14 to 0.59

19 K-W chi-square=7.87, df=2, p=0.02

20 U=3956, n=195, p=0.03

21 Kendall’s tau=0.16, n=190, p=0.029

22 U=87.5, n=39, p=0.002

23 Kendall’s tau=0.38, n=21, p=0.037

24 U=3622, n=191, p=0.008

25 U=3216, n=191, p=0.036

26 U=127.5, n=39, p=0.044

27 Kendall’s tau=0.28, n=37, p=0.047

28 U=79.5, n=39, p=0.003

29 U=52.5, n=39, p=0.011

30 U=894, n=110, p=0.042

31 U=27.5, n=25, p=0.039

32 K-W chi-square=20.14, df=2, p<0.001

33 U=122.5, n=39, p=0.032

34 Kendall’s tau=0.35, n=37, p=0.012

35 U=64.5, n=39, p=0.047

36 K-W chi-square=13.47, df=2, p=0.001

37 Kendall’s tau=0.20, n=105, p=0.038

38 U=25, n=25, p=0.046

39 U=1410, n=193, p=0.015

40 Kendall’s tau=0.20, n=95, p=0.018

41 U=102, n=39, p=0.002

42 U=22.5, n=25, p=0.025

43 K-W chi-square=7.62, df=2, p=0.022

44 K-W chi-square=7.27, df=2, p=0.026

45 U=738, n=109, p=0.012
Chapter 1

Self-Directed Support is for everyone
A REPORT ON IN CONTROL’S SECOND PHASE 2005-2007

Chapter 1

Self-Directed Support is for everyone

Simon Duffy

In this chapter, I explore the range and limits of Self-Directed Support and consider the progress there has been in opening up this opportunity to more people.

Introduction

In Control’s objective was to find a way of revolutionising the social care system, of shifting the balance of power and control so that people who need support can have more control, and can design the support that is right for them. We also wanted to help professionals identify the kinds of roles that they could usefully play in helping people to direct their support.

Between 2003 and 2005, in Control developed its first model of Self-Directed Support and, as part of this model we created or re-defined key concepts like:

- Personal Budget (also called an Individual Budget)
- Resource Allocation System (RAS)
- Support Plan
- Support Brokerage
- Individual Service Fund.

This first phase of work focused on people with complex cognitive disabilities. The model was tested with 60 people in 6 local authorities and the results were published in A Report on in Control’s First Phase 2003-2005. However, even in 2003, it was clear that social care could not
be reformed simply by focusing on one particular group. This is not just because everyone deserves the chance to be in control. It is also because social care in the UK is a broad system. Though social care is currently often divided up into ‘care groups’ these divisions are not fundamental. Usually the same kinds of systems, services and funding streams apply to all groups and any exceptions are marginal.¹

This is a good thing. Many other countries have created problems for themselves because they have tried to sort people into different categories and then set up different systems for each different group. In the UK you are entitled to support because of your needs, not because of your age, your IQ level or the nature of your impairment (although, as we will see, things do get more complex if you have needs because you are ill).

In fact, *in Control* believed that its early focus on people with complex cognitive disabilities – or people with learning difficulties – was helpful in developing a universal system because people in this group also have other needs:

- all people start as children
- some have physical or sensory impairments
- some have mental health problems, including depression
- most people grow old and frail or suffer dementia.

For *in Control*, designing a system for people with learning difficulties seemed to be a good way of designing a system for everyone. However, this view is not shared by all. At an early presentation to a seminar of civil servants and professionals, a participant said: ‘I can see that this might work for people with disabilities, but surely older people don’t want to be in control.’

This view, and many others like it, represents a widespread assumption that the labels used within the social care system represent substantial differences between the needs of people. Within this assumption, these differences are thought to be so substantial that they justify distinct approaches by society to people who have significant additional need for support. In this view, care services are rationally divided into the following categories:

- services for the elderly
- services for people with mental health problems
- services for people with physical disabilities and sensory impairments
- services for children with disabilities
- services for people with learning difficulties.

In addition, there are several other categories or sub-categories that can be distinguished, particularly at the boundaries with the NHS:

- services for people with brain injuries
- services for people who have long-term health conditions
- services for people with alcohol or substance abuse problems
- people using palliative and hospice care.

Since 2005 and the beginning of *in Control*’s Second Phase, the challenge for us has been to explore whether the *in Control* model can work for people in all of these groups; and if not, where and how must it be adapted. This last point is most important, since as a social innovation network focussed on helping people to take control of their lives and to be full citizens, *in Control* is committed to finding the best workable model for Self-Directed Support. We are always willing to change the model if experience teaches us that it needs improving.
This chapter explores the extent to which Self-Directed Support is universal by:

- setting out the kinds of challenges that were faced in adapting Self-Directed Support to wider groups of people
- describing some of the progress that has been made in connecting people and organisations from different sectors
- identifying the set of challenges that lie ahead, in particular the extent to which Self-Directed Support may be useful for some people using NHS services.

Adapting the model to include everyone

When In Control began its second phase at the very end of 2005, membership of in Control was opened up to any local authority in England that wanted to test out Self-Directed Support – for any or all of the groups currently receiving social care. At the start of this second phase, In Control had 60 local authority members. By the end of 2007, this number had grown to 107.

At first, most members focused on changing services for people with learning difficulties. However, even in 2005, there were several authorities who wanted to test the model with other groups. Some, like Oldham, had already decided that they wanted to extend Self-Directed Support to everyone. Others joined with a commitment to test the model for people from different groups. For example, Rotherham wanted to build on its excellent work offering Direct Payments to people with mental health problems.

At the end of 2007, a poll of In Control's members showed that the majority of members intended to make personal budgets widely available.

![Figure 1](image-url) Members intending to offer personal budgets – by social care group
The same kind of progress has been seen in the actual uptake of personal budgets. To begin
with, at the end of 2005, there were only 60 people who had personal budgets. But by the end
of 2007 this number had grown to over 2,500.

Figure 2 Uptake of Personal Budgets 2006-7

Within this total, the numbers from different groups are estimated, based on sampling, to
be:

Figure 3 Personal Budget uptake by social care group (estimate based on sampling)

This data clearly shows that progress has been possible, but objections have been raised in
some quarters, some of which are based on simple misunderstandings or stereotyping:

- ‘Self-Directed Support depends crucially on family support’. But many people
  with learning difficulties lack support from families and yet Self-Directed
  Support can work for them too.
‘Self-Directed Support is for people who want to live their lives as independent adults. It is not suitable for people who are growing old and frail’.

But Self-Directed Support doesn’t dictate the lifestyle that people must lead. Rather, it offers people the means to tailor their support to their preferred lifestyle.

‘Self-Directed Support only works for people with more expensive support packages’. But not everyone using Self-Directed Support has an expensive support package. The benefits of control do not disappear for people with more modest packages.

However, more serious questions and challenges have arisen and these have demanded important adaptations to in Control’s model of Self-Directed Support.

Challenge One: Improving Equity

One of the most important consequences of Self-Directed Support is that it makes the relationship between need and funding transparent. The way in which, in the old system, need does not correlate evenly with money spent is graphically illustrated below. In this graph, need is ranked from low to high – left to right. However, funding is allocated very unevenly. For example, two individuals who have similar needs might have services costing £3,000 or £30,000.

The Resource Allocation System identifies an objective level of need. This level of need is then used to determine how much money an individual should receive in their Personal Budget. This has an immediate benefit in terms of equity because it enables people with the same level of need to receive the same level of funding.

In Figure 5, we can begin to see the impact of applying the RAS. In this graph, allocations using the RAS are shown for the same group of people as in Figure 4. A trend has begun to emerge: levels of need are now more closely correlated to allocations. The presence of some
allocations that are high above the trend line indicates that reallocation has not been imposed insensitively and that transitional monies may be included.

Figure 5 Cost ranked by need showing an increased correlation between cost and need following the use of the Resource Allocation System (Oldham 2007)

However the impact of a transparent link between need and funding goes further. It can reveal differences in historical patterns of allocation. For instance, if we compare data on allocations to different groups we can see the following pattern:

Figure 6 Cost distribution across social care groups

These differences in pattern create significant challenges and uncertainties. Some might claim that the higher levels of allocation for people with learning difficulties and people with physical disabilities represent wasteful expenditure that can be cut or shifted to people from other groups. However, these patterns of expenditure could also be seen to represent costs in real services in particular markets. So the impact of any cut would itself be unfair.
On the other hand, people with the lower patterns of funding, particularly older people or people with mental health problems may ask to have their funding levels increased to the same level as the other groups. This would represent a significant inflationary pressure for local authorities.

It should be emphasised that this problem is not created by the new system of transparent resource allocation. It is simply revealed by the new system.

In practice, we have seen a number of practical steps taken to mitigate this problem. Some authorities have developed different Resource Allocation Systems for different groups. Most authorities, though, have tried to create one RAS that will work for all. Of these authorities, some have tried to reduce the impact of too great a shift in funding for groups with higher levels of funding. Oldham, for example, created a ‘market factor’ which was used to increase the personal budgets of those using services that had a higher cost base. Whether such market adjustments will be necessary or desirable in the long run will be something that Oldham and others will need to monitor as the market itself begins to change.

A further practical step has been to improve the RAS and to make it even more sensitive to complexities of needs and costs at different levels. In Control has continued to develop the technology behind the RAS as the numbers of people using it increase and the need for greater sophistication becomes apparent. Below is a brief history of the RAS:

**RAS Version 1** The first version of the RAS was developed by Simon Duffy before the beginning of In Control and it involved setting the budget in the light of three criteria: need, complexity, and community support. Inclusion Glasgow and early initiatives in North Lanarkshire demonstrated the value of this approach – but the need for a high level of intuitive judgement made it unsuitable for systemic rollout.

**RAS Version 2** At the beginning of In Control’s early work in Wigan in 2003, Simon worked with colleagues to develop a more sophisticated system. This system set personal budget levels by correlating them to the cost of typical existing service packages. Needs were identified using a simple tabular approach with key indicators mapping on to the relevant levels of funding. This system was easy to apply and effective in early piloting.

**RAS Version 3** In 2005, John Waters joined In Control as its Technical Director and brought with him a more sophisticated model of needs analysis that allowed the model to put a numeric value on different domains of need. This model, combined with a rationalisation of the previous stepped approach, was published and has been successfully used by local authorities in their early work.

**RAS Version 4** In 2006, more authorities wanted a system that could cope with much higher numbers of people from different care groups. John developed a new approach that allowed authorities to apply a ‘price point’ that would be multiplied by the figure that represented the level of need. This model, with some local adaptations, has been used by many authorities that have ambitions to make Self-Directed Support available to greater numbers.

**RAS Version 5** In 2007, John began work with our partner organisation, Symmetric SD, to develop a further version of the RAS which could be delivered through the internet. This is called e-RAS. The key innovation here has been that in Control is finally able to go beyond setting the personal budget level by reference to the cost profile of the past. Instead, it is possible...
to use the data that is coming from the field to set the budget level. The early signs are that the impact of this shift is to introduce greater sensitivity to the personal budget setting process at the bottom and top of the spectrum of needs.

in Control’s method of operation – using the experience of those implementing Self-Directed Support on the ground to create improved versions of the system – has been successful overall. While this process reveals some of the inequities in the current system, it also gives local leaders the means to address these issues:

◆ allocations are fairer and are made consistently, in accordance with transparent criteria
◆ some very high-cost services prove to be entirely unnecessary and resources can be redistributed to those who need them
◆ people with lower levels of need are starting to receive appropriate modest levels of funding for the first time, thus avoiding a path towards crisis and costly services.

Challenge Two: wider communication

The second challenge for adaptation was to ensure the style and content of in Control’s materials were suitable for a wider audience. Some people felt that a focus on the experience of people with learning difficulties would alienate other groups or that materials were somehow not appropriate for everyone. For example, some people thought that:

◆ Person-centred Planning was specific to people with learning difficulties (for whom and with whom this technology had been developed) and the ideas in it could not be used by others
◆ citizenship was not an aspiration for older people
◆ insufficient attention had been paid to the terms which had been defined by the disability movement. In particular more reference should be made to the notion of Independent Living
◆ using the term ‘disabled people’ to describe people needing extra support was too narrow and that many groups would not feel connected to it, especially older people
◆ the frequent use of illustrations was not suitable for people who do not have learning difficulties
◆ the tools in Control had developed for people to use themselves were more appropriate for the kinds of life questions faced by younger people than by older people.

In responding to this challenge, in Control has tried to strike an important balance. Some words can be unhelpful. They communicate the wrong thing, sound too professional or are too connected to one particular group. But sometimes the words are not the problem. There may be no better word. Rather, it is our understanding that needs to change. Definitions need to be broadened, new ideas accepted, and different approaches appreciated.

Moreover, some of the communication challenges faced by in Control might even be based upon prejudice. For example, some people treat people with learning difficulties in a patronising
Challenge Three: Building Bridges

In one sense, these questions of language are merely symptoms of a deeper problem. It can be argued that the whole concept of disability is an artificial construction: a result of professional groups gaining power and authority by identifying and classifying groups of people who have needs, and these needs can only be remedied by professional interventions. This process of classification is also a process of control and it reached its logical extreme in the development of institutions in which the whole life of a disabled person was put under the control of professional groups.

During the 20th century different groups of disabled people and families began to organise themselves in a conscious effort to advocate for themselves or for those they loved. The
disability movement has led the way in identifying the process by which professional power has been exercised and needs have been interpreted to the advantage of professional interests. This new interpretation of the role played by professional interests gave rise to the view that there are two competing paradigms for understanding disability: the Medical Model and the Social Model. While the Medical Model sees disability as being a function of the body or mind of the disabled person, the Social Model sees disability as arising where society is not sufficiently adapted to enable the disabled person to meet their needs.

However, the very process of becoming conscious of this kind of professional oppression requires the group experiencing oppression to come together to make common cause. In one sense, the Medical Model creates the very group that, in the right circumstances, can begin to reassert its own identity as part of the whole of society.

### Formation of Professional Group

<table>
<thead>
<tr>
<th>Over time, groups of people have emerged who have defined themselves (or been defined by others as) experts in certain physical, mental or social conditions.</th>
<th>Groups of people find themselves having the shared experience of receiving the help of the professionals and sharing in the identity of the group.</th>
</tr>
</thead>
<tbody>
<tr>
<td>If the people about whom they claim expertise are also seen as in some way problematic - requiring social attention then</td>
<td>People find they share common concerns and their own expertise about their own condition.</td>
</tr>
<tr>
<td>...these professional groups can achieve a special legitimacy within society and may be given resources from tax-payers or other donors.</td>
<td>Those groups seek to achieve their own legitimacy and challenge the legitimacy of the professional group.</td>
</tr>
</tbody>
</table>

**Table 1** professional groups and the response of groups of disabled people

So there is a paradox: in order to resist control by professional groups, it is necessary to accept the very classifications that help to give the professional groups control in the first place. Moreover, these classifications also bring divisions into the ranks of the resisting group. There seem to be so many different groups, organisations and labels for people: sensory impairments, physical disabilities, learning difficulties, old and frail, poor mental health etc. And these distinctions are not completely without meaning. They do reflect real differences in need. But they over-simplify and segregate people from each other and from some imaginary ideal or normal class. These labels can too easily distract people from seeing that, whatever our label, we are ‘people first’.

The result is that groups of people who are first and foremost people – citizens one with another – seem to be divided by these labels, both from society as a whole and from each other. These divisions make it doubly difficult for the different groups of disabled people to come together in order to fight for their right to be considered as ordinary citizens.

These problems cannot be overcome simply by changing the words we use. A real meeting of minds is required, one that can enable different people to forge a common understanding. For this reason, in Control has tried hard to find ways of linking together many of the different individuals and groups that are affected by Self-Directed Support and why in Control has tried to build new bridges.
This has not always been easy. There is a level of fear and suspicion that exists between all the different groups who have been subjected to the old social care system. Each group can identify reasons to think that it has been particularly badly treated. Each group can also identify ways in which it may even have been oppressed by another group. This is not the place to rehearse these grievances. It is just worth noting that mutual hostility between oppressed groups is a common pattern and can be witnessed wherever there is systemic oppression.

Hence, in Control has always tried to build bridges. At its inception, in Control invited the National Centre for Independent Living, one of the most important disability organisations, to sit on its steering group. Furthermore, during Phase Two, in Control invested in a number of initiatives that aimed to build a stronger sense of shared community:

- in Control supports Bob Sang’s initiative, Weaving the Fog which aims to connect the Expert Patient community to the other initiatives around self-direction.
- in Control has worked with CSIP’s Academy for Self-Directed Support, which has brought together individuals who use Self-Directed Support.
- in Control funded David Towell and John O’Brien to run a series of Reflections events that brought together leaders from across the different groups affected by Self-Directed Support.

The culmination of all these efforts was the publication in November 2007 of in Control’s joint statement with the National Centre for Independent Living: Our Goals Independent Living.

This statement is important for several reasons. It helps explain that Self-Directed Support is not competing with the important achievements of the Disability Movement, amongst which are Direct Payments and user-led support centres. Instead, Self-Directed Support is the logical extension of such approaches. It also demonstrates in Control’s own flexibility and willingness to listen, for although in Control shared the values of NCIL it did not use the term ‘independent living’ to describe the desired goal. Instead, in Control talked about citizenship, rights and control. in Control is now committed to working with NCIL and others to help everyone understand that Independent Living does not mean living alone or ‘independently’, but living the life that you want to live, with the people you want to be with as an active citizen. (See statement in Appendix)

As in Control begins its third phase, its most important achievement in building bridges has been to create a form of governance within which several of the key groups necessary to the success of Self-Directed Support are represented. in Control became a non-profit making company in October 2007 and will be registered as a charity during 2008. It has an independent Board of Trustees to whom its small core team is accountable. Currently the following organisations have joined in Control as members, able to appoint representatives and elect the Trustees:

- Association of Directors of Adult Social Services (ADASS)
- Centre for Policy on Ageing (CPA)
- Mencap
- National Centre for Independent Living (NCIL).

There is still much to do and there are many barriers to overcome. in Control has only just started to make the necessary connections with people in services for children, with people from mental health services and the world of long-term conditions. There is still fear and
suspicion of in Control itself, perhaps based on a concern that it is a threat to well-established economic interests and patterns of power and control. However, steady progress has been made and the signs are that new patterns and alliances can be forged.

Challenge Four: Defining Boundaries

This chapter began by making the claim that Self-Directed Support was a universal approach for the reform of social care. At the beginning of Phase Two, that was a radical claim. Today, it is clear that this claim has become widely accepted. On 10 December 2007 the government launched its Concordat for social care, Putting People First, which had at its heart the intention to ensure:

‘Personal budgets for everyone eligible for publicly funded adult social care support other than in circumstances where people require emergency access to provision. Lord Darzi’s recent NHS next stage review interim report suggested that in the future, personal budgets for people with long-term conditions could include NHS resources.’

This paragraph, tucked within a long list of objectives, is potential dynamite. If it is realised, if it is not watered down or corrupted, if it happens within a solid system of Self-Directed Support, all our learning to date suggest that it can transform the lives of over 1 million people in England.

This development will also have a significant impact on in Control and raises important questions about in Control’s future role. To date, in Control has been the guardian of these ideas but increasingly many other organisations and individuals will want to own and control how these ideas are understood and communicated. in Control has also been intimately concerned to ensure that these ideas don’t just remain as mere ideas but are converted into positive practice – really improving people’s lives.

But this paragraph from Putting People First also indicates another set of key questions that still remain to be resolved. To date, in Control’s focus has primarily been upon adult social care. But it is already clear that Self-Directed Support does not need to be so restricted. The principles of Self-Directed Support can be applied more widely – well beyond the confines of social care.

The set of principles at the front of this report summarises in Control’s current understanding of the proper foundations of social care. The principles are, in summary,

1. Right to Independent Living
2. Right to a Personalised Budget
3. Right to Self-Determination
4. Right to Accessibility
5. Right to Flexible Funding
6. Accountability Principle
7. Capacity Principle

These principles apply in any field where people have the right to support and where it is important that the person and their community are closely and personally involved in
designing and developing the shape that support takes. Although there may need to be some detailed work to adapt and develop the ideas to work within different environments it seem clear that there is real potential to apply Self-Directed Support in the following fields:

**Community development** – Self-Directed Support does not just need to be for people who are eligible for social care funding. Its principles also fit people who are not eligible for social care but who may need help to strengthen their community connections and avoid the risk of social isolation or vulnerability. In Control’s Small Sparks programme already demonstrates that people themselves are often best placed to initiate meaningful community development. In Phase Three, in Control will be collaborating with Eddie Bartnick of Western Australia to introduce and adapt the Local Area Coordination model of community development in England and with our partners in Scotland, Wales and Northern Ireland. Carl Poll describes these ideas in more detail in Chapter 5.

**Children with disabilities** – Nic Crosby is already leading work for in Control, in partnership with Paradigm and the Office of Public Management (OPM) to demonstrate the applicability of Self-Directed Support to children’s services. Nic describes this work in more detail in Chapter 4.

**People with long-term health conditions** – Primary Care Trusts are already beginning to experiment with the extension of Self-Directed Support to health care. In Control has recently launched the Staying in Control programme to support partnerships between local authorities and the NHS to transform the experiences of those who need health and social care.

**People with variable conditions** – Not only does it seem likely that Self-Directed Support will work well where people have predictable health problems. There is also some evidence that it can work for people with unpredictable health or mental health conditions. For example, in our discussion paper *A Voice and a Choice* there is a description of how the combination of a personal budget and an advance directive has radically reduced an individual’s dependence on acute services. Putting the person more in control can improve their ability to plan ahead, set aside resources for difficult times and strengthen the community networks that keep people safe and out of hospital.

**People who are dependent upon drugs or alcohol** – It may even be possible to take these principles and apply them to groups who are often treated as unworthy of respect. Respecting and fostering autonomy can be vital to moving away from dependency on drugs and, even where the direct control of resources might not be in the hands of the individual, the ability to tailor supports so that they really play to the person’s strengths and aspirations is vital. In Control is currently exploring the possibility of joint work in this area with the Royal Society for the Encouragement of Arts, Manufactures & Commerce (RSA).

**Education** – It is also not difficult to see many of these ideas working well in education. Innovative work has already been done with the Learning and Skills Council to develop personal budgets for learners with special needs. This kind of approach seems to create a framework in which education goals can be agreed with the individual and which enables greater flexibility in how those goals are met.

**Employment** – The same is surely true of support for people to find work. Significant funds are spent on trying to help people into work or paying...
people who are not in work. Tailoring support to help people find the right job, the right skills or the right support to sustain themselves in employment seems likely to offer a better framework than one of block provision.

**Housing** – Interestingly, the recent innovation of Local Housing Allowances for people who use private rented housing has shown similar benefits to Self-Directed Support in improving flexibility and market management. Extending such systems to the housing offered by social housing or the home ownership market seems quite feasible.

None of this is to suggest that these reforms and changes will not be complex or beset with problems. The progress made by in Control over the past four years has often been against the grain of other government initiatives that attempt to manage, control or centralise decision-making. Progress has depended upon a detailed understanding of the area requiring reform and the support of real leaders who wanted to find a different way of doing things. If in Control has a useful role to play in extending and defining the boundaries of Self-Directed Support, this will not happen without the full participation of the leaders who operate within the current system.

### Conclusion

There seems to be no reason to think that the progress of Self-Directed Support has ended. In fact we are possibly at the beginning of a wave of reform and adaptation which may surprise everyone, including in Control itself. It may be best to expect the unexpected.

in Control will continue to try and make a positive contribution to this next phase of activity. In doing so, it will work hard to identify which of its activities really add value, value that no other organisation can easily offer. Sometimes, in Control may need to leave some activities to bigger or more powerful organisations.

As we have demonstrated in the chapter, one area in which in Control has an important role is helping to forge alliances within civil society: to connect the groups, organisations and individuals who can benefit from Self-Directed Support and ensure that nobody is excluded from the chance to be in Control.

### The Author

**Simon Duffy**

Simon is a social entrepreneur and philosopher who has worked obsessively to try and make sure that all people, especially people with complex disabilities, get the chance to be full citizens and control their support. Simon was the founder of Inclusion Glasgow and Altrum and he is now the Chief Executive of in Control. He is the author of *Keys to Citizenship* and many other writings on Self-Directed Support and Person-Centred Planning. He has a PhD in moral philosophy and in 2008 he won the RSA’s Albert Medal for social innovation. Most of Simon’s writings are available at [www.simonduffy.net](http://www.simonduffy.net)
Chapter 2

The economics of Self-Directed Support
The economics of Self-Directed Support

Simon Duffy and John Waters

This chapter describes the information we have about the impact of Self-Directed Support, particularly in relation to the economic efficiency of the system. It shows that people’s lives improved significantly and that their support does not seem to cost any more money than in the old system. We also explain why the old system of social care tends to be inefficient and how Self-Directed Support can reduce some of the waste built into the old system.

Introduction

At the end of Phase One (2003-2005) of in Control’s work, many people were excited by the great improvements that Self-Directed Support seemed to have made in people’s lives. However, many seek assurance that such positive changes are affordable.

In Phase Two, in Control has gathered much more information about the impact of Self-Directed Support and the costs associated with it. We have also had the opportunity to explore new issues, such as how different funding streams might be integrated into a system of Self-Directed Support. In this chapter we give an overview of our findings to date, offer a framework for thinking about efficiency for the future and identify some of the questions that still need to be answered.
Improving Efficiency

When people talk about efficiency many of us quickly become suspicious that they really mean ‘cuts’. This is unfortunate because the idea of efficiency is important and it doesn’t have to have anything to do with cuts. Efficiency is about how much value you can extract from something compared with what you put into it.

Currently, the taxpayer spends approximately £20 billion on the social care system in England. About one million people make use of the system at any one time. If Self-Directed Support is more efficient then this means that, for the same money, either the lives of some of those million people will improve, or more people will get support (or both).

When Phase Two began there were only 60 people using Self-Directed Support in only six different local authorities. In January, 2008 about 3,000 people were using Self-Directed Support. But this is still only a small fraction of the total number of people using social care and there is still much still to learn.

in Control receives no significant research funding of its own. Instead it has worked with its local authority members to create methods of collecting information which are very low-cost and which focus on the two fundamental questions:

1. Does Self-Directed Support lead to better outcomes for people?
2. What does Self-Directed Support cost?

There are many more questions that could be asked and in Control is working with government and the research community to focus attention on some of these more detailed questions. But the focus on the two fundamental questions has generated some very important results, as we will show in the following sections.

Improving Lives

Chris Hatton and the University of Lancaster recently published the first analysis of the outcome data from Phase Two (Part 1 of this Report). The results were from 196 people, from 17 different authorities. These people were asked to think about their lives since they began directing their own support. The results were striking and a summary of the results is set out in the table below:

<table>
<thead>
<tr>
<th>Outcome</th>
<th>Improved</th>
<th>Same</th>
<th>Worse</th>
<th>Net improvement</th>
</tr>
</thead>
<tbody>
<tr>
<td>General Health &amp; Well-Being</td>
<td>47</td>
<td>49</td>
<td>5</td>
<td>42</td>
</tr>
<tr>
<td>Spending Time with People you Like</td>
<td>55</td>
<td>42</td>
<td>3</td>
<td>52</td>
</tr>
<tr>
<td>Quality of Life</td>
<td>77</td>
<td>23</td>
<td>1</td>
<td>76</td>
</tr>
<tr>
<td>Taking Part in Community</td>
<td>63</td>
<td>34</td>
<td>2</td>
<td>61</td>
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These results are very encouraging. They are consistent with the results set out in the in Control Phase One Report. Although people with learning difficulties still represent the majority of respondents (58%), there are significant numbers from other social care groups. For example, 20% were people with physical disabilities and 13% were older people. Moreover, the benefits of Self-Directed Support seem to grow over time and seem to be more marked for those people who previously used the old social care system.

We do not have the cost data for the whole sample group and so cannot be certain of the correlation between these improvements and any changes in funding. However, there are several reasons to think it is unlikely that these very significant improvements are in anyway correlated with increases in funding:

- All local authorities need to work within their existing budgets. They cannot afford to be more generous to people using Self-Directed Support.
- The systems used to set Personal Budgets have been designed to ensure that people get a Personal Budget equivalent to the cost of a typical service for someone with the same level of needs.
- All the data from Phase One and Phase Two suggests that the average cost of services for people using Self-Directed Support seem to be somewhat lower.

In the following section we describe what we have learnt to date about the costs of Self-Directed Support.

**Affordability**

in Control has worked with its members to gather information about the costs of Self-Directed Support. John Waters has gathered reliable sample data from 10 authorities for 128 individuals with Personal Budgets. This data is included in the evaluation report that forms Part 1 of this document.

Of the 128 people for whom we have information, 104 previously used social care; 14 did not. From this report it can be seen that, for the 104 people who previously had a social care service, the average cost reduced by 9% from £29,319 to £26,615. You can see the difference between those cases where we have ‘before and after’ data in Figure 1.
When we include the data from those people who did not previously require social care, the overall impact on average costs is still greater, with a reduction of 15% from £29,319 to £24,857. Another way of looking at this is to say that the number of people served increased by 23% but the overall cost only grew by 6%.

Again, it is important to note that this is still early data. The sample is biased towards higher-than-average cost services and this slightly distorts the overall picture. It may be the case that there is more room for relative efficiency improvements in larger packages of support, although there is no evidence for this either way at this stage.

However, even with these cautions taken into account, if we put together the outcomes data with the financial information, the provisional picture of efficiency is very positive. It seems that Self-Directed Support means that many more people are getting better lives, while the average cost of those services has actually reduced.

**Inefficiency of the Current System**

Many people treat the efficiency improvements of Self-Directed Support with scepticism. Sometimes they accept that the efficiencies are real but they then interpret the reason for these efficiencies in their own way – and often their hypotheses are either false or untested. For example, some people think that staff must be paid less. Such false or unproven hypotheses create obstacles for people moving towards Self-Directed Support.

in Control spent significant energy during Phase Two thinking, researching and writing about the economic case for Self-Directed Support in order to help people understand the real reasons for this improvement in efficiency. In particular, in Control produced four papers that explore these issues in some detail (all are available on the in Control website):

- Evidence on Self-Directed Support, submission to the Office of Disability Issues
- Economics of Self-Directed Support, published by the Journal of Integrated care
- Individual Budget Integration, an exploration of the possible scope of Individual Budgets, a report commissioned by the Department of Health
In the following sections we draw on these papers and other evidence that has emerged and offer our current understanding of how Self-Directed Support leads to efficiency improvements. In order to set out how Self-Directed Support leads to efficiencies we first need to offer an understanding of how the current social care system works.

Most people would probably assume existing systems are rational and efficient and would demand evidence of the need for change from those proposing an alternative. But there are several reasons to think that this may be a mistaken attitude, at least towards social care. The current system has many in-built features that seem to make it inefficient.

![Figure 2: Inefficiencies built into the current social care system](image)

At present, social care functions largely by pre-purchasing services for people. To a large extent the pattern of purchased services is shaped by the services that have been inherited from the past. Change in the kinds and quantities of services on offer has been much slower than changes in other parts of the economy. A process of rationing and care management determines which services will be made available to the person – often from a very limited menu. The inefficiency and wastefulness of such an approach has several dimensions:

**Resources are misdirected** – when services are purchased with little or no reference to the choices that would be made by the people who use the services, then there is a risk that resources will be directed into the wrong places.

**Funding streams are multiplied** – when multiple streams of funding are used to finance the same services, or services that are only marginally distinct, then resources will be wasted by the multiplication of competing systems, each with its own infrastructure.
Needs are inflated – when a system cannot provide timely or appropriate supports, and when it makes the use of support dependent upon crisis or the loss of community support, there is a danger that it will actually increase people’s apparent need and provide the wrong level of support to those eventually deemed eligible.

Creativity is minimised – when provider interests dominate and change becomes subject to bureaucratic decision-making, innovation and creativity will be minimised and, over time, there will be less and less success in finding new ways to bring value to people’s lives.

The system is over-managed – when the whole system is focused on rationing scarce resources and it treats the people who use the system as passive, there is a danger that more resources are put into the transaction process (the business of simply getting the support to the person).

In the following sections we explore the extent to which the current social care system has these features that tend to produce inefficiency. We also examine the degree to which we have seen progress towards a better approach – one that is more efficient and enables people using social care to get better outcomes.

Waste by misdirection

There is no significant literature exploring the degree to which the current social care system misdirects resources. Perhaps this lack of literature can be attributed to the fact that, until recently, there has been so little attention paid to giving people control over their own resources. However, it seems likely that a system that does not allow the person receiving support to shape that support will not give people what they really need.

The current social care system is not designed to give people a significant degree of control. Most services tend to be defined in a ‘take it or leave it’ spirit. Largely, the current system is characterised by its offer of a narrow range of slots within existing services:

- days at a day centre
- a bed in a care home
- hours of domiciliary care
- nights of respite care.

The types of services are very limited and it is often quite difficult to shape your own use of even this limited choice of services. There are only so many empty slots in the system and the vacancies are not defined by a person’s needs. Rather, the exact offer of a service is determined by who else most recently died or left the service.

There are strong reasons to suspect that much of the improved value in Self-Directed Support arises simply because people can direct resources towards supports and services that they genuinely value and away from services that they do not value.

Overall, Chris Hatton’s report shows that most people (82%) have changed the services they use. Anecdotally, we know that some people are spending their budgets on new or creative support and personal assistance but others continue to purchase traditional services – although perhaps not to the same degree. For example, some people may continue to attend a day centre but have a greater say about when they go – and they may go less frequently.
Waste by multiplication

Another source of waste is the use of multiple systems to achieve the same goals. There are many examples of this kind of waste and a more detailed analysis can be found within the report *Individual Budget Integration*. Here are just a few examples:

- Almost everyone currently receiving funding from the Independent Living Fund (over £200 million) – approximately 20,000 people – will also receive separate support from the local authority. Yet each system has its own unique systems of assessment and monitoring.

- A significant percentage (an independent report suggested 75%) of those receiving Supporting People Funding (over £1.5 billion) also receive separate support from the local authority’s social care system – yet each system has its own unique systems of assessment and monitoring.

Many people using social care (a recent report suggested 42%) will also be making significant use of Community Health services.¹

The waste caused by this confusion of multiple funding streams is not confined to the additional costs of infrastructure. Each funding stream applies a different regime of means-testing and each engages in a complex game with the aim of defending and rationing itself. For example, recipients of the ILF often face two competing systems of means-testing: an ILF system by which they lose 50% of their Disability Living Allowance or a competing local system of charging.

All these competing systems have developed for good reasons. But each focuses on trying to meet partial needs by providing particular programmes of support. Attempts to integrate or coordinate these different programmes have always proved problematic. One of the important consequences of Self-Directed Support is that it refocuses attention on the whole person. It enables a new focus on the person as the appropriate locus for integration and it demands that competing systems provide resources in ways that enable effective integration at the level of the individual.

Inflating needs

Another form of waste in the current system is its tendency to provide too much support. At first sight this third form of waste may not seem to be a problem. Many of us are inclined to think more is always better. However, in the case of social care this is not correct.

At first glance, it may also seem unlikely that a system so focused on rationing resources could lead to services being over-provided. But the rationing process is where the problem begins. In order to receive support, people need to be deemed eligible. 73% of local authorities expect to only be offering support to people who are at substantial or critical risk in one or more of the following areas:²

- life is, or will be, threatened
- significant health problems have developed or will develop
- there is, or will be, little or no choice and control over vital aspects of the immediate environment
- serious abuse or neglect has occurred or will occur
there is, or will be, an inability to carry out vital personal care or domestic routines
vital involvement in work, education or learning cannot or will not be sustained; and/or
vital social support systems and relationships cannot or will not be sustained
vital family and other social roles and responsibilities cannot or will not be undertaken.³

In a wealthy society like England it can seem extraordinary that the system seems to be less and less willing to help people and only seems to help those in the most extreme situations. In reality, the situation is not as bad as this: partly because professionals do not want to restrict support so severely; partly because some people learn what it takes to get access to help. In particular, people find that they are more likely to get help if they:

◆ minimise the help they might get from friends, families or other community members
◆ maximise the crisis and minimise their own capacities.

The price of both these strategies is that it increases the risk of receiving a support package that is not only bigger than necessary but which may well cause the person to become segregated, isolated and dependent. Moreover, some people may not have a supportive social worker or may not understand the rules. They may find themselves struggling to cope, putting pressure on family and friends. This can lead to a wholly genuine crisis; a crisis that could have been avoided if a lower level of support had been provided earlier.

One advantage of in Control’s model of Self-Directed Support is that it offers a more sensitive account of need. Also, it does not discourage people from strengthening their own capacities or their community support systems. Money can be used flexibly by the individual and the local authority applies a light touch in monitoring how the money is actually spent. A light touch in monitoring appears to build the kind of trusting relationship between the state and the individual that enables people actually to return resources to the local authority when they are not needed. For example, it is reported in Oldham that people are more likely to return money than to say their budget is insufficient.⁴
Such voluntary returns of funds are very uncommon in the current system.

Innovation failure

The fourth cause of waste can be found in the limited role that innovation is permitted in the current system. In a largely self-perpetuating system in which funding decisions are taken at a distance from the people who use support, innovations are rare and usually face stiff resistance. Only a flexible, responsive and non-defensive system can encourage innovation. Only in a reflective and communicative system can innovations be discovered, shared and spread. The current system lacks both the capacity to innovate and the capacity to learn from and spread innovation.

One symptom of this failure to innovate is demonstrated by the recent report by the Office for National Statistics⁵. This report shows that the productivity of the adult social care system has dropped by an average of 2.1% each year between 1996 and 2005: a total drop of 17% in ten years. Comparing the productivity levels in adult social care with other sectors generates another interesting statistic. The Economic & Social Research Council noted that overall productivity in the UK economy has been rising consistently at about 17.5% per decade.⁶
One explanation for the enormous gulf between productivity in social care and the rest of the economy might be that the social care system finds it difficult to innovate. On the other hand when people are in control of their own budgets we have seen many more innovations:

- Gavin uses some of his budget to purchase a season ticket and uses the season ticket to get free support to follow his team (Rochdale F.C.).
- Julia used some of her budget to buy air-conditioning to improve her health and keep her out of hospital. She used another part of her budget to make her whole house wheelchair-accessible at a fraction of the local authority cost.
- Chris organised a voice-reminder to help her mother be safe at home.
- Gary, who lives in a big city, used a one-off grant to acquire a mobile home in a holiday park near the sea. Gary’s mother is now able to support him during the week knowing that they have the weekend and holidays to look forward to. They have built up a strong support network in the holiday park. This approach has been much more cost-effective as Gary would have needed regular support during the week including regular respite breaks which previously always caused distress to him and the family.

Without innovation, greater productivity cannot be achieved. The key to innovation is to give those people with the greatest interest in solving a problem the means to solve that problem in a way that makes sense to them.

Waste in transaction

The final form of waste is the very high level of transaction costs that have grown up within the social care system. In effect, there are at least three systems of management within the current social care system:

- **senior management and commissioning** – staff who administer the contracts and funding arrangements for services. It is difficult to get figures for the cost of this layer of management.
- **care management** – staff, often social workers, who assess people, place them in services and monitor those services. Department of Health statistics indicate that 16% of the social care budget is spent on care management.
- **service management** – each service that someone uses has its own internal management costs, whether that be in the private, voluntary or public sector. Again, consistent data is hard to find but experienced managers would expect that between 10% to 20% of funding received by services is spent on management or administration.

Although more reliable data in two of these areas would be helpful, it still seems more than likely that over 30% of the social care budget is spent on transaction costs. All systems have transaction costs, of course, but 30% is an unnecessarily high figure.

This is one area where the benefits of Self-Directed Support have yet to make a discernible effect. Most of these transaction costs cannot be reduced without significant restructuring and it is only when authorities are able to begin to operate Self-Directed Support at volume that they will be able to free up resources from unnecessary infrastructure. However, early indications from the field suggest some areas where progress is likely:
Many more people choose to manage their own support directly, employ staff, or have someone they know employ staff for them.

Even for those who prefer existing service solutions, seeking out and identifying the right support provider can be a time consuming task – one that is at present almost exclusively undertaken by paid staff from the local authority. Given opportunity and information, many people will prefer to undertake this search themselves.

The current assessment process can be radically reduced. In Control’s self-assessment approach means that most of the work can be done by the person or their representative very quickly. The work done by the social worker to validate the self-assessment is much less time-consuming.

Much time and energy in the current system is spent in complaint resolution. Self-Directed Support will almost certainly free up much of this time for more productive uses.

A counter factor – new demand

In Control’s operating method is continually to try and learn how and why Self-Directed can be more efficient than the old system of social care. However, we have also been very clear about the one major financial risk that will be faced by local authorities that embrace Self-Directed Support – it will drive up demand.

At present, the unattractiveness of the current social care system acts as a vicious form of rationing – rationing by not offering appropriate services. For some people, this lack of confidence in the quality of services acts as a significant deterrent to asking for support. If they can afford to stay away from services, or can make some alternative arrangement, they do. However, when Self-Directed Support is available and authorities offer people choice, flexibility and control, ‘new’ eligible people will come forward and claim their right to a service.

A detailed description of this dynamic model and its application has been published by In Control and is available on the In Control website. The paper is entitled: Using simulation modelling to test the impact of Individual Budgets on whole system finances.

A further factor will be the impact of the new financial settlement for social care that will not be clear for some years. However, it is likely that this new settlement will lead to greater clarity about:

- what level of support people are entitled to receive
- what people are expected to contribute to their own support
- how social care funding is linked to other entitlements.

Local authorities will need to move forward towards the implementation of Self-Directed Support at the same time as many financial questions will remain unanswered. However, this very uncertainty also offers some comfort to local authorities; for while Self-Directed Support is very likely to be central to the government’s vision, the precise details of how resource allocation and means-testing will be carried out will only be known when the new settlement is fixed. Hence, local authorities would be wise to move forward while knowing there will inevitably be a period of financial readjustment within the next five years. This means that
any systems that are being set up at present will probably need to be changed. Authorities will benefit from taking a pragmatic, rather than perfectionist, approach to developing such systems.

## Challenges ahead

We began this chapter by identifying the extent to which the new system, Self-Directed Support, is more efficient than the old system of social care. While we have been able to say some things that indicate that it is more efficient, there is also a sense in which the question is slightly misleading. It tends to treat Self-Directed Support as a static model that just needs to be implemented.

The reality is more complex. Self-Directed Support consists of a set of principles and some useful models and technologies. But it is in the process of developing a new system that the opportunities and risks of increased or reduced efficiency will occur:

- **control** – it is possible that people will get the chance to control their own budgets and shape their own support. But it is also possible to borrow the language of Self-Directed Support and apply it to systems that actually give people no meaningful control and that dictate to people how they are supported.

- **integration** – it is possible that central and local government will be able to move away from multiple forms of complex funding. But this will require vision and leadership at every level.

- **rationing** – it is possible to use Self-Directed Support as the means to get resources to people earlier and to offer low level support. But it would also be quite possible to offer Self-Directed Support at the end of a rationing process – good support, but only available to those who are in crisis.

- **regulation** – it is possible to offer people control and let them use resources flexibly. But it would also be possible to impose regulatory and monitoring controls on people in ways that limit their ability to innovate.

- **transaction costs** – it seems possible to introduce Self-Directed Support in ways that reduce transaction costs. But it is also possible to add to the transaction costs. For example, in some countries, new systems of support brokerage have been developed without reducing any of the other systems of management.

The implementation of Self-Directed Support is certainly a challenge for all those involved in social care. But this challenge does not consist in implementing Self-Directed Support with a view to watching the efficiencies ‘roll in’. The challenge is to implement Self-Directed Support in a way that ensures efficiency – and this efficiency can only be achieved through a fundamental reform of management systems and the transfer of control to individuals and their supporters. This challenge will fall in particular to the leaders of local authorities who are empowered to make the necessary changes.
Conclusion

in Control has played some part in helping people to see that Self-Directed Support can be more efficient. The latest data further supports our analysis, but there is much more to do. The learning that comes from the ten Total Transformation sites will be particularly important as we go into the next phase of our work.

in Control aims to continue to work in the same spirit it has so far. We have supported the development of the Independent Research & Evaluation Committee, chaired by Chris Hatton; and we will work with our local authority members to ensure that the process of learning is simple, efficient and well communicated.

We are also going to put more of our limited energy into using the internet to help people who use services to communicate with their authorities, each other and the wider world. To this end, we have developed an online system that allows individual citizens to record the outcomes they have achieved through their support, in a way that the local authority can use to inform its reporting. This exciting innovation will open up the possibility of local authority performance assessment being informed by judgements made by local citizens.

Authors

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Simon Duffy
See Simon’s profile at the end of Chapter One.

NOTES

2 Commission for Social Care Inspection (Nov 2007). What councils are reporting on their progress in delivering services to adults with social care needs.
3 Department of Health (2003). Fair access to care services – guidance on eligibility criteria for adult social care, p. 4.
4 Report from Bev Maybury, Oldham.
Chapter 3

Enabling people to plan and arrange support
Enabling people to plan and arrange support

Jonathan Senker

This chapter argues that the right help for people who plan and organise their support is vital. Help needs to be available at the right level for all people who need it.

Though such support is far from readily available for all who need it, there is a growing number of initiatives. Many of these adopt the name ‘brokerage’. While in Control believes that it is important to encourage innovation and a range of options, this chapter also suggests the need for deliberate strategies – especially at local authority level – that will ensure support is available.

Introduction

We plan our lives in many different ways. Some of us spend time working out our long term goals, defining the steps that we need to take, reviewing our progress and adjusting our course. Others have a general sense of direction: ‘within the next ten years I want to have achieved these things.’ The goal is always at the back of the mind and influences decisions taken along the way. Some of us strive to make the best of each day and week: we would need to think hard to identify the overall direction we want to take. Some of us feel out of control: passengers on a journey not of our choosing.
For those of us who may need some form of social care, a way to plan and organise our support is almost certainly needed in order to get the best out of life. From the 1990's onwards, care management has determined the models of services purchased using statutory social care funding. Increasingly, the limitations of this method of identifying needs, care planning, allocating resources and arranging services have been acknowledged. In particular, the experience of far too many people has been that the current system is highly complex. The system takes control away from those who rely on support. Those people can find themselves exhausted by the experience of navigating a course through the winding routes and obstacles of the system.

in Control's work has demonstrated that changing the way that social care operates is possible and may lead to straightforward and empowering experiences. Having the opportunity, information, advice and assistance to work out how we want to live our lives and what support we require is vital. Evidence gathered during in Control's Second Phase\(^1\) shows that almost everyone relied on external assistance to plan. It is critical that this support is available at the right level for all people who may need it, including those who may lack formal capacity in relation to key decisions as well as those who want to minimise the involvement of third parties.

Several alternative approaches have been developed to enable people to plan and arrange social care. These approaches replace the prevailing model of professionally led assessment and care planning. It is appropriate that a variety of different approaches is available so that people can select one that matches their requirements. The hallmarks of successful initiatives are that they lead to people having a better life and that they build on people's existing capacity and that of family, friends and community, rather than displacing individual ability and the support of informal networks.

in Control's view is that it would, at this stage, be unhelpful to restrict unduly the development of potentially promising ways forward. However, it has become increasingly clear that deliberate strategies need to be agreed and implemented, especially at a local authority level, to enable people to plan and arrange social care. A failure to shape deliberately the development of such strategies will limit the potential of Self-Directed Support. Indeed, some people using social care services and organisations are already finding that a lack of capacity to enable support planning to take place is a critical factor delaying progress. This chapter indicates some elements of the approach that are needed. We suggest that local strategies are put in place and that these ensure the provision of support brokerage, advice, information, peer support and advocacy.

The need for change

The introduction of care management was intended to enable services to be fitted around the needs of individuals. Care management was to be the cornerstone about which needs-led (rather than service-led) arrangements would be developed and public expenditure rationally managed. Despite costing around £1.2 billion and often being discharged by highly skilled practitioners, the shortcomings of care management have nevertheless become increasingly clear. In particular, this approach puts the professional in the driving seat, fails to allocate funds according to need, can stifle individuality and creativity and often locks people and families into unnecessary dependency\(^2\).
Experience from in Control’s Second Phase

Throughout the first two phases of in Control, a variety of methods have been developed and used to enable people to make plans and arrangements to live life to the full and manage risks.

Information gathered from 196 people with Personal Budgets indicates that almost everyone received support to decide how to plan their budget (96%).

Almost half of this number of people had help from family and/or friends (46%), with no statistically significant differences between people with learning disabilities, people with physical disabilities and older people. Less than one in five people had help from a person paid specifically for the purpose (18%); and almost all of this support was used by people with learning disabilities. Very little of this support was used by people with physical disabilities or older people. However a large majority of people (71%) had help from a paid professional, in particular, a social worker or care manager. People with physical disabilities and older people were somewhat more likely to use this source of support than people with learning disabilities (84%, 83% and 63% respectively).

Almost two-thirds of people (65%) had support to plan how to use the budget from one of the above sources of support, with just over a third (34%) having support from more than one source. People with learning disabilities were most likely to have help from more than one source, followed by older people and people with physical disabilities (46%, 33%, 18% respectively).

These statistics appear to show that, while many people receive support from friends and family, there is still a strong reliance on the support from social workers and care managers to plan Self-Directed Support. It is likely that this is due to a combination of factors. Key amongst these factors may be the relatively early stage of development of Self-Directed Support in most local authority areas. In many places, there are still few alternatives to the support planning help available from social workers or care managers. It is also possible that the role of social workers and care managers in checking support plans spills over into providing help to write those plans.

This tendency is corroborated by Chris Moon-Willems, Service Manager in West Sussex:

In my view, care managers still have too much involvement. The best people to plan are the people themselves and those closest to them, not care managers. They aren’t usually the best people to plan. How can you be a critical friend to a plan when you wrote it? I don’t see how you can both write and sign-off a plan.

People are still treating care managers as the experts and asking them for advice. But it’s families that need to inform and guide care managers. Too often, families are not in the driving seat.
Doing it differently

It has become increasingly clear that there is no one-size-fits-all approach to planning and arranging support or ‘support brokerage’. As the Commission for Social Care Inspection observed:

…we currently know relatively little about how brokerage as a whole might operate in practice. This is a powerful argument for experimentation and piloting of initiatives to explore what might be possible, how transferable the model might be across different groups of people, and to use the evidence accumulated to inform future developments.8

Exchanging care management for a single alternative system is likely to limit the potential of Self-Directed Support and is difficult to reconcile with the principle that support should be individualised. Such an approach would run the risk of:

◆ failing to empower people. in Control’s experience demonstrates that the ability of people using social care services to develop and arrange their own support has frequently been underestimated
◆ undermining the involvement of friends, family and community and militating against the development of creative locally-based solutions
◆ unnecessarily separating people using social care services from decision-making about the resources used to plan and arrange support.

For these reasons, continued exploration and evaluation of a range of options is important.

Support brokerage

There has been a great deal of discussion about ‘support brokerage’ as a preferred method to enable people to plan and organise social care and to live a full life. There is a growing body of knowledge about brokerage in the UK, largely situated in those local authorities that are members of in Control, and there are lessons to be drawn from international experience. Yet definitions and understanding of what defines support brokerage remain contested or unclear. Indeed, the use of the term has become so broad as to be described as an ‘international shorthand for the kind of interpreters of a system which recipients may welcome’6. Further important questions exist about who should provide brokerage, how it can best be developed, delivered and funded.

It may be more helpful to think about ‘support brokerage’ as a set of tasks or functions, rather than a role. These include:

◆ assisting the person to develop a vision of how he or she wants to live
◆ reviewing, preparing and/or identifying indicative costs of creating and implementing a support plan
◆ clarifying the person’s needs and expectations, including, in the light of the local authority’s assessment, eligibility criteria under Fair Access to Care
◆ identifying and applying for funding from all government and non-government sources
◆ supporting the *Fair Access to Care* appeals process if required
◆ identifying and enabling the person to access community resources
◆ assisting with funding negotiation with commissioners
◆ liaising and negotiating with support providers
◆ monitoring and evaluating support
◆ modifying existing supports or develop new ones
◆ mediating and resolving problems (as directed by the person).  

A **support broker** can be understood as a specialist in carrying out these functions, an independent professional who can help with planning and who is not involved in providing support or rationing resources. However, other people and organisations may also be well placed to carry out some or all of these functions.

As noted, some people have undertaken these activities entirely for themselves, or (more frequently) with family support. Care managers have continued to play a very considerable role in supporting people to plan and organise their support. Some people have received this assistance from a specialist support broker, typically employed by a voluntary sector agency or working freelance. In other instances independent advocates, service providers, Centres for Independent Living or Direct Payment schemes have undertaken these functions.

Developmental strategies for brokerage must take account of the range of different parties that can provide this support. It is clear that strategies to develop support brokerage must engage at a number of different levels in order to ensure that people have a choice of different support brokerage options.

It is also clear that deliberate strategies need to be formulated and implemented to develop brokerage. A *laissez-faire* approach risks assistance not being available to people to plan and arrange support. Alternatively, such an approach may result in dominance over support brokerage by care managers or large providers. These groups have the resources to invest in developing brokerage and have some obvious incentives to do so. Both outcomes would be unhelpful and may limit the potential of Self-Directed Support.

A **five-point strategy for the development of support brokerage** is therefore suggested. As described below, action is required to:

1. Enable people and families to take their own decisions
2. Enable user-led organisations and community groups to play a full role
3. Shape support providers’ contribution
4. Focus care management
5. Promote the development of independent support brokerage.

### 1. Enable people and families to take their own decisions

The Social Care Institute for Excellence poses the question that, if brokerage has become a shorthand for interpreters of a system (of social care), why does the system need interpreting? in *Control* addresses this question by simplifying and making explicit how social care decisions are made; and by empowering individuals and families. As a result, more people play a greater role in planning and arranging their own support.
This has been done by removing barriers to people taking their own decisions, including challenging attitudinal barriers which may otherwise maintain a professional preserve over too many key life decisions. It has also involved people having access to good information, advice and advocacy. Some innovative new methods of enabling people to have the information and assistance to take control are being developed.

**Provision of free information, advice and advocacy**

The provision of independent and free information, advice and advocacy to enable people to find out about and take decisions concerning Personal Budgets, is likely to play a key role in continually increasing awareness of – and confidence in – Self-Directed Support on the part of people who may benefit from it. This may be especially so during the transition towards increased use of Personal Budgets. The continuing free availability of such services may be critical to fostering confidence on the part of people considering taking up Personal Budgets. It will also help to provide reassurance that independent assistance is available should difficulties need to be tackled at a later stage.

This is consistent with the evaluators’ early findings from the Individual Budget pilots that:

‘A strong theme to emerge was the importance of support outside of the users’ own caring networks. Access to free brokerage, professional advocates and/or mentoring by someone who has been through the process were seen as crucial to getting the most out of IBs. Without this support interviewees thought it would be difficult for IBs to work for people with complex support needs, who have little family support, or who do not want to rely on their families for help with managing their IB.’

Development is needed to ensure that providers of information, advice and advocacy are well equipped to assist people in relation to Personal Budgets. For example, the independent advocacy organisation, Advocacy Partners, is developing its services to ensure that people with high support needs have greater information about and access to Personal Budgets. The organisation will offer intensive support to people in several London boroughs and share lessons with other advocates and partner agencies. These services will be offered free at the point of delivery and are being supported financially by London Councils (formerly the Association of London Government). Advocacy Partners is also actively exploring the development of a support brokerage function, which is likely to operate at arms’ length from its advocacy role.

**sds4me – web-based information, advice and support**

Developed by Gavin Croft working with in Control, sds4me provides a wealth of information in a single website and in an accessible format for people who want to make the best of their Personal Budget and gain Control over their lives. sds4me is a user-led resource. It facilitates peer support, offers a forum, links to blogs and enables people to share expertise, thoughts and advice.

By offering a range of examples and supporting information, the site enables people to write their own support plan on-line. Employers and those thinking of employing personal assistants or other employees can download templates for contracts of employment, conditions of service, disciplinary procedures, electronic timesheets, rota, and a Good Employer Starter Kit. These templates can be amended and personalised electronically before being printed and used.
Local authorities and other organisations subscribe to *sds4me* to enable local citizens to access the site.

**Planning Live**

*Planning Live*, first practiced in Essex, demonstrates that individual planning and peer support can go hand in hand. Based on two or more whole-day workshops, *Planning Live* enables people in the process of obtaining a Personal Budget to develop their vision for the future and to draw up a support plan to enable this to be realised. *Planning Live* events are free of charge to participants and run in conjunction with Helen Sanderson Associates. Participants can share ideas, work on their plans with their supporters and pick the brains of professionals working in relevant areas, such as housing or benefits. While this approach has enriched participants’ experience and has resulted in creative support plans, the benefits do not end there. Some *Planning Live* participants formed the Liberation Partnership, a social enterprise run by disabled people. Liberation Partnership supports people to explore the benefits of Personal Budgets and enables them to plan and take control. *Planning Live* events have now been held in a number of areas, including in the North East and in London.

**Emerging practice**

In addition to these developing approaches, new methods of enabling people using social care, families and friends to obtain information and guidance are emerging, as the following examples illustrate.

**shop4support**

Arranging support is not just a matter of knowing what we want and need. It also needs to be available at a cost and quality that we want. Currently under development, *shop4support* is a website-based market place. It will provide a key tool for people who have their own budget or want greater control over their social care. It is being developed by *in Control*. *shop4support* will give access to a broad range of services and products that individuals can buy with their Personal Budget. The website will offer people buying support the benefit of feedback from other purchasers on the quality of vendors; knowledge in advance of a fixed price for goods or services; a facility to track their spending; ease of ordering; and the potential for lower costs thanks to combining purchasing power. It will benefit vendors by enabling them to publicise their goods or services, and to facilitate invoicing and payments.

Potentially an 'eBay' for people directing their own support, *shop4support* aims to increase the power of people while also stimulating the development of effective and innovative support and goods. This site also aims to keep transaction costs low. Discussions have been taking place in a number of local authority areas to scope, design and implement *shop4support*. At the time of writing the site is almost ready to go live.

**Plan UK**

Based on pioneering work in British Columbia, Canada, *Plan UK* will enable families to help their relatives to plan and arrange support. A partner of *in Control*, *Plan UK* will be run and owned by family members. Working closely with existing family-oriented organisations and community groups, *Plan UK* will enable people who use social care to build sustainable networks of friends and relations. It will equip these networks with information and guidance to help in planning for the long term: for example, around housing options, arranging social care and advising on legal matters such as establishing trusts and wills; and understanding the requirements of the Mental Capacity Act.
Recommendations

Local authorities and partner agencies should:

- develop and communicate clear messages about the rights of people to control their own support
- review the availability of – and local authority investment in – local information, advice and advocacy to ensure that this is sufficient and that it is well-directed to meet people’s requirements in relation to Self Directed Support
- give attention to information that is available to the general public (e.g. libraries, local websites and council information)
- publicise the availability of existing high-quality information, guidance and tools and develop bespoke local information.

2. Enable user-led organisations and community groups to play a full role

A wide range of different individuals and community organisations have supported people in developing support plans. This includes advocates, direct payment advisers and person-centred planning facilitators. To date, there has not been extensive use of existing community organisations with a generic rather than a social care focus, nor of local Centres for Independent Living (CILs). Central government has recognised the need for a user-led organisation in each locality, modelled on existing CILs. This government acknowledgement, together with the partnership between the National Centre for Independent Living and in Control provides the potential for a far greater engagement of user-led organisations in enabling people to plan and use Personal Budgets. There is considerable scope for user-led organisations to develop and offer support brokerage.

Herefordshire CIL

While involvement in brokerage activities is relatively undeveloped, there are some examples of a pro-active approach on the part of CILs. One such is Herefordshire CIL. Enabling people to achieve personal ambitions and getting the right support from the right person lies at the heart of Herefordshire CIL’s approach to brokerage. Results have been impressive. People taking part in the scheme are supported to adopt leadership roles in community, leisure and arts organisations; as well as to find work and start micro-enterprises. Each of the 20 people supported in the first phase of this initiative reported increased community engagement, with only one person choosing to receive support from the statutory sector. The scheme has also enabled people to take a knowledgeable and confident approach to purchasing personal support.

Yvie George, Herefordshire CIL’s support brokerage Manager, attributes the success of the initiative to its focus on outcomes, flexible individualised approach to planning and emphasis on exploring and enhancing what communities have to offer, rather than relying on statutory provision.

Advocacy, community and brokerage

It is clear that, while there is an overlap, the functions of advocacy and support brokerage are distinct. For example, while advocates frequently enable people to express their views and
vision for the future, they are not responsible for costing support arrangements or, usually, for designing these. It is, however, clear that advocacy organisations will have the skills and commitment to undertake key support brokerage functions. They may be able to use these skills to provide a rounded brokerage service that is offered separately from their advocacy role. It will therefore be worth exploring the contribution that advocacy schemes can make in this respect, while having due regard to potential conflicts of interest. This potential clash needs to be well understood, clearly communicated and adequately built into organisational arrangements.

There appears to be considerable scope for the increased use of local community organisations, tenants’ groups and existing advice and community-focused information providers to offer support to people using social care. In Control’s discussions with such organisations indicate a keen interest in identifying the ways that communities can extend their natural capacity in offering support and advice to people using social care. This is an area that requires further exploration and development.

Moving forward

Local authorities and partner agencies should explore with user-led organisations, community groups and advocacy agencies, their potential contribution to the implementation of Personal Budgets. This activity may include:

◆ encouraging organisations to develop formal support brokerage roles
◆ ensuring that they are mindful of the contribution they can make to supporting people with Personal Budgets when carrying out their current functions, building community links and when providing information, advice and advocacy.

Local authorities and partner agencies should also develop and implement plans to increase the capacity of community organisations to support citizens in using Personal Budgets – for example through access to training and information, existing sources of business advice, small grants to enable business planning and by encouraging the development of partnership initiatives.

3. Shape support providers’ contribution

Support providers have expertise in arranging support and enabling people to plan. They also have experience of employing and often managing large numbers of support staff. It could, then, be argued that support providers may be well-placed to provide support brokerage. Indeed, many of the functions of support brokerage are frequently undertaken by providers.

Castle Supported Living

Organisations that have focused on Self-Directed Support, incorporating a brokerage function, include Castle Supported Living in Lancashire. Person-centred planning is at the heart of the approach. Castle Supported Living has enabled people to use their Personal Budgets to buy their own individually tailored Supported Living from its own services as well as to purchase support from other agencies, including training, vocation and leisure services.

Each person receiving support has a Personal Budget treated as a separate restricted fund in Castle Supported Living’s accounts. This means that it must be accounted for individually
and any costs of shared support must form a part of an agreed plan. The organisation is now developing systems to ensure that people can track up-to-the-minute financial information on their Personal Budgets and is working with Helen Sanderson Associates to develop accessible individual support agreements.

**Conflicts of interest**

Critics have drawn attention to the conflict of interest for organisations in enabling people to take decisions about the use of Personal Budgets; and potentially being the recipients of a large proportion of this fund. Indeed it could be seen that such an arrangement would allow a return to an older arrangement of social care in which control rests almost exclusively with the provider of services.

How effective providers can be in providing genuine, independent brokerage remains an open question. However, if providers attempt to undertake brokerage functions, then it is clear that safeguards are needed to ensure the integrity of the service. One means of dealing with the potential conflict of interest is to create some form of arms’ length relationship between the provider and broker functions offered by any organisation.

A protocol for support providers taking a support brokerage role has been developed in West Sussex. This is intended to assist in managing the potential conflict of interest and may provide a helpful model for others to adopt and adapt. Even with such arrangements in place, risks remain. Such risks would need to be considered and managed. These include:

- a perception of lack of independence (whether justified or not) which erodes trust
- a bias in favour of services available from the provider (whether deliberate, or simply as a result of familiarity)
- a limited range of brokerage options being developed because large providers have the resources to invest in its development and could dominate the market.

**Moving forward**

Support providers, people either with Personal Budgets – or seeking to obtain them – and local authorities may be advised to:

- explore the range of support services that providers can offer to people to enable the management of Personal Budgets, including payroll, Human Resources advice and administrative support
- explore whether it is appropriate to develop further, or to use, provider agencies’ support brokerage functions, in the light of a careful consideration of the inherent conflict of interest
- carefully consider the safeguards that can be put in place to promote the independence of brokerage functions, assess their adequacy and communicate any in-built limits to that independence
- assess the importance that providers should give to developing support brokerage relative to other changes in function and practice that they face in the move to Self-Directed Support. See chapter six for further consideration of this question.
4. Focus care management

Outcomes of this phase of in Control’s development are positive. It is possible, therefore, to jump to a conclusion that future direction should be based on the current arrangements for enabling people to plan their support. In particular, we could rely on existing social work professionals to enable people to make plans (as indicated earlier, a large proportion of people in the evaluation used care managers or social workers for help with support planning). Despite the highly-skilled work by many care managers and social workers, relying on these professionals as the prime locus of support planning is likely to inhibit the potential of Self-Directed Support as it is rolled out. This is for two main reasons. Firstly, it risks the continuation of traditional service-led decision-making. Widescale cultural change is needed in local authorities adopting Self Directed Support and changing assumptions and attitudes in large organisations can be slow. Secondly, a reliance on social work professionals may blur the line between rationing resources and enabling people to plan — two functions that are, in most cases, not compatible in one role.

Evidence to date suggests that it would be unwise to rule out completely care managers and social workers from enabling people to plan their support. Indeed, at a point of crisis, or in very complex situations, this might be the best option. A care manager or social worker may also create an interim plan to enable a person to progress to a situation in which they are more able to take control over future decisions.

There is, however, a risk that, without the active nurturing and development of alternatives, the involvement of care managers and social workers in support planning could play a role that inhibits the healthy growth of Self-Directed Support. Care managers themselves often suggest that they are not necessarily best placed to support people in planning. One group of care managers said that they were the best people to offer this support in only about 15% of situations.

Moving forward

Local authorities should:

◆ refocus the care management role towards ensuring soundness of support plans rather than developing support plans
◆ review investment in care management to shift towards independent and community-based models of support brokerage
◆ develop workforce strategies to utilise fully skills of — and provide opportunities for — existing social workers and care managers
◆ define situations in which it is most likely that care managers will be required to plan and organise support
◆ provide guidance so that care managers and social workers can help people to choose between support brokerage options.

In helping people to choose, care managers and social workers will need to explain options available for people to:

◆ plan and arrange support by themselves or with the help of friends and family
◆ receive assistance from local agencies, support providers, or from specialist support brokers (see below).
5. Promote the development of independent support brokerage

Engaging a specialist support broker may have advantages. Support brokers are, one hopes, professional, competent, independent and have a clear and distinct role. Over the past two years there has been a growing interest in the development of independent support brokers. Those offering independent brokerage include organisations such as Step by Step in Rochdale and Realife Trust in Essex. There are also freelance practitioners who offer this service. The number of people working as dedicated support brokers remains relatively small and there are problems to overcome if more skilled brokers are to be available.

Funding and sustainability

Various models of funding have been developed, including block-grant funding by local authorities to local organisations. In other places, people directing their own support have been offered a one-off contribution towards brokerage costs. Elsewhere, people are expected to pay for brokerage entirely from Personal Budget allocations.

in Control has argued that the work of support brokers should be funded predominantly from people's Personal Budgets. To do otherwise would reduce the choice and flexibility that is at the heart of Personal Budgets. Creating a system of brokerage that is paid directly by the local authority may impose this support on those that do not need it and lock funds into a new professional-led system.

An opposing view is that funding brokerage exclusively from Personal Budgets may create a disincentive to the use of such specialist support. In this view, some people would not include dedicated support brokers in their range of choices.

There has also been concern about the fairness of paying for support brokers' work out of Personal Budgets. The issue is that people who are unable to plan their own support, or who rely on friends and family for help, will be treated less equitably than others. Whether this is the case may depend on how effectively the implementation of Resource Allocation Systems takes account of the individual's ability to plan and the availability of people within the individual's personal network to assist.

Notwithstanding these concerns, it is clear that if dedicated support brokers are to form part of the spectrum of available support, then people ready and able to undertake this role need to be available. There is currently an under-supply of support brokers. A consequence of this under-supply is a continuing dependence on care managers and social workers. This situation may need to be addressed by providing development funding to increase the number of brokers. Indeed, a rapid increase in the number of people prepared to offer dedicated support brokerage, especially individuals who do not enjoy the security provided by employment, may be unlikely without some reconsideration of this issue.

In considering funding options, it may be helpful to consider two questions separately. Firstly, what is needed to stimulate the increased availability of dedicated support brokers? Secondly, what is required to sustain supply in a more mature market? For example, it may be appropriate to use focused grants or contract funding to help develop initial capacity. On the other hand, using block funding arrangements as a long-term mechanism to meet the majority of the funding required for dedicated support brokerage may militate against individual choice. Long-term block funding may also run counter to the principles underpinning personalisation, and not make best use of resources.
Quality

When we receive a service we expect it to be reliable, safe to use and good quality. We also expect some form of redress if it fails in any of these respects. Systems to ensure these features typically include accredited mandatory training, customer feedback, monitoring and evaluation, regulation (by an external body or by the customer), membership of professional bodies, oversight organisations (whether consumer-oriented, lay or professional), quality assurance schemes and inspection.

Not surprisingly, in respect of support brokers there is considerable debate about the emergence, applicability and shape such systems might take. It is important that while these systems emerge and develop, there are practical ways in which statutory bodies and, more importantly, people using Personal Budgets can ensure the quality and safety of support brokerage services, whether provided by dedicated support brokers or as a part of a wider role played by user-led, advocacy, community and provider organisations.

In many cases, there are already mechanisms in place that may meet at least some of this need. For example, where support brokerage is purchased using a Personal Budget, it is within the local authority’s ambit when signing off the support plan to ensure that reasonable arrangements are in place. Similarly, when funding is provided directly by local statutory authorities, existing grant or contractual tools can be used. Sensitivity and thoughtfulness will be needed in order to promote safe practice without undermining the individual’s right to decide who is best placed to provide help. We also need to give particular consideration to the situation of people who fund their own social care – people who may have little direct contact with statutory funding agencies.

Regulation and accreditation by people and families directing their own support is a key strand to the approach that must be taken. For this to work, there need to be explicit expectations of support brokers, and an effective mechanism for well-facilitated feedback. We cannot just rely on traditional local forums to seek views on brokers. Such forums vary in their ability to elicit individual views. Sometimes, views expressed can be those of a few vocal people who are not necessarily representative.

A clear set of baseline measurements for what the individual should expect from a broker is needed. in Control is currently developing baseline standards in the shape of a code of practice for brokers. We will develop this code in partnership with a wide range of stakeholders.

One means of checking performance against these standards will be shop4support, in Control’s online marketplace (which will be launched in 2008). This will both provide a platform for brokers to offer their services and also a function that allows people buying brokerage to rate publicly (online) the services of any broker.

In this way, some people will be able to assess the effectiveness of brokers and brokerage, and to guide how the market needs to be developed further. As in many aspects of Self-Directed Support, one solution will not work for everyone and further mechanisms for evaluating brokerage will need to be developed as experience grows. Attention needs to be given especially to people who will find it hardest to access and use information on the quality of support brokerage (especially web-based resources), as well as to people who may not otherwise be in a strong position to negotiate the support they need.
Workforce

There is considerable uncertainty about the workforce implications of developing dedicated support brokerage. What is the demand likely to be and how many people are required to meet it? From what career or personal backgrounds will the support brokers of the future come? What will be the mix of self-employed and salaried workers and what business models will be developed for these services?

It is not possible to provide definitive answers to these questions at this point. Pragmatic approaches need to be developed at a local level to provide individuals and organisations with a stimulus to offer support brokerage. In this way the availability of this support can be encouraged without excessively tying up public funds in services for which there is an uncertain demand.

Costs

A guideline fee of £20 per hour has been popularised by the National Brokerage Network. However, there are a number of reasons why this figure should not necessarily determine how brokerage is charged. For example, the figure may not stand comparisons with other professional services; it may not help develop sustainable services; broker tasks vary in complexity; the number of hours cannot always be predicted. It is reasonable to question if it is practical to plan for widespread and sustainable services at this price.

Moving forward

Those responsible for planning the development of support brokerage should consider:

- identifying local agencies and practitioners that may be interested in providing support brokerage as a dedicated role. These could include CILs and other user-led organisations, Personal Budget users, advocacy organisations, community organisations
- exploring with local agencies and interested practitioners appropriate funding and business models that will balance the need for developing and sustaining support brokerage with ensuring cost-effectiveness for public authorities and Personal Budget users. This may include considering separate funding for capacity building and for continuing support
- other methods of supporting capacity-building, including providing training; and through links with business and voluntary sector capacity-building and support agencies
- making local arrangements to ensure that quality and risk are managed as far as possible using existing methods; for example, contractual relationships and the criteria applied in the process of agreeing support plans
- how best to ensure the development of support brokerage as an integral part of strategies for the transition to Self-Directed Support, so that service availability is aligned to predicted demand.

Conclusion

Support brokerage is one of the necessary components of a coherent system of Self-Directed Support. To realise fully the potential of Self-Directed Support, deliberate and proactive
strategies need to be developed and implemented including, at a local level, actively encouraging the provision of support brokerage. Without such strategies, there is a risk that the potential of Self-Directed Support is severely limited and that control is not really transferred to people who require this support.

As a consequence, support brokerage development strategies need to be based on a clear vision of maximising the opportunities for people to plan and arrange their own support, while ensuring that competent support is available when wanted and needed. To do this requires an increase in the provision of relevant and high-quality information, advice and advocacy, as well as the simplification of rules and procedures. It also depends on increasing the availability of a wide range of people and organisations that can undertake key support brokerage functions. In particular, independent sources of support brokerage need to be encouraged and a refocusing of the role of care management is needed.

The Author

Jonathan Senker

Jonathan has worked for many years to enable people who use social care to have greater choice and control. Since 1998, Jonathan has been Chief Executive of Advocacy Partners, a leading independent advocacy organisation promoting the rights, voices and choices of people in London and the South East of England. Previously Jonathan worked as a Support Broker, enabling men and women with learning disabilities to take decisions and live a full life. A key focus for Jonathan has been working alongside people moving from institutional settings. He can be contacted at: jonathan.senker@advocacypartners.org

NOTES

1 See Part One of this report.
3 The study referred to is presented as Part One of this report.
4 in Control. (To be published 2008). Interview with Chris Moon-Willems. in Control Publications.
7 Adapted from National Brokerage Network: www.nationalbrokeragenetwork.org.uk
Chapter 4

Children and families in control

Self-directed futures for children, young people, their families and carers
Children and families in control

Self-directed futures for children, young people, their families and carers

Nic Crosby

This chapter makes the argument that Self-Directed Support must start as soon as a child is identified as needing additional support. For a few this will be soon after birth; for others as they go to school and move into secondary education and for others as they grow into adulthood.

Much of the material elsewhere in this report refers to adults and uses an evidence base that is relatively well developed. Until now there has been no such evidence base for children and young people. However, this chapter offers evidence from work with young people (14-25) gathered from research and development initiatives in a number of sites. These initiatives represent the first steps towards Personal Budgets for disabled children and young people – the first steps towards a whole life approach.
Introduction

Most families practice Self-Directed Support on a day-to-day basis. They make decisions about childcare, school, transport, pocket money, who they invite into their home, what they do at the weekend, who chooses what to watch on TV. Families lead their own particular lives influenced by where they live, their cultural background, income, family history and composition and many other factors. In effect, self-determination is a natural part of a family’s life.

For families with a disabled child or young person, though, things can be very different. Those families are often reliant on a formal system of support that does not take account of all the experience, knowledge and skills that families usually possess. The natural ability to practice Self-Directed Support is denied them. This chapter argues the need to create an explicit system of Self-Directed Support that extends to children and young people.

Improving the Life Chances of Disabled People makes the first mention of the potential for families with disabled children being able to take control of funding already used to support their son or daughter. The publication of Aiming high for disabled children: better support for families (the Treasury Review of Services for Disabled Children) and the Budget Report signalled the government’s commitment to develop Personal Budgets for children through pilots and scoping exercises.

Simply to rely on policy, though, would be to deny the basis of the whole in Control initiative: one that is founded on the grass-roots understanding that, generally, existing services do a poor job of giving families control over support, of using money efficiently, and of using outcomes for an individual as the measure of successful support.

In the Treasury Review, coverage is given to the concerns of many families that are also captured in the Council for Disabled Children’s Scoping Report on Individual Budgets for Disabled Children for the Department of Education and Skills. Here, families express their concerns about managing money and staff.

This chapter gives a clear message that Self-Directed Support does not require families to manage large (or small) amounts of money. Self-Directed Support means that families can direct the way that support is provided, who provides it and when, where and how it is delivered; that families can get involved from a very early stage in decisions being taken about how their son or daughter is supported – without the family having to manage money or employ staff at all. Decisions about the level of control can be made once the family feels able to make an informed choice. Taking control can be something that they and their son or daughter do progressively – a pathway that enables them and their son or daughter to learn the skills they need to take control as the young person enters adulthood.

All those supporting disabled children from an early age will have a key role in the change. Schools will need to offer pupils the chance to learn skills and understand how to have control over life. Support agencies must ensure that families have easy access to information and people who can help families to navigate without stealing control. Local authorities must sign up wholesale to delivering a person-centred service at all times. Fortunately, there are already many developments in the emerging integrated children’s services that offer a simple way of doing this.
The chapter also offers a first model of Self-Directed Support that could work for children and young people of all ages.

**Research and Development initiatives**

The report that follows sets out a series of relevant research and development initiatives which together provide a comprehensive set of examples and resources for the initiation of Self-Directed Support for children and young people.

In summary the initiatives are:

- **Resource allocation to children and young people** – Dynamite (a programme led by Paradigm – see below) approached this work by linking to work in local authorities already applying an in Control Resource Allocation System (RAS). Later, Dynamite adopted an approach based on the 5 Outcomes stipulated in *Every Child Matters*.

- **Dynamite – Self-directed Futures for Young People** – is a two-year programme of work led by Paradigm. Dynamite has worked with 12 local authorities to develop Self-Directed Support for young people.

- **Person-centred transition reviews** – a series of pilots initiated by the Valuing People Support Team. The pilots have been a success and have spurred on many areas to develop their own approaches to person-centred transition planning for young people at school and college. This report features one of the pilots: Lambeth in south London.

- **Improving Choice** – a ‘pathfinder’ programme initiated by the Eastern Region Learning and Skills Council to develop local post-16 provision for young people with learning difficulties whose only alternative, if they wished to continue in education, would be to attend a specialist, residential college. The programme made use of ‘transition brokers’.

- **Budget-Holding Lead Professionals** – a government-sponsored pilot to explore how lead professionals can manage small budgets on behalf of individual children, young people and their families.

- **Learning and living now** – a Mencap-coordinated project that runs until December 2008 and is exploring a holistic approach to supporting young people with learning difficulties. It is testing a RAS, developing Learning and Living Support Plans and personalised supports. This initiative takes the work of the Improving Choice Pathfinder onto the next stage by formally linking funding from the local authority and the regional Learning and Skills Council.

- **Building Blocks** – a project with students and young people in South Devon and Cornwall that produced a simple set of tools that explain concepts of choice, decision-making and taking control.

- **Person-centred Curriculum** – resources for schools, setting out a curriculum that focuses on developing skills, abilities and approaches to self-directed futures for children and young people.

- **A model of Self-Directed Support for children and young people** – this chapter offers a comprehensive model of Self-Directed Support for children and young people. This model builds on four years of in Control’s work in developing Self-Directed Support for adults and draws on the lessons from the initiatives with children and young people detailed below.

- **Taking Control** – in Control’s programme for children and young people. Taking
Control works with a small number of children’s services to put in place the first framework for Self-Directed Support for children and young people. Eight children’s services began this work in Autumn 2007.

Each of these initiatives is described in more detail in the sections that follow:

- the development of a Resource Allocation System (RAS) for children and young people
- planning and experimenting with budgets
- brokers
- schools and the curriculum.

The development of a Resource Allocation System (RAS) for children and young people

A major issue in transition has been the lack of shared financial information between children’s and adults’ services. This issue is made more complex by different funding streams and eligibility criteria between the services. Further complication is added by the change in status from child to adult, low uptakes of direct payments within children’s services and the dependency created within the existing support offered to families, children and young people.

The first practical step in creating a self-directed approach to transition is establishing a way of allocating available resources fairly. Dynamite worked on this issue in two ways: firstly by linking into work in local authorities already applying one of the resource allocation systems developed by in Control; secondly by developing an allocation system based on the Every Child Matters Outcomes for allocating children’s services funding. In Dynamite, as in other transition-focused projects such as in Lambeth (see later example), the intention was to make an allocation well before the young person reached their 18th Birthday.

Of the 56 young people originally taking part, approximately half were under 18. These young people and their families were able to find out what funds would be available when they moved into the adult support world or left school. When Dynamite started, there was no comparable Resource Allocation System in place. Redbridge, one of the original seven sites, wanted to develop a way of allocating children’s services funding such that a small number of young people could access a Children’s Personal Budget.

Figure 1. A simple approach to resource allocation

![Figure 1](image-url)
Redbridge, Stoke-on-Trent and, more recently, North Tyneside and Newcastle (the first local authority in the country to agree individual allocations for young people from children's services budgets – 7 of them) have pioneered an approach to resource allocation based around the *Every Child Matters Outcomes*. This approach is now being used across four Dynamite sites and 10 Children's Services as part of the new *Taking Control* programme (see below). The approach to resource allocation builds on evidence from work in adults' services. It draws a direct link between identified support need and money by making a judgement about the amount of support needed to realise one of the five outcomes in a child or young person's life.

The questions focus on the 25 sections of the *Every Child Matters* outcomes framework and measure in three bands the amount of support needed by a child or young person and their family. The diagram above shows how each answer has a value in points and each point is given a monetary value. (This value is worked out in an exercise completed with a participating children's service.) When points are added up and multiplied by the monetary value, an 'indicative allocation' can be made – based entirely on the amount of support a child needs to realise the 5 outcomes. Below are two examples from the questionnaire:

### 1. Stay Safe

**A** I am safe and enjoy the company of the people I know and who support me each day.

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**B** I enjoy taking some risks; the support means I am safe taking those risks.

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Figure 2. Two examples of how the Resource Allocation System uses the Every Child Matters Framework as a basis for allocating funds

The outcomes set out in *Every Child Matters* – Stay safe; Be healthy; Enjoy and achieve; Make a positive contribution; Achieve economic well-being – provide a consistent framework within which all services supporting children and young people can work. Using this framework as a basis for resource allocation means that each individual allocation is driven by outcomes. Collected together, individual allocations offer a service-wide picture of expenditure on supporting disabled children and young people based on the 5 outcomes. The usefulness of this approach is already evident in the Taking Control sites.

By joining the Dynamite project with the long-established *Improving Choice* Pathfinder in the Eastern region, the first steps were made in developing a similar set of 25 questions which measured the amount of learning support funds needed to deliver a curriculum based around the five *Every Child Matters* outcomes. *Making Sense of the Money* began in May 2006 and is now a part of the wider *Learning and Living Now* initiative. This initiative, as illustrated with this example from the Resource Allocation System, is being piloted as a way of allocating an 'Individual Learning Support Fund'.
Stay Safe
This section identifies the support needed to enable the young person to be safe in college and learn about safety and risk.
The young person will...

Learn how to stay safe from harm in day-to-day situations

<table>
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<tr>
<th>Needs no additional support</th>
<th>With some support/support in some circumstances</th>
<th>With significant support</th>
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Figure 3. The corresponding question within the Learning and Skills Council-funded Resource Allocation System (Eastern Region)

Work is ongoing to explore how the Learning and Skills Council (LSC) and the local authority can reach agreement on co-funding a holistic support plan. The strength of using the Every Child Matters outcomes is that both a local authority and the LSC are responsible for delivering these outcomes in young people’s lives. Hence the two funding streams are working together to deliver a single set of outcomes.

Planning and experimenting with budgets

Once the allocation is agreed and there has been a chance to experience the benefits of Personal Budgets, the young people and their families move on to making plans. Various planning initiatives have been tried.

Dynamite – Self-directed futures for Young People is a two-year programme of work led by Paradigm, an in Control partner. Dynamite works with local authorities to develop Self-Directed Support for young people as they grow into adulthood. In each participating local authority, eight or more young people and those closest to them are supported to make informed choices about how they want to use their funding and how they want their support to be delivered and managed. The first seven sites started work in Autumn 2005 and 12 local authorities have taken part altogether. Part of the work was completed in July 2007 and there are currently 37 young people with an Personal Budget.

Dynamite focuses on working with disabled young people between 14 and 25 and offers a radically different pathway into adulthood than that usually available to disabled young people. This period in a disabled young person’s life, termed ‘transition’ by agencies, has always proved difficult. An individual’s voice and that of their family and carers is lost within a complex web of services, accompanying paperwork and the competing funding agendas of children’s and adults’ services. The outcomes in transition usually consist of being slotted into services whether or not they fit with a young person’s aspirations, of being lost in the transfer of paperwork and, commonly, a complete breakdown in the family’s confidence that services will listen to them and support them.

A self-directed approach to transition offers a young person and those closest to them the chance to plan a future around their own aspirations and support needs. The first step to making this is the creation of a Resource Allocation System for adult services which can also be used well in advance of a young person’s 18th birthday. The availability of a resource
allocation at an early age will enable the young person and their family to start making a plan using their Personal Budget.

**Developing skills – practice budgets**

Making sense of the money is the first practical step towards enabling young people to take control of their futures. The long-term introduction of Self-Directed Support and Personal Budgets will need to start with families and support them in learning new skills and in having a different set of expectations about what the future could hold for their son or daughter.

To ensure that Personal Budgets are an opportunity for all and not just for those who already have skills and abilities (in language, numeracy, literacy, planning, or managing money and people) it is essential to offer a pathway that is usable by all. Within Dynamite, the key outcome was that young people and families would be able to make an ‘informed choice’ about the future, how they wanted to be involved in managing the Personal Budget; and how decisions would be made about support and living arrangements.

In the early stages of Dynamite there were concerns (mainly on the part of professionals) that families would ‘talk over’ the young people and that plans would focus on the families’ needs and aspirations instead of those of the young people.

To give families and young people a chance to learn from experience and also to check the validity of these concerns, each young person in Dynamite had a ‘practice budget’ of £200 which they could use to plan a summer holiday activity. This enabled the young person and those closest to them to work through the process of making a support plan. This approach proved a great success. Plans focused on how the young person wanted to spend their time. They included a huge variety of individually appropriate supports and showed how families and young people can make efficient and creative use of small sums of money. For example, one young man, who is doing a degree in Film and Television at Southampton University, spent his day with staff on the News Desk at BBC Television Centre.

One family had already helped their son, Steve, to set up home and a team of supporters after his return from an out-of-borough college. Getting involved with Dynamite encouraged them to take further steps towards Self-Directed Support. Steve’s mother writes:

‘Initially we had a trial run using £200 to plan an activity and this was a big learning curve for us as alarm bells immediately rang. Who could we employ to take Steve on a trip? We needed insurance, but to take out this insurance in Steve’s name he needs to be answerable in court if any thing goes wrong (and things can). I knew he couldn’t so we then had to arrange his trust so we could stand for him.

Once we began Dynamite it became clear that we could take a much greater role in being in control of the situation by employing his team of supporters ourselves, therefore really designing the team around Steve and the other young man, James, who lived with him. It looked like the ideal solution.

We wrote the support plans together to ensure that the plans were absolutely focused around Steve and James. We have worked together to get the most from the budgets, making savings as we go along. We still have some technical issues that crop up and together we work through them until we find a solution. Don’t get me wrong, we have had our ups and downs. It’s time consuming, phone bills can be high, and some
things may work for one and not another. But I think of it as a flowing river: stand
back and enjoy but be aware there are boulders and currents at certain times – and
sometimes it can be a tranquil lily pond. All that matters is that the boys have an
enriching future that they are involved in shaping.

This is the best thing I’ve ever done for my son.’

Local Authority Lead

‘For the Local Authority, trust with the families was an issue. I think this stage proved to the
young people and their families that we mean this, demonstrating we are putting our money
where our mouth is!’

Family member

‘What’s involved can be overwhelming. If we hadn’t had a go at this, I’m not sure I would
have gone for directing all the support.’

Family Member

‘As a mum I was really used to the council making the decision. It’s not easy doing this
yourself but with support we have done it and I can honestly say we are definitely in control.’

Family member

‘It was like a tester – it went so well, we thought, we can’t stop now.’

Person-centred transition reviews

The Valuing People Support Team have piloted person-centred transition reviews. The pilots
have been a success and have spurred on many areas to develop their own approaches to
person-centred transition planning for young people at school and college.

Jo Harvey (Helen Sanderson Associates) and Harry Tuck (Lambeth Children’s and Young
People’s Service) explain what the pilot has meant for young people in Lambeth:

In the London Borough of Lambeth, Helen Sanderson Associates have been working with
Lambeth Children and Young People’s Service and Lambeth in Control to link their Person-

‘We have worked with five young people and their families. All are 19, or nearly
19 and left school in July 2007. They each had their final school review using the
citizenship model8 in January, which enabled them to begin to think about things
they may want to do when they leave school, related to the Keys to Citizenship9.
Each person was then given an indicative Personal Budget by the Lambeth Adult
Services who are piloting in Control. We held four workshops to help the young
people and their families develop a support plan that showed how they are going to
spend their Personal Budget.

‘The first workshop was an introduction to the Self-Directed Support process. The
workshop included the families and also a range of paid supporters who were going
to help the young people and their families to make their support plans. For the following three workshops we used the Planning Live approach practiced by Helen Sanderson Associates. During the workshops, we used large graphic templates to help gather information for the support plan. This information directly links to the Keys that the young people had explored in their review. We looked at the support that the young person will need and how they can spend their Personal Budget to get that support. This links directly to the support and money Keys.

‘The whole process has been absolutely brilliant for two reasons. Firstly, the investment of time in the families has been unusual and really worthwhile. Secondly, the way the process created a setting where the families were able to be really creative and could share that creativity with each other was very productive. It created a really supportive network.’

Support Brokerage

In Dynamite, young people and families have, with varying degrees of success, been linked up with a variety of different people prepared to take the role of facilitator. There is a large number of different professionals involved in supporting disabled young people through the transition period. Dynamite started from the view that each of these different people could have some future role in supporting young people with Personal Budgets. In order to maximize learning, it was important not to offer prescribed roles or job descriptions. Although in some of the sites the word ‘brokers’ was used, the term does not accurately reflect the roles played by those supporting families. The project actually used the term ‘facilitators’ and these were recruited as volunteers.

Dynamite encouraged areas to keep an open mind about what support families might want and how this could be delivered. As the project progressed, groups of people in each of the sites began to have a clear understanding of the role of a facilitator and of brokerage. Families placed a high value on trust and were less concerned about where the facilitator came from or who employed them. They reported that they appreciated a ‘fresh face’ and a single person to go to with ideas or queries – someone who know where to go to get an answer or make things happen.

**Family member**

‘The role of my broker was really useful. They were support for us, kept us on the right path.’

**Family Member**

‘The Broker has been so important and is helping us on a voluntary basis. This is worrying as without her I don’t think I could do it.’

Improving Choice

In the Improving Choice project, the Eastern region LSC went a step further in creating the role of the Transition Broker. This was achieved by redefining an existing role within the local services as a broker (rather than simply relying on volunteers).

In Cambridgeshire and Peterborough this role was delegated to the Connexions Service and one of their Personal Advisers took the role of the Transition Broker. In the context of
Improving Choice the intention was to use LSC funding more flexibly to develop individualised learning opportunities for people as an alternative to residential or specialist colleges. It was this Broker’s responsibility to use the individual learning fund alongside direct payments to construct a learning and support package that enabled the young person to attend local learning provision, to follow a curriculum designed around the young person’s own learning aspirations and to draw together a support team funded by the learning fund (which was often complemented by direct payments).

There are clear links between the role of the Transition Broker and that held by Budget Holding Lead Professionals (BHLP) in the 16 pilot areas funded by the Department for Children, Schools and Families. The budgets being held by a BHLP may differ in size and source but the skills set is identical. The Office of Public Management defines the BHLP as:

- entrepreneurial broker
- pushing boundaries
- very focused on child
- [having] time and space.

**Budget Holding Lead Professionals**

Budget Holding Lead Professionals is a government-sponsored pilot exploring how lead professionals can manage small budgets on behalf of individual children, young people and their families. Looked-after Children services have recently been included as an extension to this work.

The aim of the pilot is to move resources as closely as possible to the child or young person in need. A designated Budget Holding Lead Professional then commissions individual services and/or support that works closely with the child or young person. There are 16 pilot local authorities, some of which have embarked on a further pilot titled ‘Established BHLP’. There are four local authorities currently working with their Children in Care Services to explore the role of the BHLP for children and young people using these services.

The Office for Public Management, an in Control partner, is providing consultancy across all the BHLP sites. Clive Miller and Nic Crosby have recently published a paper exploring the links between the Personal Budgets agenda and the work of the Budget Holding Lead Professional. This paper also considers how these approaches fit well with multi-level commissioning.

**Learning and Living Now**

Mencap are coordinating an innovative approach to supporting young people to access local learning opportunities in conjunction with managing a Personal Budget from their Local Authority. Mencap are drawing in support from Helen Sanderson Associates, Palmer Consulting and Paradigm for key parts of the project work. (Mencap, Helen Sanderson Associates, and Paradigm are in Control partners).

The aim of Learning and Living Now is to explore and pilot a holistic approach to supporting young people with a learning disability between the ages of 16 & 25 to plan and manage the funding they are entitled to from a range of sources.
The Project runs until December 2008 and is currently being piloted in two LSC regional areas: the East of England LSC in partnership with Essex County Council; and York and Humberside LSC in partnership with Barnsley Metropolitan Borough and Sheffield City Council. The project is focusing on three key areas:

- testing a Resource Allocation System for the LSC (*Making Sense of the Money*)
- developing a Learning and Living support plan
- developing personalised learning and living support, resources and services.

An example of this approach is the Hamelin Trust, a small local provider supporting two of the young people on the project. The Trust has employed support workers specifically for the individuals based on the information collected through the support planning process and have ensured that the young person and their family are central to the ongoing coordination of the support they receive. The Hamelin Trust has developed a unique service agreement with Thurrock College which holds and manages the LSC funding on behalf of these two individuals.

Jamie is 19 years old and is one of the young people being supported by Hamelin Trust. His family, with the support of the Connexions service, applied to out-of-county specialist residential colleges because of the lack of local specialist learning provision. Jamie was turned down by these colleges because they felt they were unable to meet his everyday personal support needs. With the help of a support planner, Jamie, his family and people who knew him well, developed a support plan and agreed a number of actions to make the life that he wanted a reality. Jamie currently goes to a mainstream college (Thurrock) four days a week on an entry level course and is supported by Hamelin to access his college course and the other things that he said he wanted to do and learn. The support planning process helped Jamie and his family maximise the funding he was entitled to and he now receives funding from the Local Authority, LSC and the ILF as well as an income through his benefits. By thinking creatively about how this money can be used alongside the natural resources available to Jamie, he now enjoys a personalised approach to meeting his personal and educational needs that is also cost effective.

### Schools and the curriculum

**Building Blocks**

Through the early work of Dynamite – and specifically work undertaken by Pippa Murray (of ibk initiatives) with a number of the schools – it became clear that schools and other learning providers would need to support young people to expand both their self-advocacy skills and their understanding of what it means to be an adult with some control over how they would be living in the future.

Using funding from *in Control*, work was undertaken with students and young people in South Devon and Cornwall that resulted in the publication of *Building Blocks* – a simple set of tools that explain concepts of choice, decision-making and taking control.

*Building Blocks* complemented Pippa Murray’s work with Dynamite schools and the *What I want to do; Making Choices and Decisions* report based on interviews with teachers and work with staff groups and young people. This work began to explore how the school curriculum could develop students’ skills and knowledge in building a self-directed future.
These developments were welcomed by one head teacher who suggested the current system was failing children and young people: ‘One of the serious questions we are asking ourselves constantly is “what are we teaching our children for? What do they get when they leave us?” And sadly the answer for some of our children is they get bingo a couple of times a week and the occasional outing. Some of our people with learning disabilities are perhaps the only sector of society that leave school and go straight into retirement.’

Building Blocks and What I want to do; Making Choices and Decisions provided a base for a further programme of development with a number of schools involved in Dynamite, and/or the Person-centred Transition Review.

**A person-centred curriculum**

The work started by the students in the southwest was further developed in the publication of *A Person-centred Curriculum*. This publication sets out a curriculum that focuses on developing skills, abilities and approaches to self-directed futures for children and young people. At the Abbey Hill School in Stoke-on-Trent, the curriculum has been linked into delivering the outcomes of *Every Child Matters* and a person-centred transition review process. The head teacher and post-16 teacher suggest that this approach gives their curriculum greater meaning because the students are given support to think in practical terms about the future. (Stoke was one of the first seven authorities to take up the Dynamite project).

Schools have a key role in supporting their students in learning the skills they will need in the future. A self-directed pathway into adulthood was felt by many educational professionals to give more meaning to what students would and could learn at school. Several schools have begun to develop curricula and person-centred approaches to learning that reflect what will be a very different future for their pupils.

**Family members**

‘Best thing since sliced bread.’

‘*In Control* does exactly what it says on the tin!’

‘This is the best thing I have ever done for my son.’

**Where next?**

**A model of Self-Directed Support for young people growing into adulthood**

Over time, a whole-life approach to Self-Directed Support will foster a skilled and knowledgeable population of families and young people. In the meantime, it will be the role of services to make sure that families get the chance to learn new skills and gain new expectations of what the future can hold for children and young people.

Supporting young people and their families to make plans, using their individual allocation, drawing in the work of linked initiatives and listening to the feedback and input of family members: all these begin to shape a “Transition Support Programme” focused on self-directed pathways to adulthood.
In this model, the Resource Allocation System is applied using the funding streams that change according to age. The school acts as the hub (in common with many developments on the government’s ‘extended schools’ agenda).

![Diagram of Resource Allocation System](image)

**Figure 4** A proposed model for Self-Directed Support for young people in transition

Underpinning this model is the learning that will support the long term delivery of Self-Directed Support to children and young people:

- Allocations systems based on outcomes and an individual's support needs offer a fair and transparent way of making efficient and good use of the limited funding available to local authorities. They also offer a potential for drawing together funding from social and health care with additional learning monies.
- A Resource Allocation System that simply identifies additional support needs can be used by many children and young people and not only those deemed eligible for support from disability services.
- The starting assumption must be that the family is able to lead in planning and that the statutory and voluntary sector are responsible for putting in place the supports that families will need for planning. Concerns about risk and protection which may have been identified in the completion of a CAF (Common Assessment Framework) would be addressed in the completed support plan.
- Addressing the skills and experience gap for young people and families will be essential in order to enable more people to make use of the opportunities that Personal Budgets offer.
- Person-centred approaches are vital in making a well-informed support plan centred on the child or young person.
- There is a capacity within the wide range of agencies and individuals that support young people in transition to allocate good quality brokerage support. Such support will enable families to be well informed about the different
opportunities and resources available to get the best possible support for their son or daughter.

◆ The role of the Budget Holding Lead Professional offers a positive chance to explore how families can get involved in decision-making from an early age and grow into taking control of budgets and support services.

The challenge for children’s services will be how to move from one system of delivery to a radically different one, in which children, young people and their families take the lead. Many of the challenges will be similar to those that are already being addressed by adult services. However, there will be specific issues, particularly about the relationship between commissioner and provider. Within the children’s sector there are fewer support options and service providers and a large amount of in-house service provision.

Tackling this lack of diversity through intelligent and creative commissioning will be a critical factor in making Self-Directed Support work. The initiatives set out in this chapter demonstrate the appetite of all families and young people involved. The learning coming from these endeavours shows that a coherent framework to enable children and young people to direct their support (with the help of their families) is already forming. Integrated children’s services now face the challenge of making it work across the whole population.

**Taking Control**

A group of children’s services is setting out to build on the learning within this chapter and are establishing a Self-Directed Support pathway for children and young people from a variety of age groups and support needs. This in Control project is called Taking Control.

Figure 4 – A proposed model for transition – offers a framework which will inform the work of Taking Control. The end product will draw on this model and also on the learning coming from Dynamite, from person-centred approaches to transition planning and from the Budget Holding Lead Professional pilots. Developments that pilot sites are exploring with other streams of funding – for instance, education, LSC and health monies – will also provide strength to the end product.

This programme echoes the early stages of in Control in that it is working with a small number of children’s services to develop the first complete framework for Self-Directed Support for children and young people. Eight Children’s Services began work in the Autumn of 2007. The programme is working alongside the BHLP pilots and is linking in with mainstream children’s services in some of the sites. The outcome of the first ten months of work will be that a number of children and young people across the whole 0-18 age range (who have a diverse range of support needs) will have a Personal Budget and their own support plan.

The intention is to expand this programme. The nine sites already involved with Taking Control are: Gloucestershire, Staffordshire, Stoke-on-Trent, Barnet, Halton, Middlesborough, Northumberland, Redbridge and Sandwell. The programme runs for a year and offers sites the chance to begin and continue to develop key parts of a Self-Directed Support operating system.

The programme is working with many challenges, not least that presented to the local and national provider market. Providers will be encouraged to get involved. Those whose services are presented in a limited menu of options determined by the commissioning of large scale block contracts will need to consider how they can revise their service offer in response to demands from families.
The first year target – by the end of July 2008 – is 30 children, young people and their families or carers with a Personal Budget.

The work of Taking Control, through links with the Budget Holding Lead Professional pilots, has led to exploratory work with mainstream children’s services where the BHLP will manage a Personal Budget on behalf of a child or young person.

In summary, Taking Control is already beginning to deliver a framework for Self-Directed Support and Personal Budgets across the whole integrated children’s service.

**Conclusion**

Finding ways to open the door to a self-directed pathway is the main focus of Self-Directed Support for children and young people. Families need to be able to take the first steps without fear of being ‘in at the deep end’. They need to be supported to take the role they feel able and confident to take. They, their son or daughter, and those close to them need to feel able to grow into taking control of how they live their lives.

There are many challenges to be faced, not least finding ways to bring different funding streams together within a Personal Budget – from social care, health and education – and to create the maximum flexibility in the use of the budget.

This challenge involves moving from an approach which argues about which service pays for what to one which seeks to free up funds and place them under the control of the family and their son or daughter.

Strong leadership is needed on the part of lead professionals: to maximise the flexibility of funding; to delegate commissioning to those working directly with families and young people; and to encourage a more diverse range of support options.

A final challenge exists in building the leadership of a successful move from the existing system to Self-Directed Support. This leadership will be a partnership of children, young people and their families and carers, professionals, providers and organisations.

The conclusion to this chapter is really to mark the beginning of another. Through the Taking Control programme, a number of children’s services are starting out to make Self-Directed Support for children and young people a reality. The outcome of the first year’s work will be reported towards the end of 2008. In that year, the government pilots for Personal Budgets for Disabled Children and Young People will be launched.

The experience and learning summarised in this chapter already provides the model for the transformation of children’s and young people’s services into a system of Self-Directed Support.
For more information:

www.paradigm-uk.org  www.helensandersonassociates.co.uk
www.mencap.org.uk   www.ibkinitiatives.co.uk
www.opm.co.uk   www.supportplanning.org (in Control)
www.in-control.org.uk

The Author

Nic Crosby

Nic works with many people and organisations across the country promoting the introduction of Personal Budgets for disabled children, young people and their families and carers.

◆ Nic leads Taking Control, an in Control programme for children and young people
◆ he works with the Learning and Skills Council to explore more individualised uses of funds for young people with additional learning support needs
◆ he works in the on-going Dynamite project for young people growing into adulthood
◆ he is a consultant with Paradigm (www.paradigm-uk.org).

Aside from work and travelling all over the country, he ferries his hockey-star sons around south western and national venues and tries to catch a few waves near his south Devon home.

NOTES

1 Cabinet Office Strategy Unit (January 2005) Improving the Life Chances of Disabled People.
6 Every Child Matters, www.everychildmatters.gov.uk
7 Eastern Region Learning and Skills Council (May 2006) Making Sense of the Money; Developing a Resource Allocation System for Post-16 Learning for Learners with Learning Difficulties and/or Disabilities
9 East of England Learning and Skills Council, Improving Choice.
11 Crosby, N. Building Blocks; Introducing Self-Directed Support to Young People. www.in-control.org.uk
12 Paradigm Dynamite Project (2006), Murray, Crosby, What I want to do; Making Choices and Decisions.
14 HM Treasury (2007). Transition Support Programme; a key element of:
Chapter 5
Community
Community

Carl Poll

In this chapter, I set out a summary of what in Control has learned about the relationship between Self-Directed Support and community. The chapter shows how people who direct their own support generally make good spending decisions that lead to good outcomes: better relationships and more involvement in community.

The chapter also argues for a deliberate approach to community involvement. It suggests, for example, that organisations – including in Control – should build alliances with mainstream community agencies and that local authorities should adapt their resource allocation systems to include one-off grants.

Introduction

During the first phase of its work, 2003-2005, in Control made a strong theoretical case that a key to the success of Self-Directed Support is community life. It also made efforts to translate this theory into practice, for example in the testing of Small Sparks, a small grants programme for community building.

The first phase of work focused on people with learning disabilities, some of the most excluded people in our society. Despite the efforts of many good staff, organisations that support people with learning disabilities have struggled to escape cultures and ways of working that belong to the past. While ‘empowerment’ and ‘inclusion’ have been the stated aims of many organisations, genuine empowerment and real connections in community have proved elusive. People with learning disabilities often have few social networks or ordinary relationships. Instead many move around a world of special places – day centres, residential care homes, group activities1.
While those with learning disabilities are often separated from community life, they are not alone in their isolation. Those with mental health problems, disabled people (those with impairments who are disabled by barriers in society or the environment), older people who need support to go about their daily lives – all are much more likely to be poor, to have inadequate housing and to be unemployed. They are also more likely to be deprived of the opportunities to make a contribution, develop relationships and experience love that most of us rely on for our well-being, happiness, self-esteem and sanity.²

Community at the heart of Self-Directed Support

Of the six Keys to Citizenship³, community life remains arguably the most problematic for services that want to move towards Self-Directed Support.

While the other key areas – self-determination, direction, money, home, and support – are undoubtedly challenging for services, they are at least more familiar. The strategies and tasks of community development, on the other hand are, for many of us who work in human services somewhat mysterious.

This unfamiliarity with community development slows progress towards Self-Directed Support because community life is a near neighbour to the real goal of the new system – equal citizenship and social justice. The fundamental purpose of Self-Directed Support is not merely the development of a better social care system but, rather, the creation of a healthy society that is better for everyone. in Control’s Ethical Values sum up this belief:

‘….we believe that the natural diversity of human beings should be welcomed and cherished. We are all different, and our differences and our needs help make the world worth living in.

We believe that people truly flourish not as lone individuals but when they are part of communities: families, friendships, neighbourhoods and all the organisations of civil society.

We also believe that all these communities only flourish when they welcome the full membership and support the active participation of everyone, regardless of their impairment, age or health status.’

If services are unable to facilitate connections to community – or might even stand in the way of those connections – the goal of equal citizenship and full participation might be more mirage than reality.

While many of us struggled during in Control’s first phase to help people connect in communities, individuals who had their Personal Budgets were quick to demonstrate how to be part of community life. The evaluation of in Control’s first phase showed that, within less than a year, the number of people who were satisfied with their community life and social relationships increased from 67% to 100%.⁵

The evaluation methods did not uncover why this significant increase took place. Perhaps the 10 people who moved out of residential care found that they were better positioned
to make relationships in the neighbourhood. Maybe, in completing good support plans, people remembered those who in previous times were important to them and revived those connections. Whatever the immediate cause, it is clear that, in Controlling funding and support, people made choices that resulted in a rapid improvement in the quality of their relationships and community life.

2005–2007 – what in Control has learned

During in Control’s second phase, people have continued to demonstrate that control of funding enables them to make decisions that lead to happier and more fulfilled lives. The evaluation that forms Part One of this report shows encouraging results in the areas of health and well-being, quality of life and involvement in community.

Health and well-being: Almost half of 196 people reported improvements in general health and well-being since starting Self-Directed Support (48%). A similar number reported no change (48%) and a minority of people (5%) said that their general health had got worse.

Quality of life: A large majority of people reported improvements in their quality of life since starting Self-Directed Support (76%). A minority reported no change (23%) and a tiny minority said that things had got worse since starting Self-Directed Support (1%).

Involvement in Community: A majority of 196 people reported improvements in the extent to which they took part in and contributed to their communities since starting Self-Directed Support (64%). A substantial minority reported no change (34%). A tiny minority said that things had got worse (2%).

Good decisions about support

The decisions people take about how to use their support money certainly involve the use of such direct supports as Personal Assistants but might equally involve spending money on a dating agency, as George in Norfolk has, or a personal trainer and computer trainer, as Keith in Oldham has.

Others have been quick to see that money traditionally spent on respite breaks in a registered home can be used in more enriching ways. George, for example, got some ‘respite’ on a Tunisian holiday with a friend. Bob, a man in his 70’s, had no hesitation in writing a hot air balloon flight into his support plan. The balloon company went out of business so Bob settled for a microlight flight instead. Bob comments: ‘It was an amazing experience. It is great to have choice, control and independence in my life.’

Such spending decisions lead to more fulfilled and happier lives and probably the need for less support time. The relationship between happiness and health is the subject of a growing number of studies. For example, Dr Derek Cox, Director of Public Health at Dumfries and Galloway NHS, comments: ‘If you are happy you are likely in the future to have less in the way of physical illness than those who are unhappy.’ Dr Cox argues that people are happier if they are given more control at work, live in a safe neighbourhood and participate in community projects.
Family members of those directing their own support repeatedly refer to ‘improvements to well-being’. In any event, Bob and the others spend no more than their allocated funding in the most effective ways for them. The difference for George was that, as Gill Stewart, Norfolk County Council’s Individual Budget Project Lead, puts it:

‘George’s Care Coordinator was talking about respite care for him. Now that would have been in a registered home. So he would have got a break from his home, but it wouldn’t have been as life-enhancing as going somewhere like Tunisia.’

A fundamental shift to greater trust in people’s ability to spend their social care funding in a way that produces good outcomes – especially a more fulfilled community life – may be challenging for some local authorities. Moving away from a focus on processes to a greater interest in outcomes will involve a big change in systems and also mindset.

The change can be equally difficult for individuals. Viv Slater, formerly of Oldham Self-Directed Support Team, suggests that one of the most difficult aspects of change is that many people ‘are so used to being in a service box that they have real problems getting out of it in their own minds. They seek our permission to live their lives. They don’t need to do that in Self-Directed Support.’

Small Sparks

in Control wanted to make a clear contribution to real change in community involvement and had consciously adopted an asset-based approach to communities, building on the work of John McKnight (who led an in Control seminar for pilot schemes in 2004.) This approach builds on the ‘gifts’ of individuals and the assets of community and believes that communities are the poorer when excluded individuals are denied the chance to make their contribution.

Based on this approach, the Small Sparks programme – a simple community-building tool that offers small grants to people who want to start a community project – had proved successful. A modest investment of £10,000 during the pilot period (2003-2005) stimulated about 40 community projects (one of which raised £7,000).

There are simple criteria for deciding who can get a grant. Small Sparks is low-cost and easy to start and administer.

Projects must:

- involve new people in the neighbourhood – in order that excluded people have the chance to meet ordinary members of the community
- be completed within 8 weeks – to ensure that they do not become enmeshed in bureaucratic preparation
- provide a record – so that others can learn
- be celebrated – Small Sparkers must tell their stories at a party-style event.

Since 2005 around 30 local authorities and voluntary organisations have begun Small Sparks programmes. in Control kick-started the second phase of Small Sparks with a small allocation of funding (£1250) to each of four authorities. This money was matched by each authority. Individuals were invited to apply for grants up to £250.
One of the lessons from phase one was that the most successful projects – those that involved most new people from the community and promised enduring relationships between the person starting the project and their neighbours – were produced through a whole-community approach. That is to say the grants should be offered to the whole community, so that people who need support can apply for money the same as anyone else in the neighbourhood. It is then the job of their supporters to help them apply.

Chanelling even modest amounts of social services funding through community organisations proved a challenge for some authorities in the second phase and they opted to run the programme from within a particular service, even though this might inhibit the chances of community building.

Others found a way. Newcastle, for example, launched their Small Sparks programme at two community events – one in the west and one in the east of the city. About 40 people attended each event and, though the funding came from the learning disability service, the rooms were full of people from small, local community associations. Newcastle had successfully marketed Small Sparks as a whole community initiative (within which people with learning disabilities would benefit).

The second aspect of the whole-community approach is that the best projects involve others in the neighbourhood as allies in the design and execution of the project. A disabled person who wants to improve the look of their neighbourhood (and brings money) is of interest, for example, to environmental and residents’ groups. An alliance is possible and long-term relationships become more likely. A good example of this approach is Catching the History of Wawne.

Neil Atkinson lives in Wawne, a village in the East Riding of Yorkshire and used his Small Sparks grant in a way that would ‘help bring the people in our community together.’ He formed a project group of local people. The group decided to organise a day celebrating the history of the village. On the day, there was a Timeline in the village hall. People were invited to add photos and memorabilia from their own events in the village – when they started school, got married and so on. A Treasure Hunt highlighted historical interest points in the village. A Time Capsule, complete with 2006 coins and the Parish Gazette, was buried by the playing field. The day finished with a Harvest Supper.

The project group decided they wanted to involve lots of children so the Brownie leader was invited to be on the planning group. The Brownies could earn a Culture Badge by being involved in the event and some Small Sparks money was spent on the badges. There was even money left over and this was used to buy trees and Conservation Badges for the Brownies.

A bridge over no-man’s-land

The argument has been made here that many people will make their own good decisions that lead them into community life. For others, though, conscious community-building initiatives are needed. Small Sparks is a modest effort to build a bridge over the gulf between services and community life. It could, though, be just one in a range of short-term grants that form a broader highway to ordinary life in the community – particularly for those who find themselves ineligible for social services.

in Control’s Resource Allocation System (RAS) is a means of rationalising current levels of social care funding. It does not depend on any change to Fair Access to Care. People in
any given local authority remain eligible for services according to the authority’s eligibility threshold. Few people qualify if they have low or moderate needs. Increasingly, even those with substantial needs become ineligible as more authorities ‘move to critical’.

In this way, more and more people who need support are left in a kind of no-man’s-land. Some who are not eligible for services may fare badly when isolated and left to their own resources. For want of a little support, these people can find themselves on a downward spiral of problems, possibly leading towards crisis and, ironically, eligibility for services – a scenario well-known to many social services staff.

Social services say that people who have ‘low-level’ needs require services that are preventive or that intervene early. However, the prevention agenda mentioned for decades in policy documents remains largely aspirational. Local authorities struggle to find adequate funds for such non-critical work. There are exceptions, though. Oldham is one authority that has adopted a conscious approach to this problem. Paul Davies, Oldham Service Director Adult Social Care, says:

'We changed our FACS criteria to critical and substantial three years ago. At that time we created a preventive strategy. Neighbourhood Access and Prevention Officers signpost people to things available in the community. There are 1,500 using this kind of support.

Also we’ve made use of in Control’s Small Sparks grants idea and generally pursued the idea that one-off grants can be much more effective. All one woman needed to keep her out of FACS eligibility was travel training for 7 weeks so that afterwards she could get to college. A small grant worked well for her.

We can envisage using bigger one-off grants – including for equipment. We get a very clear message that people want to stay in their own homes. They say they’ve got nothing against services but they’re just not flexible enough.'

Essentially, ‘prevention’ is a service term for work that will enable people to use community facilities and avoid specialist services. However, this term does not have currency in community development organisations. Indeed, it may be that many community agencies remain unaware of any expectation that they should focus on increasing numbers of disabled and older people. For the most part, they have not seen it as their role to be the primary supporters of disabled and older people because that role has been taken by social and health services.

There is, though, as suggested later in this chapter, good reason to hope that joint working with community organisations is possible. One important way to encourage the involvement of community agencies could be to convert parts of the social care budget into a programme of short-term and one-off grants, such that community organisations see people who need their support spending money in a way that puts them into the centre of communities. Small Sparks is one example, and people are demonstrating other short-term uses for parts of their Personal Budget that lead to community life.

For example, a London man spent some of his allocation on the purchase of a caravan by the sea. The family had taken holidays at the caravan site for many years and were part of a close community of people who did the same. The purchase of the caravan enabled individual members of the family to take breaks at different times. This was important because the young man has complex support needs. The question of ‘respite’ was solved affordably. The young man is well-known at the caravan site and other caravan owners are supportive.
At the end of phase one, in Control insisted on the need to incorporate Small Sparks in the local RAS. At the end of phase two we recommend that authorities consider a programme of short-term grants – whether for community projects, a capital purchase, or other one-off spends that will help people take their place in the community – as a rational use of resources.

Separating such grants from the overall social care budget, with its traditional conditions of use for ongoing support, could be beneficial for local authorities and individuals alike. A logical starting-point for any authority that discovers efficiencies in applying the RAS would be to recycle these monies into a system of one-off grants that will enable people to increase their presence in communities. In this way, a virtuous circle can be created – people spend funds in a way that increases their involvement in community and decreases their need for ongoing support. As we will see in the next section, the involvement and contribution of people who need support increases the capacity of communities to care for all of their members. Their involvement builds social capital.

A bridge to community development

During the first phase of in Control’s work, local pilots had a problem in finding a community champion for project groups – someone who knew about communities and community development rather than about services. in Control also had difficulty in finding a community partner to inform its work and sit on the Editorial Board.

In the second phase, it was critical that in Control should engage a significant community sector partner if it was to develop a more acute community strategy – one that would link Self-Directed Support to the citizenship agenda promoted in an array of Government policy initiatives. We have been fortunate in engaging the interest of the Scarman Trust, which became a partner of in Control in 2007. The Trust, which has recently merged with the Novas Group, is ‘committed to helping citizens bring about change in their community, in the way that they want. We fund and give practical assistance to hundreds of remarkable people with a ‘can do’ attitude. These ‘can do-ers’ in their turn mobilise many thousands of others, within their own communities and across the major institutions of society - working to make fundamental life chances available to all.’

The Scarman Trust is a natural partner for in Control in that it has a strong asset-based approach and shares a link to John McKnight. Coincidentally, the Scarman Trust has developed small grants programmes similar to Small Sparks. It has taken this idea further by seeking to calculate the cost benefit to local authorities of the community projects produced. It then looks to the authorities to reinvest similar sums in local communities.

In Britain, there is a strong tradition of community development work and in Control’s partnership with the Novas Scarman Group will more clearly connect the development of Self-Directed Support to mainstream community development.

This partnership opens up very significant opportunities. Community development has a particular focus on supporting fair and just communities, working in areas of highest deprivation and concentrating on individuals who are traditionally most excluded – like those from black and minority ethnic communities. There is no logical reason why a list of excluded people should not extend to those who are disabled. However, until now, community development workers have not concentrated on those who are excluded by virtue of being
users of social care, only because social and health services have seemed content to care for
them outside the mainstream of community life.

One strategy for those in services seeking the greater involvement in community of people
they support, therefore, must be to start the conversation with community development
workers and to encourage them to be more aware of their responsibilities towards people who
need support. This could be fertile ground, and in Control’s partnership with Novas Scarman
will greatly strengthen our efforts to build a bridge into community.

Increased political interest in community development has led to a growth in activity at
the local level. A 2005 report by the Community Development Foundation suggests that
there are 20,000 workers (full-time equivalents) whose remit is to support individuals to be
included in – and make a contribution to – their communities. These community capacity-
building workers are to be found in health services, the leisure sector, voluntary organisations
and Local Strategic Partnerships (Community Planning Partnerships in Scotland), as well as
in community education.

Self-Directed Support and community
– Phase Three of in Control’s work

in Control is now embarking on a programme of community-focused work that has four
elements:

1. Extending Small Sparks
2. Local Area Coordination
3. Learning from the work of related community development initiatives, in
   particular Manavodaya in India
4. Building alliances with mainstream community organisations.

The Scarman Trust has seconded a member of its staff to develop each of these areas.

1. Extending Small Sparks
The benefits of Small Sparks grants seem clear. They are low-cost and easy to set up. They
make use of the abundant creativity of ordinary people. They enable people to demonstrate
their creativity and to spend money to the benefit of the community. Enduring relationships
can be formed between people who need support and other members of the community
because a well-conceived project gathers people around common interests.

in Control will, therefore, promote the use of Small Sparks through an improved set of
materials and continue to encourage authorities to make this community-building method
an integral part of the RAS.

2. Local Area Coordination
Local Area Coordination (LAC) is a model that originated in Western Australia in the early
1990s and has been adapted and used in Scotland since 2000. It adopts a person-centred
approach to enabling individuals and their families to get the support they need within their own communities.

Local Area Coordinators (LACs) work from within their community – usually from shopfront premises – and support an individual or family to find the support they need locally. People can walk in off the street and seek advice and help. LAC involvement could take the form of support:

- to build up a social life
- to make a contribution to the community
- to find employment or volunteering opportunities
- with educational opportunities
- to join community groups or activities
- to access social services.

In September 2007, in Control organised a meeting between Eddie Bartnick, who devised and developed LAC, people involved with in Control (both Core Team members and local authority members), people involved in implementing LAC in Scotland and Northern Ireland and agencies interested in developing LAC in England. This group considered how in Control’s model of Self-Directed Support and LAC could work together most effectively.

The session produced a draft model that in Control will test with member authorities in the coming two years.

![Diagram](image-url)

**Figure 1** Local Area Coordination and Self-Directed Support – draft model

In this model each LAC would be available to provide a general level of information and advocacy support. Some of those seeking advice would move to a level of regular or more intensive contact (say, 40-60 individuals and families within a 12-month period).
An LAC:

◆ would have small amounts of discretionary funding which they could use to support people directly
◆ could also assist people to access Small Sparks or other one-off sources of funding within their communities
◆ would have a key role in helping those people who need social care support to follow the process to a Personal Budget.

Funding for such a role will need to be found from within existing resources, for example from the Social Care Reform grant or from adjustments made to care management.

One important question to be answered in the piloting of LAC combined with Self-Directed Support is: who can use the support of the LAC? If someone is eligible for a Personal Budget, can that person still receive support from the LAC? Or is the LAC primarily there to help those people who are ineligible for social services (or to help eligible people to get a Personal Budget)? There should be no bar to people with a Personal Budget being helped to get the supports available from communities. On the other hand, LAC would be a finite resource and it will be important to ensure that those who find themselves just beneath the eligibility threshold – whether that be critical or substantial – are not denied the LAC’s support.

3. Learning from others: the work of Manavodaya in India.

There is much to learn from overseas development work and in Control has built a relationship with one particular agency: Manavodaya, a small community development institute on the outskirts of Lucknow in Uttar Pradesh. For 20 years, its founder, Varun Vidyarthi, and colleagues have been working with poor villagers – some of the most excluded people in India.

Varun was invited by in Control to speak at its June 2007 Community Solutions Conference. He also worked with smaller groups of people in the following days – including a session with in Control’s Core Team.

in Control was interested in the work of Manavodaya because it had achieved remarkable success in supporting large numbers of people to take control of their lives in often appalling circumstances. Many villagers in India work well below the international poverty line – $1 a day. If ever they need money to deal with some extraordinary event – say an illness – they have little choice but to borrow from moneylenders. If they are unable to repay the loan – and this is common because of the high rates of interest – they can lose their land to the money lender. In this situation, villagers often become bonded labourers working for the moneylender on the very fields they have lost.

Manavodaya’s success appears to come from a sophisticated understanding of group processes, but also from a critical focus on the attitude of the facilitator and on his or her personal development.

While many of us would like to claim these attributes for ourselves, Manavodaya’s approach has a level of rigour and discipline that few would recognise. This approach involves a ‘paradigm shift’ in attitude and behaviour on the part of the facilitator; and a demanding regime that includes personal and collective reflection and income sharing. This approach...
also requires that, in working with groups, the facilitator behaves with deep humility towards the knowledge of group members. When watching facilitators in conversation with villagers, it is immediately evident how little they speak and how much they listen.

For many of us, this is challenging territory and it is perhaps easy to dismiss as belonging to another continent and culture. On the other hand, most of us use words like ‘empower’, ‘enable’ and ‘include’ on a daily basis. in Control is interested in learning from Manavodaya’s work such that these words take on greater substance in our work. At the time of writing, we are discussing a joint project with Manavodaya that will inform in Control’s understanding of community work.

4. Building alliances with mainstream community organisations

When we look at the language of the government’s citizenship agenda, we see that it is very similar to that of in Control. For example, the Secretary of State for Communities, at the launch of the Department of Communities and Local Government, stated ‘my vision is of a Department on the side of people who want to make a difference, where everyone has the opportunity to fulfil their potential and to build a stake in society for them and their families.’ Government policy initiatives in this area reiterate a strategy based on a community development approach and partnership with the Scarman Trust offers in Control a link to mainstream community activity.

The Trust has drafted a strategy for in Control that takes account of the government’s policy framework for communities. This framework is structured around key strategy documents such as Strong and Prosperous Communities and includes policy themes of immediate relevance to in Control such as:

- improved strategic government partnership with the Third Sector – this partnership will create a network of strategic third-sector partners. in Control will need to engage with these partners to ensure that people who use social care are seen as important members of local communities
- a continuing drive for delivery of public services by the Voluntary and Community Sector and increased support for social enterprise – funding initiatives such as Futurebuilders and the Capital Assets Fund could support the growth of demand-led services and provide opportunities for micro and community enterprises
- a focus on localism and ‘place-shaping’ – Strong and Prosperous Communities and other policy documents place communities at the heart of what is being increasingly known as ‘place-shaping’, the idea that people who live in an area should be actively involved in making it a place in which they want to live. People who use social care must be supported to play a part in place-shaping and the Directors of Adult Social Services now have specific responsibilities to lead this work.

As argued earlier in the chapter, mainstream community development agencies may be unaware that the success of Self-Directed Support hinges on Personal Budget holders being present as citizens at the centre of community life. As well as helping in Control to develop its community strategy, The Scarman Trust will be highlighting the arrival of Self-Directed Support – the new social care system – to its community partners and allies.
Conclusion

The wish that people who need extra support will be included in communities is a long-standing one on the part of support services. Too often that wish has not been fulfilled and, even when people live in ordinary places, many have remained isolated. Fortunately, there are many exceptions, thanks to the hard work and perseverance of good organisations and support staff.

These support agencies have mostly worked within a service context. Alliances with community organisations are rare. Community groups and agencies have a brief to work with excluded people but may not think of people who use social care as a target group for their work simply because human service organisations have seemed happy to care for them for so long. There is, therefore, considerable scope to build alliances with community organisations in a policy climate that encourages the involvement of all members of the community.

Community is an important ingredient of Self-Directed Support, which will be successful only to the extent that people lead lives as citizens in their communities. However, it is more than a mere ingredient. Citizenship and a real life in the community are really the goal. Self-Directed Support is the means to get there.

in Control will try to create practical means – through Small Sparks, Local Area Coordination, work with Manavodaya and partnership work with the Scarman Trust – to get closer to that goal.

The Author

Carl Poll

In 1990 Carl Poll started KeyRing Living Support Networks, an innovative supported living organisation which relied on community involvement as an essential ingredient of its support to people with learning difficulties. He led KeyRing until 2003 when he joined in Control to work as a project consultant on three of the initial in Control pilots.

During recent years, he has contributed to raising a national debate on the meaning of citizenship for marginalised people, for example organising important conferences with speakers such as John McKnight from Chicago and Varun Vidyarthi from Lucknow.

He is now Director of Communications for in Control.

NOTES

1 Valuing People White Paper, Department of Health, 2002, is an authoritative source of information on the situations of people with learning disabilities. Though five years have passed since its publication, progress towards Valuing People’s vision of ‘Rights, Independence, Choice and Inclusion’ for people with learning difficulties has been uneven and slower than hoped for. Awareness of this halting movement towards the vision of equal citizenship drove the Valuing People Support Team’s motivation to join in starting in Control.

2 For statistics that support this statement see: Prime Minister’s Strategy Unit (2005). Improving the Life Chances of Disabled People, Chapter 2.


Bob Jamieson, George Doubleday and Keith Webster are three of the 16 people who describe their Self-Directed Support on in Control’s DVD, *How to be in control* (2007).


See, for example, *How to be in control*, DVD, in Control Publications, 2007.

in Control DVD, *How to be in Control*.

5 minutes with Viv Slater, in Control NOW!, vol 01, issue 02, March/April 2007.

John McKnight leads the Asset Based Community Development Institute at Northwestern University. See for example, *Building Community from the Inside Out*, McKnight and Kretzmann, Institute of Policy Research, 1993.

See also *Community Development*, in Control Discussion Paper, Kennedy and Poll, search the in Control library for ‘0031’.

For more information on Small Sparks search the in Control Library for ‘0026’.

See, for example, Prime Minister’s Strategy Unit (2005). *Improving the Life Chances of Disabled People*.

in Control (to be published 2008). *Interview with Paul Davis*.

‘Social capital’ refers to the collective value of all social networks that an individual has and the inclinations that arise from these networks to do things for each other (‘norms of reciprocity’). For more information on social capital see, for example: Putnam, R., (2000) *Bowling alone: the collapse and revival of American community*. New York: Simon & Schuster).


Community Development Foundation (2006). *Who are the Capacity Builders?*

An extract of Varun Vidyarthi’s presentation is available as a movie clip: http://in-control.org.uk/news/video.php

Chapter 6

Service providers and commissioners
This chapter argues that we must move away from the old ways of commissioning and providing blocks of service. A fresh start is needed based on a way of thinking that puts the citizen at the centre of everything.

Such a fresh start will present big challenges but also exciting opportunities to commissioners and providers. Fortunately, we are now in a position to build on what has been learnt in Phase One and Phase Two of In Control’s work and to set out expectations of providers and commissioners. There is an inevitable requirement for real changes in approach and in practice.

We know that we need to move money and set budgets to support providers in making these changes and we know the importance of local dialogue between commissioners, providers and citizens to keep the vision alive and on track.
Introduction

Self-Directed Support is a process of empowering individual citizens. The organisations that provide support to those citizens are very important in this process and, while some are leading changes, others may currently feel anxious.

Evidence in this report reinforces in Control’s belief that it is possible for everyone – irrespective of labels attached by professionals – to have choice and control in their lives. In publishing Putting People First, the government has confirmed that this approach to services is now public policy. It is, therefore, vital that providers – both profit-making and not-for-profit – work in harmony with local authority commissioners to keep the person firmly at the centre of the process.

The move to Self-Directed Support requires providers to be at their most imaginative, flexible and courageous. They need to find new ways of listening to people. They also need to transform the ways they manage money, staff and other resources so that it is citizens, and not ‘the organisation’ or its managers, who are in control. The change means that commissioners and providers together must reinvigorate their working relationship – and place citizens at the centre of their efforts.

The old way of commissioning and providing services

In the past social care services have been controlled by managers and professionals.¹

Some services have been ‘block purchased’. This means that the local authority agrees to give a sum of money to a provider organisation in return for a block of services, beds in a care home or places at a day centre.

Some have been ‘spot purchased’. This means that individual social workers negotiate and agree the price of a service to support a person, usually based on a care plan.

Other services have been directly provided by local authorities, an arrangement which is like block purchasing, except that the service is owned and run by the local authority itself.

More recently, there have been new and more complicated contracting arrangements as local authorities have tried to respond to a wider range of needs and demands and have tried to get more for their limited money. One such arrangement is the cost and volume contract. This combines features of both block and spot arrangements.

What all these old contracting arrangements have in common is that none of them pays sufficient attention to the expressed aspirations of the person and none of them is controlled by the person. Even spot purchasing – in some ways the best of these arrangements – begins with a traditional care plan, usually structured around a set menu of ‘options’ that leads to social workers considering a short list of suitable potential providers. All these approaches are, in Simon Duffy’s terms, examples of the ‘professional gift model’² where ‘care’ comes as a pre-wrapped gift package – take it or leave it.
The thinking that created this old way of doing things was very much that of the 1980’s and early 1990’s. The 1990 National Health Service and Community Care Act was based largely on a report by Sir Roy Griffiths (one-time Chairman of the Sainsbury’s supermarket chain). This was the legislation that gave local authorities the responsibility to assess people and to arrange the services that would meet their assessed needs. It set up the system of care management as we know it today – effectively a system in which agents of the local authority act as intermediaries between citizens and support services. (It is perhaps not facetious to note that there is no equivalent role standing in the way of a customer choosing goods in a Sainsbury’s supermarket!) The system pushed providers into a position where there was little choice but to respond with a limited set of services corresponding to the assessments and care plans produced by those care managers.

This system has not worked particularly well either for local authorities or for the people on the receiving end. Local authorities have found that, as greater numbers of people came to them needing more and more support, they could afford neither the expensive residential packages for those with highest needs nor the preventive services for the majority – people who just need a little help to stay independent.

People using services have found available services to be more and more restricted. Eligibility criteria have become tighter and tighter as local authorities squeeze the system to get more out of limited funds.

As the recent Commission for Social Care Inspection State of Care report makes clear: ‘the shift of expenditure from residential services to community services over the last five years, 2001 to 2006, appears marginal’. For people of working age the trend has been towards more care and support away from home and community. The rise in Direct Payment take-up, and thereby of choice and control, though steady, still falls far short of the dramatic increase many had hoped for ten years ago. Direct payments make up only a fraction of the total gross costs of social care: only £2 in every £100.

Increasingly, we hear now about regional purchasing consortia, smarter procurement and other techniques from the world of business. These approaches may work well for paper clips and toilet rolls but they are not able to assist people who need extra help to stay independent, maintain their dignity, or exercise choice.

Where has this difficult situation left the providers themselves? In short, there appears to be confusion and concern over what might happen next. There are a number of reasons for such understandable apprehension. Firstly, such anxiety is a response to what many see as the mixed messages from government and local authorities: new, larger longer-term block contracts are available but how do these fit with the quality-driven, consumer-led services demanded by the White Paper Our Health, Our Care, Our Say? Eligibility criteria become tighter and community services are closing but how does this trend fit with the need to help people stay at home and retain their independence? What do local authorities really have planned for Self-Directed Support? Is it the future for everyone? Or is it just of marginal interest because it is only going to be available to a lucky few?

A second reason why providers are apprehensive can be found in the fact that many feel completely excluded from discussions about the future. Others suggest that the local authority only talks to them when wanting to convey bad news about contracts or when the authority needs the provider’s help.
In many parts of the country – and particularly in those areas where the local authority persists with the old way of doing things – the working relationship between commissioners and providers appears to be weak or strained. Most importantly, those citizens who rely so much on social care providers seem to have very little opportunity to contribute to the conversation.

Values-driven providers know that there is a real problem here. The problem is not that such providers do not want to plan in partnership with citizens but rather that the existing system conspires against doing this effectively. The Learning Disability Network, a group of forward-looking providers and their allies uncovered this problem while running a simulation exercise to model the transformation of services in a London borough. An important learning-point from the exercise was that the system encouraged competition and the identification of savings, but led to very little time in discussion with people using services and their families:

‘Perhaps the most startling learning from the scenario was our behaviour towards families and users. As providers, we pride ourselves on our inclusive approach and partnership working with users of our services and their families and carers. Yet during the role-play, those playing provider roles spent most of their time competing with each other and offering up savings to the commissioners rather than looking at quality and innovation. On reflection we were surprised at how little time had been spent with the people playing the roles of users and families to build up new relationships. We failed to see the crucial role users and families play in strategic planning processes and we fell into the trap of marginalising the very people who should be at the centre of this process.’

The challenge for commissioners and providers

If we agree that change is needed in order to bring real choice and control to people needing support, then how might we think more constructively about these challenges and how might we all begin to work together to create the most helpful conditions?

There are three broad lessons from the first years of in Control’s work.

The first is that some local authority commissioners have succeeded in making a strategic move away from block contracts and impersonal care.

In Hartlepool, for example, the Director of Community Services reports that:

‘With providers we’ve tried different things – generally taking a more pro-active approach to developing the market. For example, we offered a development loan to an organisation that provided a day centre for people with Alzheimer’s. This has always been block-contracted. We said ‘you can have this development money to set up services that are individualised and you can pay us back from individual contracts over time.’ They went for it.

Of course, people with their budgets start to shape the market. An interesting development is a group who used to go to a day service. They now run and pay for a drama group using their budgets. They’re quite separate from the day service.'
They own the group. They're the ones grappling with things like what to do if people don't pay when they are off ill or on holiday.

There are a number of projects moving in this direction. People are using their budgets for sports and recreation. Some people are making use of the Disabled Footballers' Association mobile home. People are driving innovation. Since December everyone has had the option of Self-Directed Support so you get an incremental change and providers will have to respond.

To make the kinds of changes needed, commissioners report that they needed to:

◆ shift their focus from ‘doing’ to ‘enabling’ – in particular to make sure that the best possible up-to-date information is available to help people make choices

◆ position Self-Directed Support at the heart of all local authority strategies. For instance: if day services need to be ‘modernised’, this modernisation is done by helping individuals to choose whether to buy into day services or not – and by helping those running the day service to think how to respond to this new level of consumer choice

◆ model ‘empowering behaviour’ by finding ways to interact with and really listen to people who need support by joining community events and helping to organise festivals, parties and celebrations (rather than more meetings)

◆ ensure that care managers and social workers understand the values as well as the technology of Self-Directed Support, help them to see how their jobs might change for the better and how they might rediscover the reforming heart of the profession

◆ get the money to the right place in the budget – so that it is available to be allocated to individual citizens in a fair and transparent way, not as arbitrary ‘blocks’ to services

◆ see the expiry date on any block contract as the opportunity to specify more individual arrangements, rather than a chance to set up larger, longer-term contracts that seem to give better value now

◆ change the questions that commissioners ask providers when they are reviewing services, so that the questions focus on outcomes – how people’s lives are changing

◆ work with people in local communities to help them understand what is changing and what they can do to help

◆ learn from what has worked well previously, including the ways in which people with their own funds (so-called ‘self-funders’) have been supported.

The second lesson is that, while commissioners have been identifying critical success factors for moving to Self-Directed Support, providers have been learning that they too can make radical changes. This was certainly true of the group of forward-thinking provider organisations which came together with local authority commissioners in early 2006 for a series of seminars at the behest of the Care Services Improvement Partnership and in Control to explore solutions to some of the difficult challenges we face. The providers included large, small and medium-sized organisations and those working with all the main adult care groups.

The lessons learned from those discussions combined with the experience of personalisation already evident in early 2006 informs both this chapter and in Control’s subsequent work across the country. These providers have been experimenting with arrangements that divert resources to support individuals to get the life they want and need (as set out in their own
specification). These experiments contrast with the traditional approach that allocates money to traditional ‘units of service delivery’ such as day centres and care homes.

**shop4support**

As more people become able to choose their support, the need for accurate, accessible and up-to-date information grows rapidly. *shop4support* is a web-based tool that, at the time of writing, is about to be launched by in Control. *shop4support* will enable citizens to search an online catalogue for support that suits them. It will enable providers to market their ‘products’. It will also help commissioners to have confidence that citizens – the purchasers in the new world of Self Directed Support – have the means to identify and access the services they really need.

It is expected that *shop4support* will stimulate the local market in support services by bringing a greater opportunity for price and quality comparison: individuals will be able to rate (‘quality check’) providers and to make this information available to others. There will also be a facility for a simplified means of paying for support – something that is particularly helpful for those buying from a range of providers, or for those who buy only occasionally.

To make this shift, providers need to:

- change how they use money they receive from commissioners, so that it is dedicated to individuals and not to units or teams
- change how staff work, so that they work for individuals and not for services
- change how they judge quality and success, so that the criteria are defined and designed by people who use support and not by regulators or managers
- find ways to raise expectations and stimulate the imagination of people who use support so that their horizons progressively expand as they learn or re-learn ways to behave and interact; and these widening horizons are reflected in support plans and ultimately in their engagement with others in the community
- find new ways of helping people connect to their fellow citizens – whether by supporting community initiatives, helping people to develop social enterprises or getting families and friends more involved in the life of the organisation
- identify new roles and possibly new organisational forms for the provider organisation. There are numerous possibilities ranging from modest adjustments – such as offering advice about being an employer – to more radical changes such as moving into community action or social enterprise. Certainly, organisations could, for example, develop expertise in helping people plan or organise support (or any other means of getting the life they want)
- think about how the organisation should develop in response to people’s growing confidence and thirst for choice and control. Providers need to be constantly alert to new and creative ways to assist people to become active and productive, to develop relationships with others and to achieve lifestyles of their choosing
- think about how they (as ‘specialist providers’) might connect with and support ‘mainstream (non-specialist) providers’ to provide a welcome for people who need extra support.
One organisation that is experimenting in new ways of offering control over support is KeyRing. As well as beginning to convert existing funding for its Living Support Networks to Personal Budgets, the organisation has begun a radical support co-op in Newcastle.

This initiative came out of discussions with the City Council. The project is aiming to become a co-operative, owned jointly by KeyRing members, volunteers and staff. In this way members with learning difficulties gain new legal status and come to share power and responsibility. Newcastle City Council will contract with the co-op and the new ‘co-owners’ will each have a Personal Budget to purchase support from people in the neighbourhood. The project has built strong links with community groups and organisations, particularly through promoting volunteering, and the expectation is that the project will enrich and enliven its community as it empowers individuals.

The third lesson we have learned is that these new approaches will only work if commissioners and providers work together and remain steadfastly committed to keeping the citizen at the centre.

To do this commissioners and providers need to:

- meet regularly and develop an atmosphere of mutual trust
- include people using support services in some of these meetings – but avoid tokenism. They must find ways to talk with people about their understanding of active citizenship and how best to develop involvement. The jargon for this process is ‘co-production’ – but this is much more than a buzzword. It is an attitude of mind towards all citizens.

The practice of co-production needs to become common currency amongst all commissioners and providers. This practice will involve:

- working out together the best systems to nurture person-centred planning and support planning in provider services; and establishing the best ways of checking that plans are effective in the design of services
- talking about resource allocation and money: is there enough to meet the realistic aspirations of people and if not, who will take steps to address the issue?
- thinking together about different ways of moving from old style arrangements to new – for example, using individual support plans as specifications for newly-contracted services.

in Control has also pursued a number of other initiatives to support the development of new forms of provision including:

- the launch of an in Control provider network facilitated by Paradigm
- facilitating a group of voluntary sector Chief Executives to meet and develop practical tools to make Self-Directed Support work
- working with a small group of commissioners and providers from across England to think through how these processes can work. There are two relevant papers on the website: Strategic Commissioning and Self Directed Support, A Think Piece and Commissioners and Providers Together, the Citizen at the Centre
supporting the work of the National Association of Adult Placement Schemes (NAAPS) to explore how smaller providers can be developed and supported. This work with micro-providers now forms a separate and very exciting project, starting in Kent and Oldham.

actively supporting a number of other initiatives with commissioners and providers to change their thinking and develop person-centred solutions. These have included the Engage and Deliver conferences in several locations across the country and workshops and conference sessions in Newham, West Sussex, Cheshire and elsewhere to stimulate debate and raise issues.

the submission of comments to the government in response to the Commissioning Framework for Health and Well Being.

support to providers to work more effectively with families through initiatives like Planning Live where families meet to plan together.

starting work with authorities in Yorkshire and Humberside to reconsider the contracting process and the most effective ways of doing this in ways which maximise choice and control for citizens. This work is captured in the in Control paper, Smart Commissioning.

Last word

Self-Directed Support will only succeed if providers and commissioners come together with citizens in a joint enterprise, based on trust and on mutual respect. And the providers who will thrive in this fast changing world are the ones that embrace change and begin to fan the sparks now beginning to smoulder amongst those who use their services.
Choosing a support provider in Cumbria – Adam’s story

Adam is a young man with a high level of complex needs, including a very significant level of physical disability. He lives at home with his family and currently has a package of care and support that includes home-care, day services and short breaks / respite. When Adam’s family thought of the future, they were nervous about what level of service would be available.

Adam’s social worker met with him and his family to complete a Resource Allocation assessment to get a Personal Budget. The social worker showed the family example care packages and these seemed to help the family to envisage what Adam’s life might look like living away from the family home. In order to consider how to make Adam’s Personal Budget go further, the social worker suggested that the family might consider his sharing with another one or two young people whom he knows well and who are in a similar situation to his. The three families agreed that this would prove to be a good solution all round and Adam’s father attended a Trade Fair to find out about potential support and housing providers with whom the group might be able to progress their plans.

The three families went on to interview care providers and chose between them what they thought was the best provider from a group of four who expressed an interest in working with the group. A housing provider was identified that was in the process of purchasing a property in which the three young people would share ownership. Each young person would own 20% of the house, giving them real long term security. They would then pay rent on the remaining 40% of the property which would remain in the ownership of the housing association. The young people would have interest-only mortgages and the monthly payments would be met by benefits. This side of things was difficult to negotiate but the families had support from the housing association to understand the process and feel it has been well worth the effort to ensure the long term future for their young people.

While a property was being found that met the needs of the three young people, the Personal Budget arrangements enabled the support provider to begin to work with them and their families straight away. The provider got to know the young people and drew up support plans that would inform the recruitment of staff and the planning of the moves. Adam’s social worker said: ‘It’s been really nice to see the families make the big decisions and complete each step where this previously would have been done by commissioners. The in Control system really has put the control in the hands of the people closest to the young people concerned.’

Andrew Tyson

Andrew is a social worker who has worked mainly in services in Sussex supporting people with mental health problems and learning difficulties. From 1999 he was a strategic commissioning manager in West Sussex and later became involved in the in Control pilot there. He has written over the years about how to involve and empower people who use services. He is now System Change Director for in Control, which means that he is responsible for the in Control Total programme.
NOTES

1 This is not to say that managers and professionals have not been formally accountable to local people through the political process. That process is changing now, however, and the public expectation is for much more direct control.


3 Commission for Social Care Inspection (2008), *Making Social Care Better for People*


5 *Interview with Nicola Bailey* (to be published 2008), in Control publications.

6 The full story of this change is available from the in Control website library: [www.in-control.org.uk](http://www.in-control.org.uk), document number 0235: Haworth, K. (2007), *Support Providers Embrace Change*.


Chapter 7

Reflections on in Control
Reflections on in Control

John O’Brien and David Towell

We write as critical friends, invited by in Control’s leadership to facilitate reflection on the learning emerging from its work and to contribute some of our observations to this report. In this chapter we cover the following:

◆ in Control as social acupuncture – what has worked for people; what is right
◆ What is likely to transform social care? Learning from history; multiple strategies
◆ What form of organisations will facilitate deep change? A distinctive structure; weaving into others’ webs; strong metaphors for organising.

Introduction

in Control’s commitment to discovering effective ways of supporting those eligible for social care in ways that protect and promote their full citizenship matches our own convictions. Self-Directed Support – the means that the in Control network is developing to reform the social care system – seems to us a robust and creative response to many of the challenges facing the government of a society that aims to improve the chances of people who require publicly funded assistance to lead their daily lives in the way they want.

We each view in Control from different perspectives. David Towell works primarily in an English and European context as a policy advisor and facilitator of system change. John O’Brien, a student of innovation in supports to people with disabilities and their families, has
been a regular visitor from the US for nearly 30 years. Our occasional collaboration began in the early 1980’s, when David led the initiative, *An Ordinary Life*, for the King’s Fund – a network that shaped the development of community supports for people with learning disabilities. In the past year, we have facilitated three reflection days that have brought together some of in Control’s core staff, leaders in local implementation and leaders in national policy and civil society. This chapter is based on what we have learned from thinking about these conversations, talking further with some of those involved in the change and reading some of the extensive documentation of in Control’s activities available at www.in-control.org.uk.

We aim to describe some notable aspects of in Control’s ways of working, as they appear to deeply interested observers like ourselves. In doing this we have interpreted what in Control does in our own terms. We recognise that commentators with different interests and experiences of in Control may produce very different accounts. We hope that our interpretations add to an understanding of in Control.

**in Control as social acupuncture**

Guided by a map of the body’s energy flows, acupuncturists apply very small but very sharp needles in order to achieve energy balance and thus improve health. Social acupuncturists seek those points in a system where highly focused intervention will yield deep change and a new balance that will better promote human flourishing.

From in Control’s viewpoint, the greatest potential energy to transform social care is released when all the people who require assistance have the opportunity to direct their own supports. This diagnosis focuses energy on shifting the way the person requiring support is perceived, the way power is distributed and exercised and the way social resources are organised. The person is seen as a citizen entitled to the assistance necessary to lead daily life as he or she chooses. One responsibility of citizenship is to decide on the best use of the resources available to provide necessary assistance. Another responsibility is to engage available capacities outside the social care system in support of the life the citizen chooses. The organisational systems responsible for allocating available public funds and offering supports must adapt in order to honour and facilitate these responsibilities.

![Figure 1. Pressure point for social transformation](image)

This shift in perception aims systematically to increase the number of people who confidently engage social networks, civic associations and publicly funded resources with the expectation that they will be able to generate adequate support to pursue what matters to them in life. While in Control enters through the door of social organisation by establishing procedures and practices within local authorities for allocating and assisting people to direct individual budgets, its purpose is to transform the nexus of perception, power and organisation, moving from the classification, placement and supervision of clients to recognition and active support for citizenship.
This singular focus on Self-Directed Support as the way to promote citizenship provides a filter that informs decisions about what not to work on. *in Control* argues that the point of greatest leverage is getting a few people in control of their supports as soon as possible, learning from that initial experience and repeating with another group, taking the shortest possible time to get the greatest possible number of people in control of their supports.

Transformation entails revised expectations, new connections and learning through action by people who require support, people who provide support (including mainstream service providers) and people responsible for assuring that a locality responds adequately to its citizens' needs. It requires changes in culture – mindset, relationships, structures and practices – at three levels.

Though *in Control* strives for fluency in all three ‘languages’, its messages are grounded in people’s everyday lives. Its materials typically connect people’s stories to system design or policy recommendations; and its interventions often bring people who rely on social care and their family members into direct contact with decision makers.

**Both practical and moral foundations for deep change**

*in Control’s* effort to reform social care by implementing Self-Directed Support rests on two footings: a careful review of what has worked to improve the life chances of people with disabilities; and a well developed moral argument that systems should actively promote the conditions of citizenship rather than inhibiting them. *in Control’s* approach to stimulating
change permits continual updating of each of these accounts of the system’s purposes, practices, and limits.

What has worked for people?

In Control benefits from its core team members’ past active involvement both in improving the life chances of people with complex and challenging support requirements; and in previous efforts to reform the social care system. Practical experience, mostly with services to people with learning difficulties, informs their understanding and underwrites their confidence in the feasibility and benefits of self-directed supports.

Figure 4 Six keys to citizenship

Assisting people with long histories of institutionalisation, isolation from family and community life, and complex needs for assistance to re-establish themselves as participating citizens, has demonstrated the effectiveness of designing individualised supports based on six keys to citizenship:

- **self-determination** – making our own decisions, in control of our life
- **direction** – having a meaningful life that suits us and the kind of unique person that we are
- **money** – being able to pay our way and to decide how we will meet our own needs
- **home** – having a place of our own where we are safe, where we belong
- **support** – getting help when we need it to do the things we really want to do
- **community life** – playing an active part in our family, our circle of friends and our community.

These six keys to citizenship, which In Control claims apply universally, specify that a social care system’s reason for being is the promotion of citizenship. They guide the collaborative design of supports and the evaluation of services. A system is effective to the extent that it protects or provides access to these six keys. Clinical interventions are useful to the extent that they protect or promote access to them.

Taking these keys seriously stimulates social inventiveness: for example, finding practical ways to support self-determination, direction and control of money when people experience impairments in communication or cognition by developing methods of substitute decision-making that keep decision-making as close to the person as possible. Implementing self-directed supports in a local authority and a nation creates systemic capacity to assist people to strengthen the keys to citizenship in their own lives.
What is right

Many people identify in Control with an important procedural innovation: a thoroughly specified, continually improvable, seven-step process for getting, using and learning from experience with an individual budget that offers people great flexibility in the way they make plans, control money and develop supports; and provides local authorities with a fair and transparent method for allocating available social care money and generating a range of effective supports.

in Control is also a disciplined attempt to generate a clear understanding of the moral foundation for social care and to gather support for it. It is an attempt that looks beneath ideas about good public management. It asks what claims people who require assistance can legitimately assert on their society. Its answers begin by recognising people who require assistance as citizens.

"Citizenship is the right ideal because it implies a vision of society where everybody is an equal member of the community, but where the natural diversity and differences between individuals are seen as positive opportunities for interdependence (not as some big problem). Citizenship also reminds us that communities must be constructed from the willing efforts of free individuals; full and active citizens build and sustain the communities they belong to."

Citizenship can be -- and often is -- constricted by common social care practices that demand an unnecessary and morally unacceptable sacrifice of autonomy in return for assistance. Everyone has something to offer others but contributions can be obscured or erased by service practices that treat the heightened interdependence occasioned by impairments as though interdependence both cancels people's gifts and is incompatible with their independence. This is wrong. People are entitled to the support they need to function as citizens (though currently this entitlement is vague and hence difficult to enforce). Support should be delivered in ways that maximise autonomy. For example, citizens who require support have a right to know how much public money is available to them and the process by which it is allocated.
should be understandable to them. They should be free to spend their allocation in any legal way they believe supports their living a life that makes sense to them.

This effort also asks what duties it is fair to expect of citizens who receive assistance. One of these duties is to exercise as much choice as possible about how they wish to be in control of planning, selecting and managing their supports. Another is to contribute to mobilising the support they require and to exercise as much creativity as they can in designing their supports. Another is to explain their decisions, reflect on what they are learning from their experience of support and share what they have found with others. To accommodate individual differences in capacity and preference, in Control’s approach to Self-Directed Support offers both a thoughtful approach to substitute decision-making and a menu of choices for dealing with planning, direction and support management. (See also Chapter 3 – Brokerage and Support Planning).

This understanding puts priority on interdependent autonomy thus sharpening the focus of change by pruning a number of reform ideas in good currency from in Control’s proposition to local authorities.

One example: there are strong advocates for requiring independent brokers whose task is to conduct person-centred planning and to support people in connecting with services that will suit them. in Control recognises the case for service brokerage, identifies independent brokers as one of several options to support planning and finding supports and offers some help to people who want to become independent brokers. However, in Control resists requiring people to use brokers.

This resistance is consistent with the principle of maximising autonomy: pre-purchasing brokerage amounts to a sort of tax on people’s individual allocation and promotes one alternative to the likely exclusion of others. Another example: many reformers, including in Control’s leaders, have seen the benefits of highly individualised services and the drawbacks of such congregate settings as registered care homes.

![Figure 6 Individualisation and freedom to choose](image)

However, in Control advises that local authorities should not deny people the choice of using their allocation to buy a place in a registered care home: in a trade-off between choice of preferred supports and an option that probably limits choice, in Control prioritises choice of...
supports. In Control’s prioritising of more individualised and individually managed supports is highlighted in the examples the organisation uses to illustrate the concepts involved in Self-Directed Support; and demonstrated in its many investments in providing opportunities for people to learn about personalised alternatives and how to organise them.

The search for a clear and widely accepted foundation is also a search for adequate language. For example, in Control prefers ‘support plan’ to ‘care plan’, in part because ‘care plan’ carries the baggage of a professionally defined and controlled process for assigning a client to a pre-purchased slot.

The set of principles at the front of this report succinctly summarises in Control’s current understanding of the proper foundations of social care. The principles are, in summary,

1. Right to Independent Living
2. Right to a Personalised Budget
3. Right to Self-Determination
4. Right to Accessibility
5. Right to Flexible Funding
6. Accountability Principle
7. Capacity Principle

Principles derived from careful thought remain inert if they are not embodied in different ways and tested and refined in action under a variety of local circumstances. So there is a further commitment to making implementation feasible that guides in Control’s approach to self-determination. Its models, policies and procedures meet two tests. Firstly, they are affordable in that they can be implemented within existing local authority social care budgets. Secondly, they are legal. In other words, they do not violate any existing laws or require relaxation of existing rules. These constraints don’t apply when in Control provides advice. Its representatives advocate changes in law or policy that would expand the resources available for citizens to self-direct.

What is likely to transform social care?

Learning from history

Despite substantial attempts at modernisation – which have generated a great deal of activity to re-organise, redefine roles and make plans in collaboration with users and carers – the social care system has proven remarkably stable in terms of what most people who use its services experience. Despite great investment in care management and its refinements, far too few people can make basic choices about where they live, who supports them and for what purpose. A close look at past efforts and the systemic limits they reveal has informed in Control’s focus and strategies.

Consider one example: direct payments. Leaders in the Independent Living Movement conceived direct payments as a way for disabled people to control their lives. They designed the policy, lobbied successfully for its adoption and organised effective ways to mobilise disabled people to gain and use them. Yet while many have benefited from direct payment and demonstrated its effectiveness, the actual uptake is far smaller than the potential. The social
care system seems to have encapsulated direct payments as one small offering rather than use direct payments as a lever to change the pattern of service.

The creative energy arising from organised disabled people and channelled through central government policy is damped at the point of local implementation. The limiting system dynamics revealed in this case include:

- fear that direct payments will break the bank, bringing sanctions from central government
- fear that decreased professional oversight could be judged as a breach of the duty of care
- uncertainty about how inspection and regulation regimes will treat the consequences of implementing direct payments
- a widely shared assumption that people who request and use social care are untrustworthy or incompetent
- a mindset that defines social care as welfare or compensation rather than as assistance necessary to allow full citizens to lead daily lives of their choice
- defence of local services provided by local authorities or purchased in blocks
- a history of recurrent reorganisation and multiplying central mandates which creates overload and encourages a disengaged stance: ‘wait and soon the requirements will change’
- a history of distance and ritualised interactions between local authority officials and advocates for change that leads to mutual blame rather than collaboration and drains energy from the change effort.

Several important lessons can be drawn, including the following. Central requirements can founder without local leadership. Real change is more likely when mobilised citizens with a stake in the quality of supports meet officials and professionals who share a commitment to their vision. So it is important to begin by identifying, connecting and aligning leadership from both inside and outside. If a change is to benefit citizens historically separated by different modes of service (e.g. older people in need of support and people with learning difficulties), influential members of separated groups will need to discover common interests in change and a common language. New forms of organisation, for example Centres for Independent Living, must develop to do new kinds of work. Unless mindsets change and devaluing assumptions are challenged by implementing practices based on a positive view of the capacities of citizens who require support, the system will trap the change in the smallest possible organisational space, where it can affect the fewest people.

**Multiple strategies**

As the limits to deep change listed above have different sources, *in Control*’s network deploys a variety of strategies to engage them. Some limits yield to technical problem-solving and regulating uncertainty by adopting a process of testing and refining procedures and decision rules in an expert network that involves many localities. Some limits may relax at least a little by engaging central policy makers, inspectors and regulators in refining the model and in problem solving. Some limits arise from organisational culture.

The number and variety of structures, roles, and functions affected by the shift to Self-Directed Support make the change process complex. *in Control* provides a number of guides for the transformation process that outline and sequence critical change tasks.
One useful way to think about the different sorts of strategies necessary to implement Self-Directed Support is to consider two different kinds of skilled change work: technical problem-solving and adaptive work. In Control’s network supports both kinds of work. Successful technical problem-solving develops effective and efficient practices; successful adaptive work sets new parameters for technical problem-solving.

### Technical Problem-Solving

| Manage the current system to its highest potential output within system limits. |
| Address problems that can be fixed through a known or discoverable series of steps (no matter how complicated) that can be described and disseminated. |
| Necessary learning can be done by instruction and captured in documents. |
| Necessary change can be accomplished through exercise of authority. |

### Adaptive Work

| Re-design own roles, boundaries and practices in order to learn how to thrive under changing conditions. |
| Address the political and emotional issues in identifying gaps between desired and actual capacities, what must be conserved and what must be lost, and how the costs of transformation are to be distributed. |
| Necessary learning requires engagement in acting/reflecting under real life conditions of risk and uncertainty. |
| Necessary change requires mobilising commitment among people with different perspectives, interests and definitions of issues and goals. |

### Table 1 Two kinds of skilled change work
in Control attends first to the point of performance, adopting a local perspective to define implementation problems and generate solutions for them that will strengthen local capacity to support citizenship.

A common insight into the nature of self-directed supports informs in Control’s approach. Self-Directed Support is a local co-production, created by interactions among people who receive supports, the various networks and associations that comprise their communities, providers of mainstream services, providers of social care, those responsible for commissioning social care and those responsible for local place-shaping. This view highlights the importance of managing boundaries intentionally to discover productive interdependencies at every level of local organisation.

Figure 8 The co-production of Self-Directed Support

People reach out to those they know and the associations to which they belong in order to enlist supports and opportunities to make a contribution. Support providers are active in assisting people to participate in local life, including its economic, civic and political dimensions and to make good use of mainstream resources. Those responsible for commissioning and providing social care look around to see how they can build alliances that will increase the whole capacity to support citizenship for people at risk of losing control of their lives.

Understanding Self-Directed Support from a local perspective also provides a place to stand to assess the effects of central government policy and practice on local supports for citizenship. in Control complements local work with efforts to loosen constraints by stimulating its national partners and allies to consider changes in law, policy and regulation; to re-think the multiple flows of public money allocated for people eligible for social care; and to encourage national organisations to recognise the benefits of personalised supports.

What form of organisation will facilitate deep change?

A distinctive structure

in Control’s structure reflects its chosen position as an authoritative source of knowledge on Self-Directed Support. Rather than structuring itself as another campaigning or service improvement organisation, it has found sponsors among established organisations with that mission. Rather than become another consultancy, it has made partnerships with several
consultancies. Partners use their capacities to work with clients who seek their assistance in a way that faithfully applies the in Control approach and generates learning. Partner relationships are governed by a detailed agreement that safeguards in Control’s distinctive position. Rather than selling customers a product, it has a low cost membership open to any local authority and a system for freely distributing what it learns.

This interdependent structure – which includes sponsors, members and partners as well as a core team – keeps the core team small while allowing large amounts of work to be done by – and in collaboration with – partners and member authorities. It provides multiple links to the deliberations of central government without stretching the organisation, to establish an independent presence at the centre. As the workload grows, the core team remains compact, exerting leverage through its partner and sponsor relationships and through mutual aid among member authorities. This allows the core team to continue to focus its efforts on the new problems that emerge as implementation proceeds, while website users and members apply – and may update and improve – documented best practices.

**Figure 9** in Control’s distinctive structure

Boundaries for local authority membership are lower than they are for partnership. Membership has expanded from 6 collaborating authorities in 2003 to more than 100 members in 2007. To join, a member local authority pays its dues, indicating an interest in implementing Self-Directed Support, and observes the rules for use of in Control materials.

Member authorities choose how they will implement ways for people to exercise choice and control over the supports they need and whether and how they will involve in Control and its partners. As the table suggests, some members have committed very substantially to self-directed supports while others are considering their investment. Lately, 10 local authorities
have committed themselves to Total Transformation, an accelerated process of moving everyone funded by the authority to self-directed supports. This openness reflects in Control’s desire to form a community of learners and its recognition that community is built from the free choice of members to cooperate with one another.

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Table 2 As reported by local authority members of in Control: February 2008

Weaving into others’ webs

in Control’s work resonates with some streams of thought about how to create better public services and is discordant with others. Proposals that seek to solve the problem by generating efficiencies through smarter contracting for more efficient versions of today’s typical services grasp the problems much too far from their roots. These kinds of approach start with a flawed assumption that current service models are adequate and create an unfriendly environment for self-directed supports. Taking support for citizenship as the centre for any reform effort re-orders accounts of the economics of social care. The problem is not so much that existing services are wasteful of money that might be spent more efficiently; the issue lies in the way the system as a whole is massively over-invested in ineffective services. The solution is not to look for bargains in the warehouse of typical service models, but to invest available funds in self-directed supports – an approach designed to generate innovation by enabling those who require supports to design and modify them to suit the way they choose to live their daily lives.

The themes of re-invention and co-production are growing in currency and some of the explorers of these ideas have identified in Control as a source of practical examples to illustrate, test, and expand their ideas. The tag cloud in Figure 10 suggests an expanding context for Self-Directed Support. The tag cloud shows some of the terms explored in recent publications that have featured accounts of in Control’s work. Many of these concepts are simply trial balloons in the debate on more effective public service. Some point to networks that might be informative, inspiring or influential. Some point to ideas and arguments that might strengthen in Control’s case; or may be signals to orientate in Control towards new resources. in Control has invested a modest amount of time in tying into some of these networks.

in Control also interweaves the growing interest in stimulating sustainable social innovations. By design, in Control’s operating system gives people who are eligible for social care and their

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allies the tools to generate innovative support arrangements to meet their own needs and encourages the sharing of what works with others. At the local level, in Control’s strategies for transformation emphasise measures that will synchronise a growing demand for personalised support – through such initiatives as Partners in Policymaking – with a growing capacity to supply individually tailored supports – through such efforts as a forum for Chief Executives of provider organisations facilitated by one of in Control’s consultant partners. At the national level, the core group mobilises a social innovation system by functioning as an intermediary body: connecting people throughout the network to produce solutions and encourage culture change; harvesting and disseminating fruitful ideas, strategies and ways of thinking; informing the centre of local implementation issues; and continually testing practice against the principles that define Self-Directed Support and the principles against the life experience of people who receive Social Care.

Strong metaphors for organising

in Control describes itself as a research and development community committed to Self-Directed Support and defines its role as helping people learn about Self-Directed Support and ensuring that learning is shared. Three metaphors – Operating System (OS), Open Source, and Brand – guide the way in Control organises itself. in Control wants to manage an open process by which an expanding network invents and implements the means to transform the social care system to universal Self-Directed Support.

Operating System

An operating system makes a computer useful by defining the way that the applications access and use the machine’s resources in order to do the work that a person wants from the computer. In in Control’s analysis, the social care system needs a process analogous to an operating system to mediate between Government policy and citizen experience. Policy sets requirements that local authorities must meet if citizens are to experience the benefits the policy promises. Implementation requires local interpretation, and big changes – like those called for in the 2006 community services White Paper Our Health, Our Care, Our Say – require correspondingly complex interpretations. Currently the social care system lacks effective ways to consider the variety of local interpretations and test their coherence with the policy. This lack generates a pattern of being stuck: central authorities, frustrated by limitations in implementation, push for change by publishing further requirements and regulation; local authorities look for interpretations that minimise external pressures; citizens see what looks to them like big promises without delivery.

Some see the way out of this pattern as stronger imposition of top-down authority, reducing the need for interpretation with more and more detailed specifications. Some see the way out as letting innovation grow from the ground up by allowing even greater latitude in local interpretation. in Control sees another way: an explicit and regularly revised set of policies, practices and tools that reflect most promising local interpretations of Self-Directed Support. Compiling local interpretations not only allows sharing of inventions and ideas; it also provides a common point of reference for identifying areas where central policy requires revision; or where implementation demands a more joined-up central effort because of conflicts among policies or practices.

The operating system metaphor reflects in Control’s simultaneous work at two boundaries. The first is in the relationship between people entitled to support from the social care system and local authorities. The second is in the relationship between local authorities and central government and its agents. In each case in Control works to support those on both sides of the boundary. This is apparent from the offerings in the website Library. There are materials and tools to inform and support people entitled to social care to play their central role directing
the supports they require. There are also materials that structure the local system in ways that offer people choice and control over the support they need to lead their daily lives. There are policy suggestions to local authorities and submissions to influence central policy and practice. At each boundary, in Control functions like an operating system: translating requests from one context into another. There is a notable difference. While the computer’s operating system commands the allocation of the computer’s resources, in Control advises and assists human actors in generating necessary support within the constraints of the systems in which they live and work.

Open Source An open source approach to software development publishes the code for an application and allows people to modify it on condition that they share the modifications they make with a custodian of the application who holds responsibility for whether and how to adopt modifications.

in Control has adopted this approach to developing the means necessary to implement Self-Directed Support. Open source implies continual improvement based on iteration. in Control core staff, or partners, or member local authorities, or sponsors identify an implementation problem which in Control core group members or partners often collaborate in solving. The results are disseminated and form the basis for the next round of improvement and revision. The Editorial Board holds responsibility for judging best practices, maintaining the integrity of the approach, and incorporating improvements. The Resource Allocation System, for example, now stands at version 4.0.

The web site: www.in-control.org.uk makes copies of policies, procedures, and tools freely available. The open access copyright notice reserves in Control’s right to the materials and grants permission to people wanting to direct their own support, member local authorities, and partner organizations to use and modify the materials for local conditions provided that proper credit is given and modifications are shared with in Control.

Brand A brand is a set of images and ideas that represents the identity of an enterprise and shapes people’s expectations of it. A brand is typically communicated by a logo and a distinctive look and feel to products and their presentation.

in Control brands itself with its name, logo, and style for its materials. The name itself communicates purpose. Its dual house styles – easy to read materials with distinctive artwork from know what i mean and materials formatted as organisational manuals, policies and training materials tied together by a common style sheet of typeface, layout and colour – define its position on the boundary between people and families who require assistance and the authorities responsible for social care. Several complex diagrams are more than informative graphics. They are iconic representations of in Control’s approach, turning up regularly in various contexts.

The identity that in Control wants to communicate through its work and its branding might be paraphrased like this: We are the best source of information on assuring that people have choice and control over the support they need to lead their daily lives. We want the information we provide to be practical and accessible for the people who are entitled to social care and for the people who are responsible for administering the social care system. What we have learned is freely available and we encourage anyone who is serious about Self-Directed Support to use and add to our knowledge.

Seeing in Control as a brand builds and protects a recognisable identity that attracts increasing strength as more and more people invest confidence in it.
Looking Forward

We drafted this Chapter in September 2007 but the production schedule for producing this in full report meant that we were able to look at it again at the start of 2008 and add this final section on looking forward. In the meantime we had facilitated the third workshop in the series of reflections with in Control stakeholders – focused on lessons for national policy and implementation – and, more importantly, this had coincided with a major change in the environment for in Control’s work, publication of the national Concordat Putting People First.5

The Concordat heralds a major increase in the scale and pace of change towards Self-Directed Support. It offers national and local government leadership in delivering precisely the system-wide changes which in Control addresses. Its twin themes of achieving transformation in social care through co-production strongly resonate with the approach to deep change modelled by in Control. Indeed, we take the intentions behind this Concordat as one key validation of all the work that this Chapter summarises. However, great opportunities also bring great challenges.6

in Control has notable strengths: its starting point in renewing interest in universal citizenship; its approach to stimulating deep change in current systems which are supposed to enable disabled people to get appropriate support; its wide investment in working with many partners to promote local change; and its commitment to codifying and sharing the learning from this investment. By the standards of past innovation in social care, it is impressive how fast interest has spread, best reflected in the rapidly growing numbers of people who are gaining more control over the support they need to live their lives in the ways they choose.

The programme now required by Putting People First, however, represents something of a quantum leap in the momentum for change, a momentum, which is likely to be further reinforced by the national Independent Living Strategy (whose publication is awaited as we write). If many more authorities – or indeed the national system – now seriously take up the goal of total transformation, we shall be deep in uncharted territory. As the scale and pace of change accelerates, experience suggests that in both subtle and unsubtle ways, ‘the Empire will strike back’. Already there is the challenge of finding a language of citizenship that has meaningful resonance across the wide range of people and groups who have some claim on publicly funded social care; and building the alliances required to strengthen their collective influence as well as their individual autonomy. There is the related challenge of winning public support for the kind of re-appraisal of investment in social services that the Wanless review legitimated in relation to health.

Moreover, while greater autonomy and more personalised support should strengthen individual participation in the mainstream of life, there are other kinds of work required to tackle discrimination (for example, in health care) and open up opportunities (for instance, in the labour market) that have to be addressed collectively on the basis of political will. Individual budgets may prove a weak lever for radical change if these wider conditions do not develop.

More narrowly, the pressure to produce results across the country on quite a short timescale may fit uneasily with the Concordat’s commitment to co-producing change, not least with ‘users and carers at every stage’. There is an obvious trap of focusing most effort on the technical work of introducing individual budgets across the board without equivalent attention to establishing the conditions for the major shift of power towards disabled people and their networks.
And in Control itself could be marginalized in the likely rush of other kinds of ‘change agents’ to join the party.

in Control is working hard to understand and to influence these wider forces and to remain clear about the boundaries around its contributions to social change. As interest and action spreads in ever wider circles, it becomes more and more important for in Control to strengthen its foundations by deepening shared understanding of the conditions of citizenship.

The Authors

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David is a life-long advocate for his sister, Pat, who doesn’t use words. Learning from her experience, he has for nearly thirty years played a leadership role in UK efforts to build a society which values disabled people as equal citizens, notably through the King’s Fund An Ordinary Life initiative. Currently he directs the Centre for Inclusive Futures and is Visiting Senior Lecturer in Social Policy at St. George’s University of London. Among a number of voluntary roles he is also Strategic Adviser to Inclusion International.

John O’Brien
John O’Brien learns about building more just and inclusive communities from people with disabilities, their families, and their allies. He uses what he learns to advise people with disabilities and their families, advocacy groups, service providers, and governments and to spread the news among people interested in change by writing and through workshops. He works in partnership with Connie Lyle O’Brien and a group of friends from 12 countries. He is affiliated with the Center on Human Policy, Syracuse University (US), InControl Partnerships (UK), and the Marsha Forest Centre: Inclusion. Family. Community (Canada). For more information on his books, visit www.inclusion.com; to download some of his papers, visit www.thechp.syr.edu/rsapub.htm. You can reach him by e-mail at johnwobrien@gmail.com

NOTES


2 Simon Duffy (Summer 2006). In Control. Llais, P. 9. (Download from in-control.org.uk)


4 See, for example, Geoff Mulgan, Rushandra Ali, Richard Halkett, & Ben Sanders (September 2007). In and out of synch: The challenge of growing social innovations. London: NESTA

5 HM Government (December 2007) Putting people First: A shared vision and commitment to the transformation of Adult Social Care

6 We develop this analysis more fully in John O’Brien and David Towell Reflections on in Control 3: Lessons for national implementation which can be downloaded from www.in-control.org.uk
Appendix

Our goal is Independent Living
NCIL/in Control joint statement
Our goal is Independent Living

Working in Partnership

Statement of Agreed Position and Actions

The National Centre for Independent Living (NCIL) and in Control have come together to share good practice and to state their jointly held view that:

◆ the goal for disabled people, whatever their age or impairment, is Independent Living – to have choice and control in how support needs are met
◆ Self-Directed Support is the route to achieving Independent Living.

In this context the term 'disabled people' refers to all people with an impairment, whatever their age, and their families.

The principles of Independent Living

The phrase Independent Living first entered the English language during the 1970’s following its adoption by disabled activists in the United States. Since then it has become an established term in the United Kingdom, across Europe, and in many other parts of the world. There is general agreement that the philosophy of Independent Living is founded on four principles:

◆ That all human life, regardless of the nature, complexity and/or severity of impairment is of equal worth.
◆ That anyone, whatever the nature, complexity and/or severity of their impairment, has the capacity to make choices and should be enabled to make those choices.
◆ That people who are disabled by societal responses to any form of accredited impairment – physical, sensory or cognitive – have the right to exercise control over their lives.
◆ That people with perceived impairments and labelled ‘disabled’ have the right to participate fully in all areas – economic, political and cultural – of mainstream community living on a par with non-disabled peers.

From these principles it follows that, in promoting Independent Living, we are promoting the right of all disabled people to exercise choice and control over how their support and assistance needs are met – not only in health and social care but in all aspects of life.

Self-Directed Support

The route to achieving Independent Living is through Self-Directed Support.

In a rapidly changing social policy field it is inevitable that particular terms will be used in different ways. This inconsistency in use can lead to confusion and misunderstanding. Language is constantly evolving and to some extent reflects the motives of those using the term. For example, disabled people are more likely to use the term ‘personal assistant’ to refer to someone giving support because they reject the concept of care, which to them suggests a passive relationship of disabled people to their support. On the other hand, a family member may prefer the term ‘carer’ because they believe caring is the natural function of family members. Because of the potential for confusion, it is essential to clarify use of the term ‘Self-Directed Support’.

‘Self-Directed Support’ is used here to denote any situation where support needs are being met through a system that allows the individual to have choice and control over how that support is met. The term ‘personalisation’ is also sometimes used to describe such situations – particularly by Government. However, the term ‘personalisation’ is not used here because of its common use in the so-called consumerist agenda, in which the standards of public service are increased through consumer choice. Self-Directed Support is about disabled people exercising their rights to determine their own lives with the clear goal of achieving Independent Living.

Self-Directed Support began, after a sustained campaign by disabled people, with the passing of the Community Care (Direct Payments) Act 1996. For the first time local authorities were granted the legal power to give a cash payment to disabled people with a physical or sensory impairment under the age of 65 in lieu of commissioned services. Since that time direct payments have been rolled out to all groups. They have made possible an improved quality of life because people are able to choose their support. Direct payments have also (arguably) much improved efficiency in the provision of social care, and have ensured that disabled people have a relationship with personal assistants that is rooted in dignity and respect.

Direct payments have created some problems; not because there is anything fundamentally wrong with the concept, but because of the way they have been implemented. Commissioning has continued to operate relatively unchanged with the result that local authorities still rely to a large extent on block contracts for service provision. Also, those people considered by the authority to be incapable of managing a direct payment have not been offered an alternative
that would bring similar benefits. Finally, monitoring processes developed by local authorities have been onerous. All these factors have created barriers to the beneficial implementation of direct payments.

Partly to overcome these barriers in Control has developed a system of Self-Directed Support. This system involves setting individual budgets so that people know up front what funding they are entitled to for support. It also reduces restrictions on what the money can be spent on so that people can plan the creative use of their budget, meet their support needs in a way that makes sense to them and exercise their rights as citizens.

In 2006 the Department of Health (DH) began a project to pilot individual budgets in 13 local authority areas. In these pilots there are many similarities with in Control's system but also one significant difference – individual budgets in the DH pilot areas are attempting to integrate a number of funding streams alongside social care.

These systems of support – direct payments, in Control's system of Self-Directed Support and the DH's individual budgets pilot programme – stem from the same philosophical base. People should be able to enjoy Independent Living and this can only be achieved by having choice and control over how support needs are met.

Integration

If the systems of Self-Directed Support outlined above all have the same intended outcomes, it follows that these systems are not opposed to one another.

In fact, it is possible to have a ‘mix and match’ situation where, for example, part of an individual budget can be received as a direct payment. It therefore makes sense for local authorities to be integrating direct payments with individual budgets.

Support

To get the most benefit from Self-Directed Support disabled people and families need support in exploring ideas of how support needs can be met, how to put together a support plan, and how to manage support (including support with employing personal assistance if that is the chosen route).

Experience of direct payments indicates that such support is more likely to be successful if it is provided by organisations controlled by disabled people or people who use social care services. This is because these organisations are able to offer peer support – support provided by people who may have had similar experiences and have practical ideas about what does and does not work.

People who receive direct payments and individual budgets should have a portion of their payment that can be used to buy help with planning and managing support. They should be freed to choose where they get this help. This arrangement will have implications for providers of direct payment support services working under contract to local authorities – not least that these providers will need to move to marketing their services to individuals who can shop around for support.
Some interim arrangements may be needed in order to help these organisations make the transition. In particular, work needs to be done with user-led organisations to ensure they are able to get their message across about the support they offer. Despite the difficulties of change, the logic of Self-Directed Support determines that people should be able to choose who provides their support.

**Agreed Actions**

- NCIL will promote more widely the value of in Control and individual budgets as a means to achieving Independent Living
- NCIL will work with its member organisations to ensure they are informed about individual budgets and can offer support and advice
- in Control will promote more widely the goal of Independent Living through Self-Directed Support
- in Control will promote the value of user-led organisations in providing support for Self-Directed Support
- NCIL/in Control will work with the Association of Directors of Social Services (ADASS) to revise NCIL’s existing protocol with ADASS to cover all areas of Self-Directed Support
- NCIL/in Control will meet regularly to share ideas, good practice, and to plan joint approaches to public bodies and Government.

**November 2007**