A report on in Control's Third Phase

Evaluation and learning 2008-2009

in Control®

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Evaluation and learning 2008-2009

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Foreword

Since 2003, In Control with its friends and allies has been highly influential in helping people in England to define what they want from their public services. This is the third in a series of reports charting the changes that have resulted.

The two earlier reports focused largely on the work done to transform social care for adults. This latest report reflects the way that leading thinking and practice have moved on in the last couple of years to encompass many other aspects of a citizen's life, from before their birth to the time of their death. In particular, the work described here seeks to reflect our universal need to make real connection with those around us in our own community. In making that connection, we each try to register our personal contribution to community life – socially, economically and in other ways.

This does not mean that In Control's work on adult social care services – the development of Self-Directed Support and Personal Budgets – is behind us. One of the issues that we continue to encounter every day is the prevailing organisational requirement that, in order to gain access to public support, customers are divided up on the basis of their age, health, and a host of other things. Our recent experience shows us that we can effectively reform social care only if we put these divisions and labels aside and take our thinking and practice deeper and wider – well beyond

the territory of the traditional social services department. People, in other words, are people. They are much more than clients of a particular local authority department. The thinking and learning in adult social care continues and now influences the approach we take to the challenges we face in other areas.

What this has meant for us in Lancashire is that we have had to go back to basics in many respects. We have had to form and develop new relationships and conversations, not only with our own citizens but also across our communities and with colleagues in all sectors. Invariably, the people we meet and talk to bring their own ideas and expectations about how we should shape our offer in the future, and no one could say that the path is easy. The prize, however, is significant: it is that of a life worth living for all citizens – regardless of age, disability or health status. This prize is something that an increasing number of people have now glimpsed. The work described in this report and the social movement which is growing around it are beginning to form a tide which will not be turned back.

The journey we are on is exciting and not without risk. But, together, we are setting out the template and model for the future shape and offer for all public services.

Richard Jones

Executive Director of Adult and Community Services
Lancashire County Council

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Thanks

In Control gratefully acknowledges the help that we have received from many people and organisations in compiling this report. Some are named in the text. But many others have contributed – too many to name individually.

We are on a journey together. This report is part of the shared record of that journey.

Introduction

Real-life stories

The Introduction to this report starts and ends with stories about how people are using their Personal Budgets.

People and families are pioneers in the development of personalisation. Because they know their situations so intimately, they can often create innovative solutions that professionals may not be able to imagine.

So, stories feature throughout this report and give some sense of the creativity that is available and can be released by Self-Directed Support.

Lewis

Lewis and his family live in Newcastle. He was 16 last year when he and his parents got involved in Newcastle Children's Services pilot project on Self-Directed Support.

Lewis has a Support Plan that makes sense for him and his family. It covers all the day-to-day support that he needs. Creating a support plan encouraged Lewis and his family to talk about their hopes and aspirations for the future. One of Lewis's big plans was a trip to the Nou Camp stadium to see Barcelona play football.

Shirley, Lewis's mother takes up the story:

When we first heard about it, we thought the In Control scheme sounded great. But I must admit I did have my reservations about whether it would work out to be as good as it sounded.

However, I signed up for our son's Individual Budget and we set about creating a plan to suit him.

As part of his plan, we decided on a trip to Barcelona. Lewis is an avid football fan and Barcelona is his favourite European team. The match we went to see was a derby match against Espanol. The day after the match, we did the tour of the Nou Camp and museum, giving Lewis many more happy memories! All weekend, Lewis smiled like a Cheshire cat – a memory that will stay with us for a very long time.

The icing on the cake for him was at Barcelona Airport on our way home. The Barcelona team followed us through security! We managed to get a few photos with the players – including Thierry Henry. It was a fantastic ending to a fantastic weekend!

It was at this point that we fully realised that having control and an Individual Budget is far more beneficial to Lewis. He has the choice and freedom to do things in his life that mean a lot to him. Our only regret is the fact we didn't decide earlier to go for an Individual Budget.

This story illustrates many of the good things about what has come to be known as Self-Directed Support. It reveals how, at its best, Self-Directed Support involves people doing things that reflect their personal passions in life. It shows how important families often are in the process and that Self-Directed Support works for young people as well as for those of working age.

END

Sally

Sally is a woman who has Multiple Sclerosis. She is no longer able to speak.

Sally has a team of Personal Assistants (PAs) to support her at home. She was unexpectedly admitted to hospital and wanted her PAs to help her with communication and personal care while she was there. The Primary Care Trust (PCT) could not allow the PAs to help with personal care because they would not be insured to use the hospital equipment. Sally was not allowed to bring in her own equipment. Also, the hospital did not have room for the PAs to stay during the night.

However, Sally was able to make use of a Personal Health Budget, a means of funding health care using the principles of Self-Directed Support. Having a Personal Health Budget meant that Sally was helped to write a Support Plan outlining the support she needed each day. The PCT staff then worked with the PAs before Sally was admitted. They carried out an assessment of the PAs' use of equipment to ensure all safeguarding issues were satisfied.

This means that, when Sally is admitted to hospital in the future, her PAs will be able to help her with her personal care and free up the nurses to care for other patients. Sally also plans a rota system for her PAs in the event of a hospital admission. This arrangement will get around the accommodation problem.

This story shows that Self-Directed Support can help to meet people's health and social care needs. When Sally goes into hospital, she can be cared for in a way that she is used to, with the support of people she knows and trusts. This is a very important development.

END

Graeme: life before and after Individual Budgets

Before

My name is Graeme Ellis. I am now 52 years old. I have had physical and visual problems since the 1980's. In 2003, I started to suffer from depression triggered by bullying and discrimination. Eventually I suffered from Post Traumatic Stress Disorder. Apart from my GP, no one wanted to know about this.

I became isolated in my home and lost most of my social contacts. Social Services said they did not have a remit to help me get out of the house, so I got more and more isolated. I just wanted to give in and do as I was told. I love travelling and was finding it more and more difficult as my care plan was not flexible enough to get care away from home. My self-esteem was becoming lower and lower and I was starting to feel worthless. I was in a tug of war between Social Services and Health regarding my physical health. I was at rock bottom and wondering what was the point of trying when all I got were knock-backs.

I spoke with someone I knew in Lancashire Social Services about how I felt and said that I was considering complaining. I was advised to consider a Personal Budget as a more progressive way of managing my care needs.

As I researched Self Directed Support (SDS), I became disheartened as every thing I found on the topic was about learning difficulties service users. Eventually, I made contact with Kate Burgess at the project office dealing with SDS in Lancashire Social Services. She told me that they had now moved on to work with people with physical disabilities, and she agreed I should go through the process. Talking to Kate, it became apparent that things that were making me more and more housebound could be tackled using a Personal Budget.

I had to wait to have a social worker assigned to me but, when that happened, Kate arranged to visit with her. At the assessment, we looked at my care needs then filled in a Self-Rated Questionnaire. Kate encouraged me to talk about what was important to me. My need to get out and about came across very strongly, as did my lust for travel. Also, my need to be productive and to work was a strong point. The need for equipment to handle my visual impairment in areas such as dealing with correspondence was identified. After some coming and going, a budget was finally agreed that was more money than my Direct Payment.

After

I drew up my Support Plan and set out how I was going to live my life, and also change it. This was approved and I started to put things in place.

I manage every aspect of my budget, including the payroll and employment of my own staff. Instead of having someone sleeping over to help me at night, I pay someone to be available. I call them when I need to. This makes me feel more in control and able to live my life to its fullest. I can bank hours when I feel I can do more for myself, and use the hours when I need extra care – without fear of the social worker saying *if you can mange without sometimes, you can do it all the time*.

I was studying law at the Open University and my budget now covers the assistance I need to travel away from home and receive support when I'm away. For instance, the Disabled Students Allowance covers educational support when I go to tutorials.

I now have a life again and have a sense of my own worth as I actively give back to the community through voluntary work and through my own social enterprise. My

social enterprise provides assistance to those that cannot easily manage a budget themselves, so everyone can enjoy the benefits. I work with people across Lancashire and Cumbria. I am now getting to a position where I can give employment to other disabled people. My personal well-being has rocketed and I am playing a meaningful role in society.

I am travelling again because I can treat people from my budget to come with me on short shopping or theatre trips. I can take my carer with me if I want a holiday. I have been to Brussels twice, Berlin, Warsaw, Munich, Vienna and Budapest, all by train. My carer came with me and, in 2009, his accommodation costs and travel were subsidised from the budget, instead of me struggling to find the money and taking a loan out, as I did in 2008.

Innovation has played a big part in the process. I am registered blind (though I still have residual vision) and am a wheelchair user with physical problems. I was able to purchase IT equipment from my budget, which enables the computer to read my mail to me and take notes at meetings. There was money in the budget for a carer to have a gym membership in return for taking me four times a week but that fell through due to accessibility problems. Following advice, I got permission to buy a Wii for a friend who brings it along, sets it up and helps me do passive exercise using Wii Fit and Wii Sports. The outcome of that has been the frozen shoulder I was developing has corrected itself, preventing me from becoming more dependent.

My laptop has a webcam and I can now use that so a carer can help me manage my blood sugars and insulin doses remotely. At one time, I could not access health care at my local hospital. My budget allows me to pay for support to do this now.

Through In Control I have been given the opportunity to tell my story around the country at different events and, hopefully, by doing this I have inspired others. This has also contributed to restoring my self-esteem. I am not the person I used to be. I like to think that I have become a better person.

As for Personal Budgets, I would advise anyone to go for it and change their life. Ask for help if you feel you cannot manage but do not let the opportunity pass you by. I am now a person again. I can hold my head up high. I am now giving back and helping others.

This story suggests many of the important themes in this report, but it illustrates in particular the importance most of us place on our ability to contribute to our community. In Graeme's case, this contribution is made through volunteering and paid work using his social enterprise. The importance of community and of contribution receives further consideration in Chapter Four.

END

Introduction

This report is about the third phase of In Control's work, 2008-2009. The four chapters of Part One each reflect on different aspects of our learning over this period. Part Two – Evaluation – offers more detailed information and analysis about the impact of the changes.

In the report on the first phase of In Control's work, 2003-2005, we described a seven-step model, a **new operating system** for adult social care services – Self-Directed Support.

That report described what it meant in practice for local authorities to work in this new way. It gave examples of how people were beginning to make use of the new system to get choice and control. We summarised Professor Chris Hatton's research findings that drew on interviews with 31 people in six pilot local authorities. All the people involved at that time used learning disability services. Many were younger people, often in their late teens or early twenties, living with their families.

The 31 people (and their families) were all asked to report on changes in their lives since beginning to make use of the new system. Simon Duffy's **six keys to citizenship**: self-determination, direction, money, home, support and community life were used as a way of organising and interpreting these findings. The outcomes were very positive. However, both the sample and the total population of people using the system at that stage were very small.

In the report on the second phase of In Control's work, 2005-2007, Chris Hatton and John Waters provided more substantial evidence that people were experiencing positive change when they directed their own support. This report was based on larger numbers of people who had more diverse needs.

196 people in seventeen local authorities were interviewed. They came from a wide range of social care groups (though people with learning disabilities still formed the largest number at that time).

They were asked about how things had changed for them since the introduction of Self-Directed Support in key areas of their life:

- their general health and well-being
- spending time with people they liked
- their general quality of life
- taking part in and contributing to the community

- choice and control
- feeling safe and secure at home
- personal dignity
- economic well-being.

The outcomes were, once again, very positive. The report concluded that:

> *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.*

The second part of this report included reflections on the learning from this phase of the work.

Several of the themes selected for attention highlighted a shift towards a broadened scope, beyond people with learning disabilities and their needs for social care:

- Children young people and families: a chapter drew on early evidence from the *Dynamite project* and *Taking Control*. It suggested not only that this approach was welcomed by many young people and their families but that there was also an opportunity to channel families' energies in a positive direction, instead of into fighting the system.
- Health services: there are many aspects of health care that overlap with social care and many people find the distinction confusing. The report reflected that many lessons learned in local authorities seem readily transferable to the health sector.
- Communities: citizenship and a real life in the community are the goal; Self-Directed Support is the means to get there. Between 2005 and 2007, a number of local authorities began testing *Small Sparks* schemes, *Local Area Co-ordination* and alliances with mainstream community organisations.

We pick up these themes in this report.

Beyond social care

The final chapter of the second phase report – by David Towell and John O'Brien – was particularly significant. It tried to look more deeply and further ahead, to define what is needed next to achieve what they refer to as a *quantum leap in the momentum for change*. They concluded that, as momentum for real change builds and is set alongside (and sometimes compromised by) the pressure to demonstrate results, the need grows to root the work more strongly in a social movement that is defined and led by citizens themselves.

The changing picture, which In Control has been painting since 2003 has to be seen against some very significant changes in the UK economy, society, and in the public understanding of these issues. This is not the place for a full review of these changes, but suffice it to say that the consensus view of UK social policy-makers has, in the last few years, moved away from an approach in which social and economic progress is seen as steady and sustainable – based largely on tried and tested management practice and

rational models of commissioning and procurement – to one that is more concerned with issues of sustainability and environmental impact and the problems associated with bureaucracy and over-regulation.

The new thinking favours approaches that recognise these issues and value innovation, creativity and more genuine and thoroughgoing partnership between citizens, their communities, publicly funded organisations and private businesses. It is a perspective that sees economic security and sustainability as achievable through active use of the **social capital** that individuals and groups bring with them. This changed thinking has been made more urgent by the recent economic downturn. But, fundamentally, it is the result of a deeper shift in perspective, a growing realisation that the post-war welfare consensus was simply unable to deliver the safe, sustainable high-quality public services at low costs that consumers now demand. The rhetoric out-ran the reality, and things had to change.

This adjustment has been marked by a number of important policy documents since 2007:

- *Putting People First*, a shared vision and commitment across government departments to transform adult social care. This document and the guidance that followed set out a strong cross-government commitment to *personalisation* in adult social care, and made it clear that this would only be achieved through an approach that encompassed *universal services*, *social capital* and *prevention*.
- *Strong and Prosperous Communities*, a White Paper from the Department of Communities and Local Government which proposed a change in the relationship between central and local government and ordinary citizens. There are a number of specific actions set out in the paper. Taken together, these actions signal a significant change in public policy. They focus on the assets that members of a community bring rather than on their difficulties. This is very much the approach that In Control has advocated since 2003.
- *High Quality Care for All: Personal Health Budgets, First Steps*. Lord Darzi announced in this paper that the Department of Health would launch a pilot of Personal Health Budgets in 2009 as a way of giving people greater control over the services they use and who provides them. The document sets out the principles that would underpin Personal Health Budgets. It also reported on early lessons and invited expressions of interest in the pilot programme.
- *The Children's Plan* from the Department of Children, Schools and Families included a commitment to use the model of Personal Budgets and Self-Directed Support for children and families and suggested that the use of the model would bring a better life for many.
- *Shaping the Future of Care Together*, the 2009 Green Paper crystallised many of the ideas set out in the above papers. It applies to adult social care and proposes a new national care service. The government then launched the *Big Care Debate*, an exercise that focused particularly on the funding of services for older people in the coming decades.

These Government documents were complemented by a series of important discussion papers and other contributions to the debate.

They included:

- *Making It Personal*, a highly influential Demos paper, which set out the economic and policy basis for personalised services and which tried to define the potential and the limits of the approach across sectors.
- *Citizenship in Health*. This In Control paper provided an overview of the work of In Control Members during the first phase of *Staying In Control*, our work with Health Services. It set out key issues and ideas around Self-Directed Support in the NHS.
- *Co-production, A Manifesto for Growing the New Economy*, a paper from the New Economics Foundation which extended some of the most imaginative and fruitful ideas and practices from the world of community development, and showed how these link with the values and practices of Self-Directed Support.

This last paper encapsulates the culture shift implied by the term **co-production**, an approach to thinking about society and community and the ways we work together for mutual support.

Community and co-production

This New Economics Foundation paper is critical of the old model of progress through the work of large organisations – those which are both bureaucratic and distant from ordinary people. The paper discusses how these organisations hold public resources and make decisions about their use in a way that is difficult for ordinary people to understand and which often seems perverse. The paper suggests that we should start instead from the premise that society should provide everyone – without exception – with the opportunity for personal growth and development so that citizens are positive contributors, rather than burdens on an overstretched system; we should invest in strategies that develop the capacity and emotional intelligence of people and their communities to make this possible; and we should use peers and citizens – not just professionals – to provide support and share learning about what works.

So, society and the way we think about social progress are both undergoing a process of significant change at the start of the 21st century.

In Control has tried both to reflect and to influence these changes. More than this, In Control has sought to capture and channel the energy and the excitement that is now building around these ideas. This is the energy of the social movement which John O'Brien and David Towell describe. It is energy stimulated by the vision of a better tomorrow, and as such it leads to projects that may sometimes appear wildly idealistic.

This idealism is a very different brand from much of that of the past. It has its roots in the lived experience of ordinary people – frequently, disabled people and those who support them – who we see joining together, planning their futures and entering into partnerships with professionals to bring their plans to fruition. These are plans which go with the grain of people's lives; they make the presumption that, without exception, everyone has a contribution to make to society and community, and that everyone has valid hopes, dreams and preferences – as well as dislikes and anxieties – that publicly funded agencies must recognise.

This perspective is, of course, quite different from that of the welfare state as we have come to know it: not because the approach of the old welfare state was wrong or unhelpful in the latter part of the twentieth century. Rather, it is that our world, our economy, our society, the technical resources now available and the challenges we face demand something different.

These changes, challenges and threats loom ever larger. They include the demographic and fiscal concerns (we are an ageing population, and tax revenues and resources available for public spending will decline) that prompted *Shaping the Future of Care Together*, the 2009 Green Paper for social care. The national debate (known as the *Big Care Debate*) which followed the publication of this important document was, in many ways, admirable. It engaged with thousands of older and disabled people, as well as with local politicians, professionals and managers. But there was a problem: in homing in on a small number of funding options and asking people what they thought about these, the debate missed an opportunity to gain from the experience of people whose lives have been touched by the deep changes we are describing here.

Social movement

We are focusing here on a movement with strong historical roots. These roots include the **Independent Living Movement** of people with physical and sensory impairments, which fought for and won the landmark Direct Payments legislation of the 1990s. The roots are also found in the **Inclusion Movement** of people with learning difficulties and their allies, which helped to crystallise ideas about **self-advocacy** and **person-centredness** around the same time. They are also in the **survivors' movement** of people with mental health difficulties, and in the diverse groupings of older people and pensioners dedicated to promoting our rights in later life.

More recently, these strands have been complemented by a new alliance of disabled people, professionals and, particularly, family members (or *carers*), keen to work together to learn about how to influence and improve local systems. The intent is always, first and foremost, a better outcome for the individual or family; but, critically, this alliance is both focused and also broad in its outlook: it seeks to foster improved outcomes for the whole local community. This alliance has come together under the banner of *Partners in Policymaking*, a network and programme of learning, inspired by a model developed in the United States in the 1990s and led in the UK by Lynne Elwell and her colleagues and friends. If anything merits the designation *social movement* it is this inspiring collective of energetic and mutually supportive individuals, whose membership crosses so many of the boundaries and battle-lines that have divided social and health care in recent decades. (There is more about the *Partners* movement in Chapter Four.)

So, how do these developments intersect with the work of In Control, and with that of the local authorities and service providers that we seek to represent?

Partnership and technical solutions

Firstly, from In Control's early days seven years ago, it has been clear that In Control is a people's partnership, one which gains its strength and legitimacy through bringing people together in ways that are based on an appreciation of our common humanity

and the desire for a better life for all. This is the same impetus that inspires *Partners in Policymaking* and many Centres for Independent Living and self-advocacy groups.

Secondly, In Control's success to date has largely derived from its understanding of the importance of seeking technical solutions to problems of accountability, governance, finance and practical partnership that our welfare systems have thrown up. This means that In Control and its partners have spent a good deal of energy developing and testing the new systems for resource allocation, supported self-assessment, brokerage, support planning, risk enablement, review and all the other technical scaffolding that local authorities and their partners now have in place to make Personal Budgets a reality. We discuss the development of these systems in more detail in Chapter Two.

In the period covered by this report (2008-2009), much of this technical progress was pioneered by a self-selected group of *Total Transformation* local authorities. In these authorities, elected members and senior mangers took the brave step of making a particularly strong commitment to Self-Directed Support. This group of twenty authorities (listed in Chapter Three) made significant progress over this two-year period, both in terms of the numbers of their citizens in receipt of a Personal Budget and of their contribution to the creation of new systems and processes. This report could not have been completed without their contribution.

This new **operating system** has been at the heart of the practical change process that has now enabled tens of thousands of people to gain real choice and control over their money, support and lives. While recognising the critical importance of these technical changes, we also need to acknowledge that what many authorities have in place is a set of policies, guidelines and procedures which are helpful but not sacrosanct or complete. The fact that these technical changes are only part of the story is at the centre of this report. This incompleteness provides the challenges for the next phase of In Control's work.

Challenges in the next phase:

- In Control and its allies must move beyond a focus on adult social care to embrace the whole of life. This means thinking about a person's life story, from conception to death. And it means all aspects of life: education, work, friendship, leisure, faith and community. This shift in focus demands that we engage with citizens and families, but also with those institutions and agencies which represent, reflect on and regulate this breadth of activity.
- We must think more about physical and emotional health and engage with those individuals and organisations (governmental and non-governmental) with an interest in health matters. We need to carefully consider how **health** and **social care** intersect, and how ordinary people can best use professional services.
- We must think in more depth about the many facets of community in 21st century Britain and, in particular, about the huge changes in community that we have seen in recent decades. We need to think about ordinary, **universal**, services that everyone uses, and how these can be made more accessible to older and disabled people in particular. And we need to think more about how community can work to strengthen citizenship for all.

These are the strands threaded through this report. They are strands that interweave with the growth of the new social movement we have alluded to: In Control formally became a public-membership organisation in 2009 – open to all who share its values. In Control

already hosts the *Partners in Policymaking* programme and, as the report on the second phase of work made clear, has a valued formal partnership agreement with the National Centre for Independent Living (NCIL), and the movement of disabled people that NCIL represents.

We have learned a great deal in the last seven years about what a local authority needs to do if it is to transform – create the local conditions that will enable choice and control for all. Much of this learning has come through the work of colleagues in adult social care departments; but it has become increasingly clear that the principles and many of the practical lessons apply equally in children's and family services, in NHS Trusts and beyond.

Transformation

In Control's early work suggested that there are four key aspects involved in the early stages of this process. We have described these as the four corner pieces of a transformation jigsaw.

They are: leadership; understanding or legitimacy; resource allocation; supports.

Leadership

Nothing happens without leadership. Leaders require courage to take responsibility and seek support. Leadership cannot be taught but it can be nurtured, encouraged and celebrated.

Leadership involves:

- positive collaboration with peers
- the sharing of ideas and information
- the recognition and valuing of others' positive contributions.

Understanding or legitimacy

Systems cannot change unless there is enough understanding of what is wrong with the current one – and how it might be improved. Communicating the new, shared purpose is vital.

This means:

- developing good, clear written materials that eliminate misunderstandings
- listening to people's accounts of their experiences
- exploring the deeper values and drives that underpin change.

Resource allocation

Resource allocation should enable citizens to know how much money they are entitled to from the public purse and what they must contribute themselves. Self-direction is not possible if people are not given the means to control their lives. Attempting to implement change without being clear about entitlements leaves people as passive recipients.

In practice, this means progress must be made on:

- developing a Resource Allocation System so that people know their Personal Budget
- amending charging and contributions policies so that the system of calculating the contribution does not undermine Self-Directed Support
- integrating other funding where possible – for example, from the Independent Living Fund, Supporting People and Disabled Facilities Grants.

Supports

Self-Directed Support does not mean that people have to organise everything themselves. Supports and supporters need to be available. Most people need help to plan, and to get what they set out in their plan.

This means that local authorities need to work on:

- reform of the care management system
- development of an infrastructure to help people manage their Personal Budgets
- development of tools for support planning
- promotion of more personalised support options.

Work with local authorities over the past two years has underlined the importance of these four elements, and we have been able to fill out the other pieces of the jigsaw, as illustrated in the following diagram.

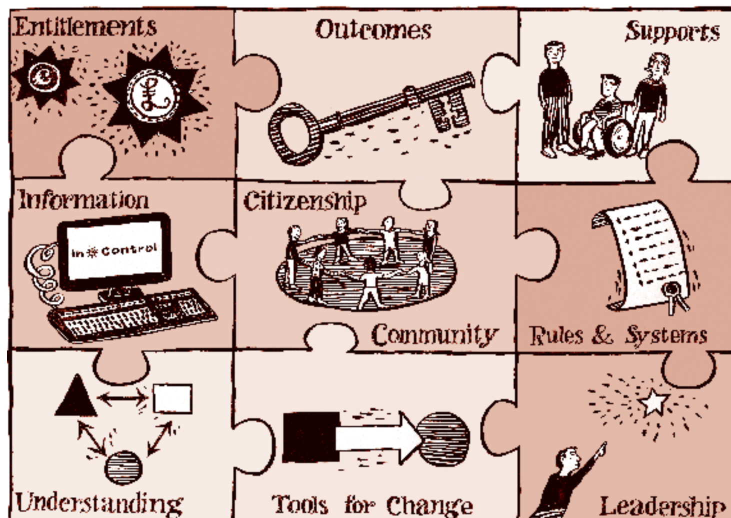


Figure 1: In Control's transformation jigsaw

The In Control website describes the jigsaw in detail and provides examples that illustrate its practical application.

What we have also learned over the past two years is that a change in mindset is more important than the technical steps needed. Self-Directed Support will work if local leaders believe in it and are prepared to give up power, and if managers and staff are empowered to find creative solutions to the challenges they face. It is evident that Self-Directed Support will not work if it is seen as a set of mechanical changes about money or as a pre-defined menu from which people can buy services.

A path to total transformation

In Control has also become more and more conscious of the size, scope and complexity of local authorities and their need for careful planning and structure in the process of transformation. With this in mind, and drawing on many project plans and project initiation documents, In Control has produced its own *Critical Path to Total Transformation* **which sets out twenty elements in four broadly sequential phases. This is a deliberately simple document: although we recognise the complexity involved, we are still convinced that the promotion of truly personalised support requires systems that are more straightforward and less bureaucratic. We can develop these if we keep in mind a clear and manageable route-map. Some of the elements of this critical path do, of course, need their own plans with supporting documentation, staff development, political decisions and so forth, but others are best viewed as relatively simple changes based on an underlying commitment to put the citizen at the centre of all activity.**

In Control 's Critical Path to Total Transformation

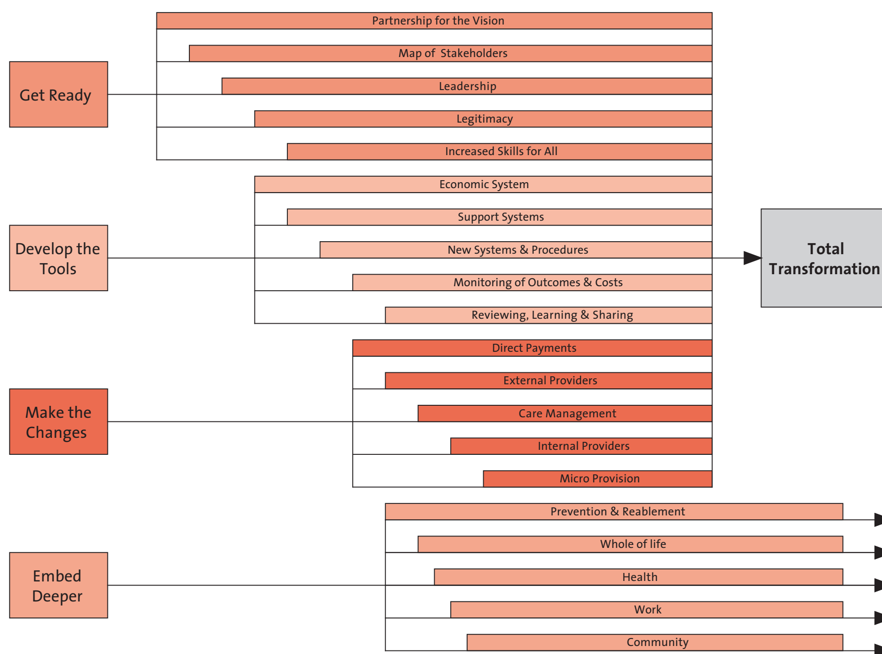


Figure 2: In Control's Critical Path to Total Transformation

This illustration also provides the broad structure for the remainder of this report. It is inspired by learning in and draws examples from local authorities across England. In particular, it is animated by the experience in *Total Transformation* authorities and especially in Hartlepool, which has taken this approach further than most other authorities.

The major phases of the process, which are reflected in the chapters of this report are:

1. Getting ready for Self-Directed Support
2. Developing the tools
3. Making the changes
4. Embedding deeper.

It is this last phase – Embedding Deeper – where we look ahead and where much of the new learning is to be found. Chapter Four deals with this phase and we describe our emerging experience with whole life, health and community.

As will be clear now, Self-Directed Support is only partly about local authority systems and processes: these are the levers we had available to develop and promote this approach in its early days (and local authority colleagues have been among the key leaders of the change process). Ultimately, though, the processes we are describing will be led by individuals with their families, allies and communities as they assert their right to control.

Partners in Policymaking

Partners in Policymaking **is a leadership development programme for parents and relatives of disabled children, along with disabled adults. The course first ran in 1996 in the north west of England and is now held in authorities across most regions.** *Partners* **comprises eight two-day sessions held once a month over eight months.** *Partners* **is now one in a cluster of local, regional and national programmes that welcome disabled people and their supporters, as well as professionals and family members. We return to the work of** *Partners in Policymaking* **in Chapter Four of this report.**

Partners champion and national co-ordinator, Lynne Elwell, says that *Partners* graduates come from many backgrounds but share a common experience:

> *The course brings together people who may up till this point have felt quite isolated – and often very angry. Through the course, people are helped to understand the reasons why systems have come to work in the way they do, and are encouraged to find more productive ways of channelling their energy.* Partners *gives people the tools and strategies to work in partnership and bring about change. The changes you see in people are quite remarkable.*

Equally remarkable is how *Partners* Graduates have gone on to influence policy and practice. We conclude this introductory chapter with two of many inspirational stories and personal testimonies. Others follow later in the report.

Strength in numbers

Lucy from Tyne and Wear attended a *Partners* course in 2006. She has a daughter who was diagnosed as being on the autistic spectrum when she was three and a half. Lucy had previously been to support groups for parents of autistic children but found there was a lot of anger – people were frustrated and didn't know where to start. She says *I really got stuck. I wanted to withdraw from that group.*

Through *Partners*, Lucy learned a lot about the history of disability, about personalising services, and success stories about inclusive education. *With Partners I learned about what other people were doing*, she says. She was determined to use this new knowledge to improve the experience of other parents of young children.

She set up a small community group to support parents of children with Attention Deficit Hyperactivity Disorder and autism. The group set out to share examples of the positive experiences of children in mainstream education and learn from each other in order to communicate more effectively with professionals.

The group started with three parents and gradually grew to ten. It became so successful that parents from across the region began to attend. Now Lucy is looking for funding to help the group make the next leap. She envisages the group providing training to volunteers to support children in mainstream education. Local politicians and public servants have already sought the group's advice on policy related to mainstream education.

Lucy has learned that speaking as an individual is powerful, but it is more powerful if you represent the collective interests of a community group.

END

Margaret: there is a way forward

Margaret Upham from Cornwall describes her experience of *Partners*.

It is three years since I first learned of Partners in Policymaking, when Lynne Elwell was speaking at a carers' meeting in Cornwall. Like many others attending this event, I felt negative, disillusioned by all that had taken place in our County. I was anxious and fearful of the proposed changes to services and the impact they might have on the lives of people with learning disabilities – especially my own daughter, Zoe. By the end of that meeting, however, I felt positive. I had been introduced to Partners!

With Lynne I arranged a Sharing Knowledge course in Cornwall in 2007 and began to connect with people with effective skills, knowledge and experience. Carers and self-advocates became empowered and started working closely and effectively with the Local Authority.

In 2008, I attended the National Partners Course. It was a great privilege, an amazing learning experience and gave lasting empowerment. It developed belief, confidence, leadership skills, and immeasurable and invaluable mutual support that only come from true understanding, trust and the recognition of those values.

Since the course ended, John O'Brien has visited Cornwall and helped us think how we can engage with the community. At two conferences, staff, carers, providers and elected members have been enlightened by the presentations and support of speakers I met on National Partners. At present, Cornwall is exploring the concept of starting Natural Breaks with the help of the Merseyside group. All this is a direct result of my attendance of the Partners Course.

My life and my daughter's life are richer because of Partners. *Zoe, employs three Personal Assistants with her Independent Living Fund money and is in hot pursuit of a Personal Budget. Together we can show others what Partners showed me: there is a way forward.*

END

NOTES

1 Poll, C., Duffy, S., Hatton, C., Sanderson, H., Routledge, M. (2006) *A report on In Control's First Phase, 2003-2005*, In Control, London.

2 See: Duffy, S. (2006) *Keys to Citizenship, A Guide to Getting Good Support for People with Learning Disabilites*, Paradigm, Birkenhead.

3 Hatton, C., Waters, J., Duffy, S., Senker, J., Crosby, N., Poll, C., Tyson, A., O'Brien, J., and Towell, D. (2008) *A Report of In Control's Second Phase, Evaluation and Learning 2005-2007*, In Control, London.

4 Department of Health (2007) *Putting people first: a shared vision and commitment to the transformation of adult social care*, London

5 Department of Communities and Local Government (2006) S*trong and Prosperous Communities - The Local Government White Paper*. London.

6 Department of Health (2008) *High quality care for all: NHS Next Stage Review final report*, London.

7 Department for Children, Families and Schools (2007) *The Children's Plan, Building Brighter Futures*, London.

8 Department of Health (2009) *Shaping the Future of Care Together*, London.

9 Leadbeater, C., Bartlett, J., and Gallagher, J. (2008) *Making it Personal*, Demos, London.

10 Brewis, R., And Duffy, S. (2009) *Citizenship in Health* at www.in-control.org.uk

11 New Economics Foundation (2009) *The Challenge of Co-production, How Equal Partnerships Between Professionals and the Public are crucial to Improving Public Services*, New Economics Foundation, London

12 What we mean by developing capacity and emotional intelligence in this way will be made clearer later in the report when we discuss community, Partners in Policymaking and public membership.

13 About 30,000 people had a Personal Budget at the end of 2009.

Chapter 1

Getting ready for Self-Directed Support

Getting ready for Self-Directed Support

Over the past two years, it has become more and more evident that good preparation is a key to success in making the switch to truly personalised support services.

Two stories from Hartlepool illustrate the importance of preparation. Hartlepool is one of the local authorities that participated in In Control's *Total Transformation* programme in adult social care. (There is more on this programme in Chapter Three.) Many of the examples in the early part of this report are drawn from Hartlepool and the other *Total Transformation* authorities. This chapter makes use of the experience of these pioneering local authorities to describe what is needed to prepare the ground for Self-Directed Support.

E

E is a 20-year-old woman who has significant learning disabilities. She lives in Hartlepool in her parents' home. E's mother says that, through the personalisation process, E has been able to access innovative short breaks of her choice instead of traditional respite care services. These breaks have included trips to Newcastle, Whitby, Cadbury World and Chessington World. The Personal Assistants (PAs) have supported E for some time now. E's mother thinks that the PAs have enabled E to have friends, are people E can trust and they have confidence in her. E's PAs are of a similar age to E and are able to engage with her about the latest fashions and music. This has led E to move on to exploring and experiencing the usual beauty therapies that teenagers are fond of. E herself has said that she likes to go away without her mum and dad. She likes to go to the theatre and see shows.

E's Personal Budget has enabled her to get the support and confidence to experience a quality of life that every teenager would like. E's mum says that E *now has the opportunity to lead a normal life.* No-one tells her what to do and where to go.

END

Including Eleanor

Eleanor is a child who has high level support needs. Last September, she transferred from primary to secondary school. A review of Eleanor's support was held in January in order to make the transition as smooth as possible.

Before the meeting, Eleanor's parents and two friends of the family drew their hopes and suggestions for the transition as a large picture diagram. They took this picture to the meeting and stuck it on the wall.

At the meeting were Eleanor's Mum and Dad, her Personal Assistant, and two family friends. Also in attendance were Eleanor's current teacher, her educational psychologist, her speech and language therapist, two local authority officers, her social worker and the Assistant Head Teacher from Eleanor's new mainstream school.

Eleanor's mother went through the plan on the wall and after discussion it was agreed that:

- Eleanor would have a core curriculum of music, art and sport every day with the other pupils
- each day there would be some time for reflection, therapy, reinforcement and individual learning
- other options such as design technology, food technology, citizenship would be explored
- there would be a team of four named teachers working with Eleanor
- the Local Education Authority (LEA) would employ two learning support assistants who would work in school and help Eleanor to attend two after-school activities a week (1.5 full-time equivalents). Eleanor's parents would be part of the interview panel
- the LEA would provide some input from Educational Psychology to help set up a circle of friends within Eleanor's tutor group
- the school would allocate staff development time for Eleanor's parents to talk to the school about her gifts, interests and ambitions
- Eleanor would be invited to join the *Jonah* programme with other children who are not from the school's catchment area to help introduce her to the school
- Eleanor would have her own timetable. Each period would include learning goals set by the teacher. From these, Eleanor's progress would be measured.

Eleanor's mum, Liz, sent us this update on how things have been going since then:

Eleanor started at St Hild's school in September 2006. The plan was given to the school and they found it useful for their timetable planning. From Easter, Sarah Norman, a teacher from St Hild's visited Eleanor's primary school each week. This helped Sarah understand how Eleanor learned and how to adapt materials for her use. We were very grateful to Springwell School for allowing this opportunity, as it helped Eleanor make a smooth transition from primary to secondary school.

Mark and Stephen, pupils from St Hild's also visited Eleanor at Springwell and made friends with her. From May, Eleanor began to visit St Hild's every week so she got used to the surroundings and people there.

Her timetable is very much as described. Every day she does one or two classes with her year group – she enjoys drama the best. Every day she has one period that is one to one. Her teaching assistant has learned some physiotherapy exercises, which help Eleanor a lot. Every day she does either literature or numeracy with a smaller group

including Mark and Stephen. Eleanor enjoys school very much and has made lots of friends. Sarah designed a target sheet that is used in every lesson and helps keep track of Eleanor's progress. There is also a home/school book that helps us find out what Eleanor has done at school.

The plan also helped build relationships and trust with the school and Local Authority. So often I hear about situations where things promised in reviews aren't implemented and that must be really frustrating. In Eleanor's case, what was promised was delivered. Eleanor is valued as an individual. At one open evening, the Head Teacher thanked Eleanor for how much she had given the school.

END

These stories illustrate important possibilities: Liz, Eleanor's mum is a graduate of a *Partners in Policymaking* programme. E is one of more than 1,300 adults with their own Personal Budget in the town.

These examples are about people rather than systems. Although much of this report describes In Control's learning from English local authorities which are Members of In Control (and particularly from our in-depth work with Hartlepool Borough Council), the real story is about how ordinary citizens get on with life in their own home and community.

Eleanor's and her family's determination to be included at school demonstrates the sort of commitment and action that sets a new standard. Their action creates foundations for the future – for Eleanor herself, but also for other students, teachers and professionals who meet her and work with her.

Hartlepool began preparing for Self-Directed Support in 2005, when Nicola Bailey was appointed as Director of Adult Social Services. The changes that followed illustrate the importance of putting in place the four corners of the jigsaw we refer to in the Introduction: Leadership, Legitimacy or Understanding, Resource Allocation and Supports.

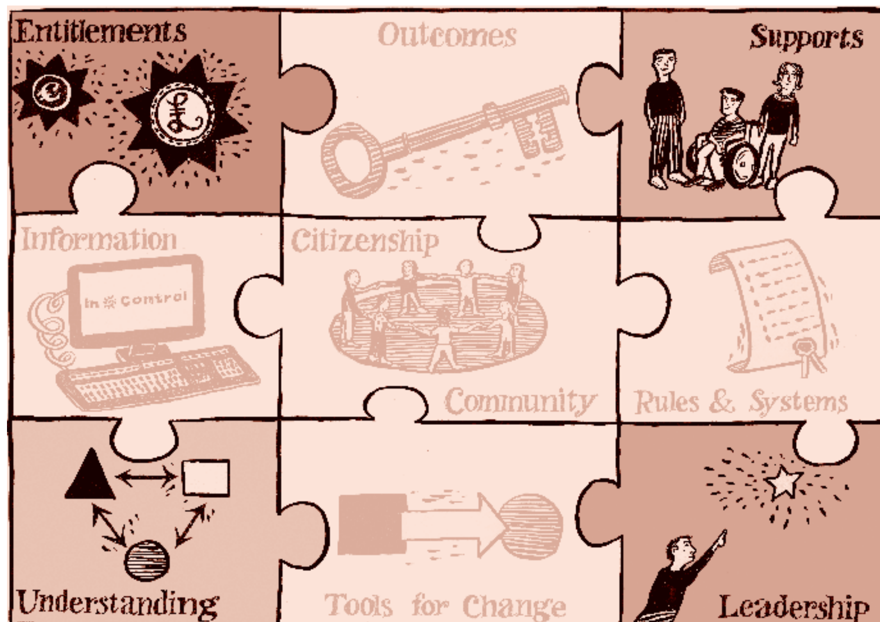


Figure 3: Four corner pieces of In Control's Transformation Jigsaw

Leadership

In Hartlepool in the early 2000s, the Social Services Department was a fairly traditional one, albeit with some highly motivated staff who had pride in their work. Two things are striking about Nicola Bailey's reflections on her early days in the job.

The first is her single-minded conviction of the need – despite the positive attributes of her Department – to change things radically, and to do this for the clear and simple purpose of enabling citizens in Hartlepool to take control of their lives.

The second is the equally clear conviction that this change could only come about through others. There needed to be a rigorous and continuing scrutiny of the job at hand and the skills needed to move forward with that job. Then a process was needed to assess, nurture and deploy the human resources available to do that job.

As Nicola put it:

> *Early on I saw that the staff were great but were very traditional. I spent some time in my early days getting to know people, spotting who were the rising stars, who was able to manoeuvre, and who wasn't. I set up the Direct Payments Steering Group to provide a bit of structure. I addressed their whys and wherefores and gave them a bit of encouragement.*

She described how she managed *up* as well as *down*:

> *I spent a lot of time with the politicians. I went to the Labour Group and showed the In Control DVD,* How to be In Control*. I talked a lot to the Portfolio Holder and the Chief Executive, who was brilliant and never once questioned the need for change. It's about the culture you create, the corporate culture as well as the departmental culture. Departmental culture is about getting things done, corporate culture is an encouraging, hands-off culture.*

Nicola also talks passionately about the need she saw at this stage to widen people's horizons:

> *After a couple of months we joined In Control and then the* Total Transformation *programme. This meant that staff have had the opportunity to grow, and be exposed to lots of other people they wouldn't have met otherwise. Having In Control alongside us helped to re-energise the staff.*

Thinking through and taking the first careful (but not tentative) steps to actually handing over money to people was important:

> *The review team was our first port of call. Everyone due for a review was told what their resource allocation was. Some older people said 'Thanks, but I'll carry on as I am', but were shocked to know how much was spent on them. Others wanted to get on with a support plan. Some people with mental health problems jumped at the chance and some said they were very keen to leave residential care.*

We consider these issues in more depth in Chapter Two.

In describing her part in the process, it is notable how thoughtful and flexible Nicola has needed to be:

> *In the beginning, my role was to be very directive. I told them what was to be done. People hated it. I gave them a hard time if they were not at the meetings. I was the project leader initially. Later, I was more supportive when the going was tough for people. Recently, I've stepped right back to see how others take up the challenge, but now I see the need for a bit more direction again.*

Leadership then requires a highly tuned set of behaviours – more akin to conducting an orchestra than to flying a plane or driving a car. The leader has to look, listen and sense what is going on and stay alert to what is required from them at any moment.

Legitimacy or understanding

The second corner piece of the jigsaw is legitimacy, an understanding that is both deep and widespread, the perspective shared by key decision-makers in the system that personalisation is the right way and that new ways of operating are both permitted and necessary.

This sort of shared vision was not entirely in evidence in Hartlepool in mid-2006 when In Control first became involved. The picture was a mixed one, however, with high levels of understanding and enthusiasm evident in at least some of the important places – particularly among senior staff in adult social care. There were much lower levels of understanding and ownership among staff in the wider Council and among care managers and their seniors.

To unpack this a little more: the broader leadership from the Director and her management team was in place and was very clear about future direction, but they were yet to win over the politicians or most of their less senior colleagues. However, there was a plan. Ewen Weir, the Assistant Director at the time commented:

> *The work planned and in hand with Elected Members is crucial to embedding, sustaining and protecting Self-Directed Support within the culture. The intention is that there is an event in 2007 for Members, and that they are exposed to success stories from Oldham and elsewhere.*

Looking back, Sarah Ward, the Borough's Social Care Transformation Manager reflects on this period: *The work with Elected Members was invaluable. We sent packs to those who didn't attend events. It was all done from a values viewpoint.*

Operational and administrative staff were not merely informed of the changes, they were involved:

> *We wrote the basic process with the help of staff from different disciplines, including admin, social care and others. All were mixed sessions. This gave them a good sense of ownership, the feeling of having contributed to the process. We also did a desktop Resource Allocation. It was much more than a technical exercise. We got a nice venue and, although we had lots of arguments, we came to agree the best way.*

Understanding grows – as it does in every field – through persuasion, discussion and learning about what does and does not work.

Resource allocation

Self-Directed Support will not function without a robust system that can put money in the hands of ordinary citizens in ways that are fair, transparent and efficient. Too often, though, a concentration on getting the Resource Allocation System (RAS) right becomes the dominant feature of the early work – to the extent that councils could become preoccupied with the issue to the exclusion of all others.

The fact that this was not the case in Hartlepool was not entirely the result of financial systems being already attuned to the requirements of Self-Directed Support: in some regards, particularly the capability to capture detail about care packages and the mapping work on unit costs, the systems were fit for purpose; but in several other respects there were real concerns.

In mid-2006, managers were worried that the overriding importance given to *Fair Access to Care Services* criteria would seriously undermine the Supported Self-Assessment process. They also had unanswered questions about how they would accommodate charges for non-residential social care services in someone's Personal Budget.

However, these challenges and anxieties did not appear to be seen as insuperable barriers: in 2006, financial management of the Department was strong, and clearly benefited from integration with strategy and operations. This was perhaps why the resource issues were given due weight without obscuring all else.

Jeanette Willis, the Principal Finance Manager / Transformation Lead, reiterates the importance of getting the fundamentals of the RAS right from the very beginning:

> *Sustainability is assured if you build the RAS well in the first place. The way to do this is to use existing spend and take a good percentage off. Getting the Supported Self-Assessment questions right is important as part of this process. This has to be seen as more than a Personal Budget calculator. It starts by building in the presumption of citizenship and framing the questions on that basis.*

From the earliest stages, the key designers of the system in Hartlepool were thinking about Personal Budget holders as citizens with something to contribute, rather than as passive *clients*. They recognised the importance of the gifts and resources that individuals and families brought with them, and understood the importance of sustaining communities as the bedrock of viable support systems.

Managers in Hartlepool also understood that the only way of testing a system of Personal Budgets was through actual trial (and error), that is to say actually putting the money in the hands of individuals who needed it. This was the only way to produce real learning about what worked. As they allocated real resources to people, they were able to experiment with the underpinning systems and processes and think through the difficult outstanding issues – including the rules and regime for charging for non-residential services.

Jeanette Willis sees the resulting *Hartlepool Contributions Policy* as a major achievement, one which breached a significant barrier:

> *Self-Directed Support meant we clearly needed to change the charging policy. Practicalities dictate that if we assess someone for SDS holistically, then we can't charge them for A and not for B. So, in effect, we introduced means-testing at the front end to ensure people were paying what they could afford to pay and no more. People know what their contribution is going to be before they do their support plan. We levy the contribution at 25% of support plan cost, whatever they end up buying. The key message is that we – the Local Authority and the person – are sharing the costs; hence we call their share a 'contribution' not a charge. If they are not happy with what they have, the person can always use the money for something else. This works!*

Support systems

Self-Directed Support is premised on good support systems that help people to make plans and think through how best to get what is set out in those plans.

In 2006, Hartlepool had done no work to develop support planning, and the work on **brokerage** was limited (*brokerage* is defined here as a system to help people get what is in their plan). The existing Direct Payments scheme was under review. There was an intention to improve and upgrade it to allow for genuine choices about what users of the scheme could spend their money on. There was an active voluntary and community sector with a number of energetic user-led groups. There is little doubt that these were and are helpful conditions: a good Direct Payments scheme is a means of demonstrating that the local authority is attending to the expectations of those disabled people who campaign for independent living. An active community of service users means that there is an opportunity to work with, and not just for, citizens to co-produce systems that address local conditions and the needs of different groups.

In some other authorities, these conditions may not prevail, but there will almost certainly be other helpful factors which can be levers for Self-Directed Support: a strong record of person-centred planning across service areas, for example, or a good understanding of citizen-defined outcomes.

Neither of these features were particularly evident in Hartlepool in 2006. What was important, however, was that these (and other deficits) were recognised, scoped and factored into the programme plan. It was observed at that time that the clarity of vision and broad understanding among key managers of what was needed to make a success of the new system was bound to assist implementation. By the same token, it was also observed that, in doing this mould-breaking work, managers would be confronted by the anxieties of more junior staff (care managers, for example) who were responsible for making the system work on a day-to-day basis. The need to deal with and address these issues and anxieties thus became part of the plan.

A further aspect of support is what managers in Hartlepool referred to as *financial brokerage* – services to help someone manage their money and purchase support. In 2006, there was already a recognition that in-house support services were inadequate, unable

to help with payroll or develop **indirect payments**, and a contract had been tendered and awarded to an outside provider. Continued attention to the issue of financial brokerage was to be a feature of the Hartlepool story over the next three years.

What is striking, looking back from 2010 is, firstly, the clear sense that managers had of the flaws and deficiencies in the system, and the equally clear plans they were able to draw up to address these by introducing simple but thoroughgoing changes; and, secondly, the sense over the intervening period of systems and processes which remained under constant scrutiny, and which were changed when necessary. This flexibility is a feature of the transformation process to which we will return in later sections of this report.

What we learned from Hartlepool's experience

Hartlepool's story is useful to others involved in developing Self-Directed Support[1]. It is not intended, however, as a detailed template for others to copy. Each local authority is different. Each has a different history and a different set of demands and patterns of services. The way in which Self-Directed Support is established will be different in each place. Nevertheless, there are helpful lessons from Hartlepool and elsewhere.

Principled leadership is the most important factor

There are many metaphors for organisations and for the style of leadership that is said to bring deep change. Some contrast *transactional leaders* (or managers), who focus on processes and procedures, with *transformational leaders*, who focus on cultures and whole systems.

Beverly Alimo-Metcalfe and John Alban-Metcalfe[2], for example, suggest that the transformational leader is someone who leads and develops others by empowering them, delegating and developing their potential and encouraging a questioning attitude. The transformational leader has certain important personal qualities including honesty, consistency, integrity and decisiveness. This kind of leader concentrates on unifying the whole organisation by setting and sharing a coherent vision, putting in place a process to agree individual and organisational priorities and communicating these with all concerned, including external stakeholders.

Transformational leadership is not an issue of personality as such. Within this broad approach there are many different individuals, each with their own leadership style. It is notable, however, that all the senior people who are successfully introducing personalisation share a similar perspective about the pervasive and chronic problems of the old system, and all are clear that these problems can be tackled only by a fundamental shift of money and power to ordinary citizens.

The other notable feature shared by these leaders is a deeply held sense that transformation will come about only through genuine partnership with others: the old conflict model (conflict with people using services and their families; conflict with other agencies) has to

be transcended by an approach which reaches out and recognises shared humanity and joint interests.

A clear vision of what needs to be done to create a system of Self-Directed Support is vital

Leaders need to understand the systems that they are seeking to re-model, and, in particular, what it is that needs to change.

To some degree, they need a technical understanding – at least a technical overview – of how the new approach will work. This was quite challenging four or five years ago when Self-Directed Support and Resource Allocation Systems were ideas in development: now we see many examples of standard policies, procedures and guidelines gathered by In Control. The Social Care Institute for Excellence has published rough guides and the Department of Health has produced a set of expectations with specific milestones. Perhaps, more importantly, local authorities and their partners in almost every region of England are proving that Self-Directed Support can deliver benefits to citizens needing social care support.

Stay flexible – change things as necessity dictates and circumstances change

One of the great challenges (and joys) of the move to personalisation is that there is no simple mechanical model that can be taken off the peg. In the years covered by this report (2008-2009), In Control has seen many approaches to implementation. Some are tightly structured and controlled. Others are driven almost entirely by the passion and creativity of a few committed individuals. What all the successful approaches have in common is that those involved have shown a willingness to review, re-think and respond as new circumstances and challenges arise.

In some places, these challenges have been presented by specific cases: for example, someone has asked to use their Personal Budget for something unusual. Gavin Croft's season ticket at Rochdale Football Club, which became a story in the Manchester Evening News[3], was one such case. Other issues arise from within local politics or national policy. The relative failure of the Individual Budget pilot process to bring together funding streams as had been hoped was a particularly striking challenge.

So, implementing this agenda requires a certain relentlessness on the part of the leaders. They need to stick to the vision while remaining clear that the map may need re-drawing along the way.

Work though others – senior managers need to lead and manage their staff team

This may seem a self-evident truth. But, to achieve deep transformation, leaders need a focus on their key staff – their co-leaders – that is both subtle and robust. In Hartlepool,

Nicola Bailey spoke about getting to know her staff, spotting the rising stars and then finding ways to energise and inspire them. Many other leading local authority directors say similar things: change management at this level can only be realised through a joint effort by a team of skilled and motivated individuals, and this team needs to be selected and nurtured. Personalisation is about people and their personalities, their gifts, passions and their flaws. This applies as much to managers and staff as it does to ordinary citizens.

Don't obsess about any one aspect or set of issues – move forward on a broad front

There are many examples of stalled progress on the route to Self-Directed Support. Momentum can reduce dramatically if an authority becomes too concerned with one particular aspect of the process in the early stages.

Often, the knotty issue is the Resource Allocation System and worries about the financial viability of the new system. Concerns about legal issues or an acceptance that long-term contractual obligations to providers are entirely inflexible can create similar roadblocks.

When such issues present themselves, leaders must lead from the front, showing a relentless commitment to the vision, and being clear that the values and principles that underlie that vision must permeate the whole process. Leaders need to be equally clear about the need to apply flexibility, partnership and inclusivity in order to find pragmatic solutions.

Get money to people early in the process

This simple idea carries a powerful message. Self-Directed Support is about the dispersal of power to citizens, and the main means of signalling the change is money. Real allocations of resources obviously benefit the individuals and families concerned. But they also transform concepts into realities.

People demonstrate how effective and imaginative they can be in organising their money, support and life. Their example provides the evidence and confidence that will support further change.

Look to your strengths as an authority and build on these

As we have already noted, every local authority area is different. Every locality has some strong services and some weak ones. There are some inspiring managers and practitioners and others who feel detached or depressed.

Some towns and cities have good citizen-led Direct Payments support services or self-advocacy organisations with a history of person-centred planning. Others have universal services (libraries, leisure centres and some commercial services) that are particularly welcoming to disabled and older people. Others have mainstream schools with a good record of including disabled children, or a Connexions Service or Disability Employment Advisor who really understands how to support disabled people to get jobs.

Good leaders analyse the available resources, seek out available opportunities and capitalise on them.

Summary: getting ready for Self-Directed Support

Good Practice	Avoid
Start with an individual, their family and friends. Try and get them to think positively and think ahead.	Don't worry too much about client group labels or specialisms.
Build trust and relationships with other local agencies working with the individual. Think whole life.	Don't be too rigid. Change your plans as you need to.
Help the person to grow and develop, through new relationships with others – on a *Partners in Policymaking* programme or similar.	Don't be deflected by your areas of weakness: instead build on your strengths.
Nurture principled leadership at all levels of the organisation.	Don't obsess about any one aspect or set of issues, particularly Resource Allocation. Move forward on a broad front.
Adopt a clear vision and strategy for what needs to be done.	Don't be afraid to experiment and test out systems and processes that address outstanding issues, such as the contributions / charging policy.
Get the money to people early in the process.	

Figure 4: Good practice and things to avoid when getting ready for Self-Directed Support

NOTES

1 For a fuller account, see Tyson, A. (2009) *Self-Directed Support in Hartlepool, 2006-9*, In Control and Hartlepool Borough Council.

2 Alimo-Metcalfe, B and Alban-Metcalfe, J. (undated) *The Transformational Leadership Questionnaire (Public Sector Version)*.

3 Manchester Evening News, *NHS pays for season ticket*. **www.manchestereveningnews.co.uk/news/health/s/1028627_nhs_pays_for_season_ticket**

Chapter 2

Basic tools for change

Basic tools for change

This chapter reflects on the experience of some of the leading local authority adult services departments in developing and testing key technical mechanisms of Self-Directed Support over the last two years.

The chapter concentrates on the central aspects of the basic operating system, particularly:

- Resource allocation and Supported Self-Assessment
- Support panning and review.

The chapter ends with observations about Direct Payments and Personal Budgets.

As the last chapter made clear, Self-Directed Support and the introduction of Personal Budgets require the radical reorganisation of the old social care system by adopting the following seven steps:

- **Step 1:** the person is told their financial allocation, their Personal Budget, and they decide what level of control they want to take over their budget.
- **Step 2:** the person makes a plan about how they will use their Personal Budget to get the help that is best for them. If they need help to plan, advocates, brokers or others can support them.
- **Step 3:** the local authority checks that the plan will keep the person safe and makes sure that they have any representation they need.
- **Step 4:** the person takes control of their Personal Budget to the extent that they want. There are, at present, six distinct ways of exercising control. These include Direct Payments at one extreme and local authority control at the other.
- **Step 5:** the person makes use of their Personal Budget in a flexible way. They can use statutory services (the cost of which is taken out of the Personal Budget) and other forms of support. If they change their minds, they can re-direct their Personal Budget to more appropriate forms of support.

- **Step 6:** the person uses their Personal Budget to achieve the outcomes that are important to them in the context of their whole life and their role and contribution in the wider community.
- **Step 7:** the authority works with the person to review things, to check they are achieving what they intended. Both agree what needs to happen next and make any changes needed in the Support Plan or the Personal Budget.

Resource allocation and Supported Self-Assessment

Personal Budgets: the challenge

At the heart of Self-Directed Support lies a simple yet powerful idea – the Personal Budget. Each person who needs support receives an individual allocation of money. They are empowered to decide how this resource is used to meet their needs.

In 2003, In Control pioneered the development and introduction of Personal Budgets. As we have seen, the first two phases of In Control's work demonstrated how the use of Personal Budgets can lead to a range of improved outcomes for individuals who need support, and how they can be an affordable option for local authorities.

The take-up of Personal Budgets has increased steadily in the last three years. In England in 2006, just sixty people across six local authority areas had a Personal Budget. By the end of 2009, some 30,000 people across 75 local authority areas were reported to In Control as having a Personal Budget. This figure increased by an average of a thousand people every month. Each month two *new* local authorities would allocate their first Personal Budgets.

Just over two thirds (68%) of the reporting local authorities included a breakdown by social care group. Just over one third (36%) of these reported take-up of Personal Budgets by all four social care groups. The breakdown showed a relatively modest uptake by older people (53%) while reported uptake by people with physical disabilities was relatively high at 23%. (The overall number of older people using social care is high, hence we might expect even more than 53% of budgets to be taken by older people. The opposite is true of people with physical disabilities.)

This take-up may initially appear dramatic. However, when considered in a wider context, the figures are perhaps less impressive. Just under a million and half people every year in England receive state-funded social care. Given that some 70% of the people who have a Personal Budget live in just ten local authority areas, it is clear that Self-Directed Support is still a fledgling technology, one that needs to be adopted and implemented with care.

See Part Two of this report for more information about take-up.

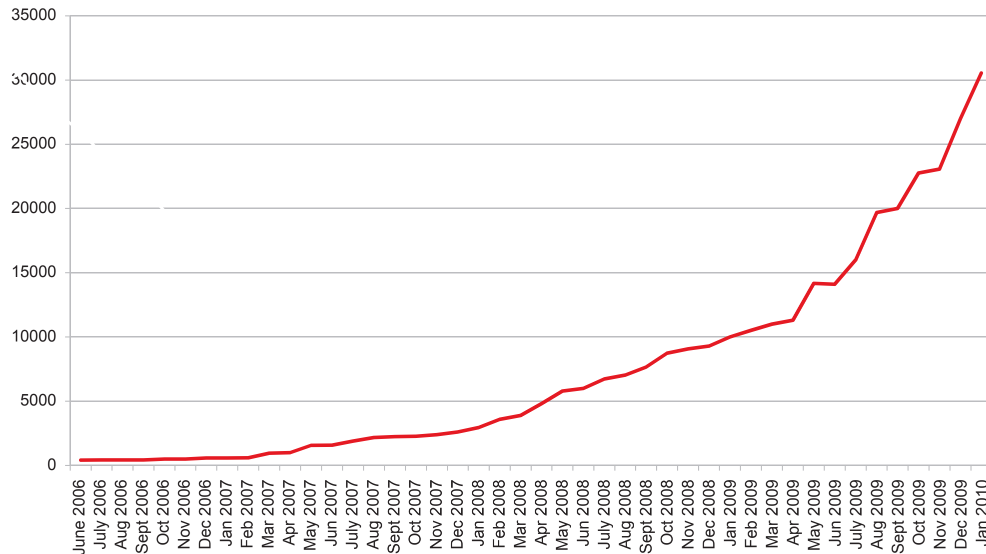


Figure 5: Take-up of Personal Budgets 2006-2009

Self-Directed Support and Personal Budgets are now a foundation stone of the Government's plans to transform social care in England. Each local authority has been charged with ensuring that every individual who is entitled to social care on a continuing basis has a Personal Budget. Local authorities have been given additional financial resources to implement this change. Targets and milestones have also been set, and authorities' progress is being closely monitored.

While the Government's enthusiasm is a cause for celebration, we also need to sound a note of caution. In 2006, Self-Directed Support lay in the hands of a small number of enthusiastic pioneers. Today, it is official policy, a requirement of all local authorities regardless of whether they are enthusiastic about the change or not.

In Control has always understood that implementation represents a significant technical and – more importantly – a profound cultural challenge for local authorities. Managing such a massive transformation process in an environment of high expectation and significant political investment is not without risk. There is a real danger that Self-Directed Support processes become a technical and bureaucratic mechanism, which is, in effect, assimilated into existing local authority processes and structures – old wine in new bottles, perhaps. In the current financial and policy environment, local authorities will have to make strenuous efforts if they are to adopt and maintain the spirit and ethos of Self-Directed Support as they implement the technical changes necessary to hit targets.

One of the risks associated with implementing Self-Directed Support on a large scale and at speed is that the core ideas may become corrupted and misshapen. To try to protect against this tendency, In Control has worked with a careful definition of a Personal Budget.

In Control defines a Personal Budget as follows:

A Personal Budget is money that is available to a person who needs support. The money comes from their local authority social ervices.

The person controlling the budget (or their representative) must:

- know how much money they have for their support
- be able to spend the money in ways and at times that make sense to them
- know what outcomes will be achieved with the money.

This definition captures the important elements of a Personal Budget: clarity of resources, control by (or close to) the person who needs support, and objectives that are shared between the individual and the local authority.

If they are to adhere to this definition, local authorities will need to work in new and very different ways. The story of Hartlepool's transformation (see Chapter One) provides a good example of how far-reaching the change must be. Authorities must allocate their resources on an individual basis by creating a new Resource Allocation System (RAS). The RAS, whatever the finer detail, must contain at its centre a simple set of transparent rules to demonstrate how the individual gets a fair budget, according to their needs and their social circumstances. The aim is always to achieve a set of agreed outcomes, which both the individual and the local authority acknowledge.

Thought of in this way, Personal Budgets require that local authorities design their RAS to determine:

- how much money someone gets, and why
- what restriction – if any – should be placed on the use of the money
- how people get money allocated to them easily
- how the money is used to best effect
- how the whole system operates in a timely manner with low transaction costs
- how the system remains financially sustainable.

This has proved a complex and demanding task that In Control and its local authority Members have worked on together since 2003. During that time we have worked with local and national partners to provide a model RAS.

- Version 5 of this System was used in 2009 as the basis of a *Common RAS*, endorsed by the Association of Directors of Adult Social Services. Almost all local authorities currently offering people Personal Budgets are using a variation of In Control's RAS. The system and accompanying tools and guidance can be downloaded, used and adapted by In Control Members from: www.in-control.org.uk

In Control adopted an approach to innovation and development of the RAS that involves a spiral process of developing – testing – improving – further developing. This is set out in the diagram on the next page.

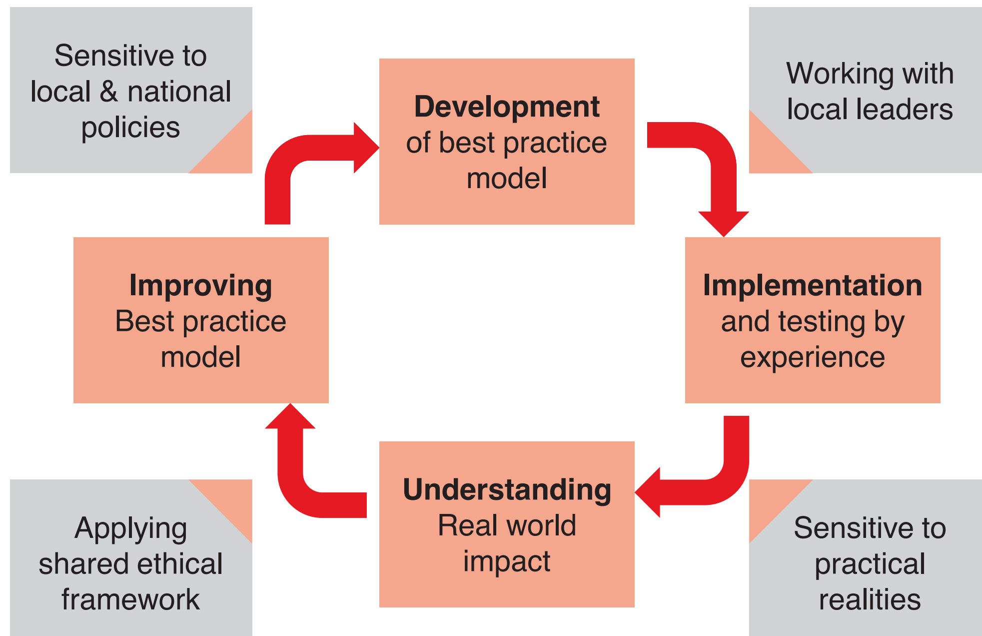


Figure 6: In Control's RAS development cycle

Resource allocation: a new relationship

It is not hard to see how a Resource Allocation System that provides a framework of rules of this kind can stimulate the emergence of new relationships. The interface between the local authority and local people who need support is reshaped. By working to develop simple approaches to resource allocation, many local authorities begin to foster these new relationships.

This process has been underpinned by two important ideas, fundamental to each of the rules: **conditionality** and **sufficiency**. These two ideas lie at the centre of an effective Resource Allocation System.

In the context of Resource Allocation, **conditionality** is the idea that Personal Budgets should be available to people who meet certain conditions. These conditions refer both to a defined need for support because of age or disability, and to the use the individual makes of the money. Conditionality also means that the money should be used in a way that achieves a set of outcomes, contained in the Support Plan that forms an agreement between the person and the local authority. Structured in this way, a Personal Budget approach is quite different from the traditional social care a person may receive from a local authority and also from the welfare benefits a person may receive from the Department of Work and Pensions.

Rather than constraining how money is used, this agreement, focused on reaching specific outcomes, can mean that people have an increased level of discretion in how money is spent and so have more control over their support. Local authorities charged with allocating finite budgets have traditionally restricted the range of services available to people. Often, services for intimate personal care were funded, for example, but funding for housework or hair-washing was not allowed.

In Control's approach to Personal Budgets challenges this surreptitious rationing by service type. What it does not do, of course, is remove the need to manage finite local authority resources. The tension between demand and resources must be brokered in other ways. Local authorities will inevitably establish some form of ring fence around the money they have available for social care. A focus on funding which is geared toward achieving agreed outcomes can provide just such a ring fence, one that is transparent, understandable and which should be politically acceptable when properly explained. It is a much more logical way of rationing scarce resources than the old one.

In the context of Resource Allocation, **sufficiency** concerns the amount of money made available in the Personal Budget. The sum of money made available to the individual should be sufficient for a plan to be developed that achieves an established set of outcomes. We can regard any individual's allocation and Support Plan as the acid test for the **reasonableness** of the allocation: is it really possible to achieve what the person wants for this sum of money?

These two ideas demonstrate the importance of ensuring that the resource allocation system defines both the outcomes to be achieved and the amount of money to be made available in an individual's Personal Budget.

Assessment: measuring needs and defining outcomes

The introduction of a simple Resource Allocation System has proved demanding and complex. One reason is that the new rules force local authorities to re-examine their fundamental processes. The **assessment** process has had to be reconstructed from the ground up. This has led, in many areas, to a helpful shift away from assessing to **establish formal eligibility** for services towards a more genuine **needs-led approach**. This has meant that authorities have had to more clearly define the concept of needs and to do so in a way that people who need support are able to recognise and own.

In the past, complex professional assessment processes have often meant that people who approached the local authority for support have been assessed for services provided or commissioned by that local authority. Their real needs have not received proper scrutiny. It has been common for a person who needs support to be described as *needing day care* or *needing respite*. Unfortunately, a number of local authorities have tried to apply this old thinking to the task of resource allocation. They have attempted to define levels of need through hours of personal care needed or numbers of staff required to carry out certain caring tasks.

In Control's has rejected these narrow, service-led definitions and created a system that views needs in relation to ordinary aspects of everyday life. This approach comes from the belief that we all share a broad set of needs: for food, warmth, shelter and friendship, to work and to contribute to our communities. The task of the RAS is to help determine the level of support required for a particular person to meet their personal version of these fundamental needs. Approaching the task of resource allocation in this way ensures that it focuses on the **outcomes of support** rather than the **nature of services**.

In Control's RAS considers important areas of life and offers a simple, scored assessment questionnaire to calculate a level of support needed to achieve defined outcomes in each area.

For example:

- Complex needs and risks
- Meeting personal needs
- Meals and nutrition
- Work, learning and leisure
- Making important decisions about life
- Being part of the local community
- Essential family / caring role
- Available social support.

Below is an extract from the questionnaire.

Area of life	Outcome
I do things I want to do in my community. I need support to continue to do these.	To keep doing things I want to in my community.
I need support to do more in the community.	To be part of and take part in the local community.
I need someone to support me closely to help me to make connections with people in the community where I live because I have difficulty making friends or get very lonely.	To be part of and take part in the local community and use a range of community facilities on a regular basis.

Figure 7: An extract from the assessment questionnaire: being part of the local community

As well as measuring level of need, the Resource Allocation System takes into account the level of support that is readily and reasonably available from family and others. This approach ensures that those who have less support available receive a greater allocation of money in their Personal Budget.

In Control's RAS is constructed in such a way that the degree to which family support is taken into account can be fine-tuned by individual local authorities to reflect local circumstances and realities. Certain other resource allocation systems measure only those needs that are not met by family members. This approach is unhelpful as it does not give a full picture and does not enable councils to make open, informed decisions about how they will use their limited resources.

In Control seeks to establish a social care system that is organised in a way that supports families to care for their members, drawing on the widest possible use of the community's resources. (See Chapter Four's discussion of the concept of **real wealth**).

This means that the system should be constructed such that:

- everybody who is eligible gets an allocation – even those with high levels of family support
- the system takes account of both the support offered by family and the effect providing that support has on family members.

Assessment questionnaires

Over the last three years, In Control has made model assessment questionnaires available on its website. Local authorities have taken, tested and adapted these standard assessment questionnaires, and this testing has led to a number of positive adaptations and innovations. This has led in turn to updated versions of the questionnaires.

A number of less helpful adaptations have also been tried. These are noted here by way of caution.

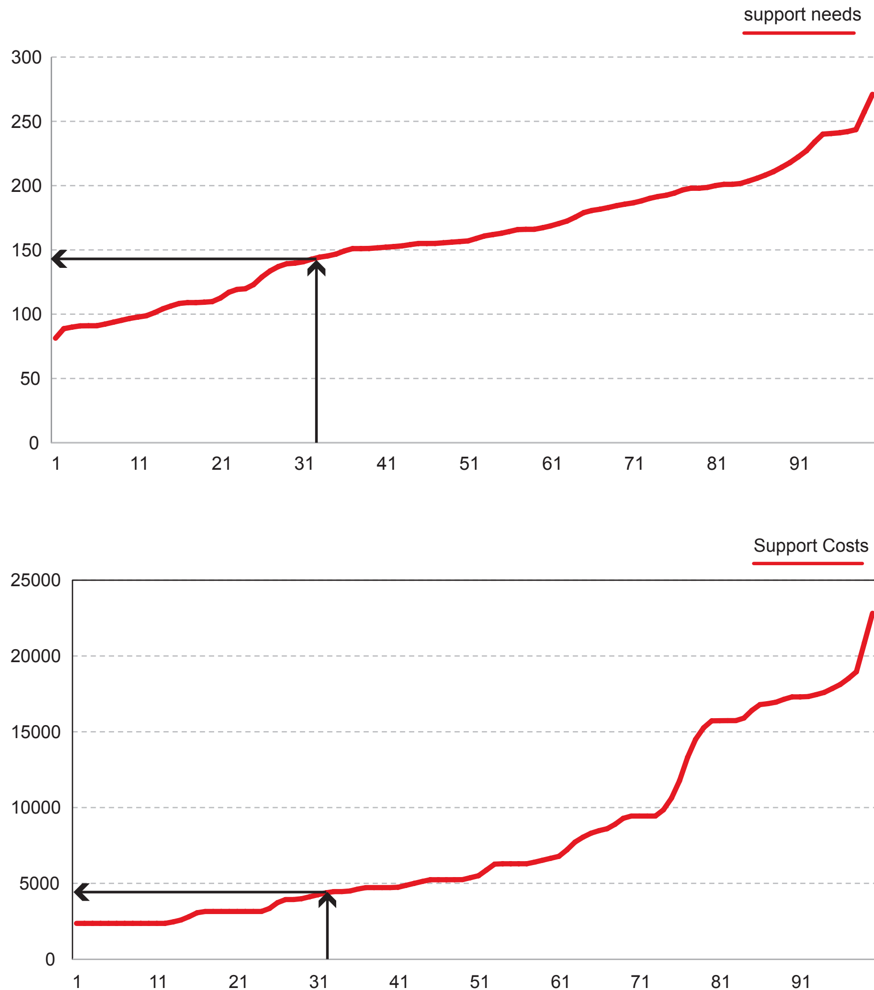
Adaptation	Risk
Integrating the assessment questionnaire with existing community care assessment paperwork.	The system becomes too complex – transparency is lost and transaction costs are high.
Removing the defined outcomes from each section.	Outcomes provide an essential ring fence around the usage of money and justify the use of local authority money in creative ways.
Adding numerous additional domains.	The system becomes too complex – transparency is lost and transaction costs are high.
Measuring need by describing typical service types or hours of care.	Creative solutions and innovation are inhibited.
The system measures and scores only those needs not already being met by family carers.	It becomes difficult to form a fair partnership, as the basis of the deal is unfair.

Figure 8: Distorted adaptations of In Control's assessment questionnaires

Allocation of money

Having created a simple assessment questionnaire that provides a score for different levels of need, it is possible to quickly build up local intelligence about these levels of need across a community. Most authorities have done this by undertaking **desktop exercises** in which social workers have applied the scored assessment questionnaire to people they are working with at the time. In many authorities, these exercises have had the positive side-effect of familiarising staff with the principles and practice of Self-Directed Support.

In Control's RAS tools have then been used to analyse the needs information from the scored assessment questionnaires, thus making it possible to identify the needs scores of each percentile of the population. The cost of support for each individual is then analysed in the same way. This information has then been used to establish an indicative allocation of funding for each level of need. By connecting the scores from each percentile in the population with the costs at that percentile, an allocation table is produced.



Figures 9/10: Needs and costs: in this example data set, the 31st percentile for needs is 141 points, while the same percentile for costs is £4,244, thus 141 points would allocate £4,224

Calibrating the system – making sure allocations are attuned to local conditions

Initially, cost and needs information is drawn from existing care packages. However, once the Resource Allocation System has been operational for some time, it becomes possible to recalibrate allocation levels using information from people who have a Personal Budget.

Having been through this process, one might expect that the Resource Allocation process will be self-managing. But Resource Allocation is not a mechanical technology.

There are several reasons why the RAS needs to be managed dynamically over time:

- Initial pricing information used to create the system will be heavily influenced by traditional commissioning and purchasing patterns.
- Changes in the technology available to support people and changes in pricing will affect Personal Budgets.
- The outcomes that the social care system is able to achieve will evolve.
- Fiscal, demographic and political changes will alter the resources that can be made available.

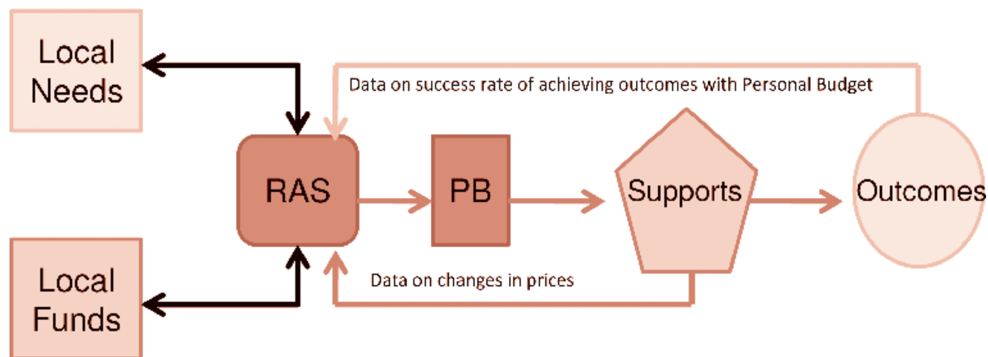


Figure 11: RAS – a dynamic process

Design criteria for Resource Allocation

While the work undertaken to implement a Resource Allocation System has presented many opportunities, it has also posed local authorities with a series of technical and cultural challenges. In Control has drawn from this experience to develop a set of design criteria that can now be used by local authorities implementing or reviewing their RAS.

These design criteria set out key characteristics of Resource Allocation Systems now in use that best reflect In Control's model of Self-Directed Support. They are outlined here to provide the basis of a quality standard for the development of Resource Allocation Systems.

Criteria	Rationale	Measure of success
Choice and control	The RAS should give the person needing support or those closest to them genuine control of the money allocated.	People can spend money in their Personal Budgets in any legal ways that meet the outcomes defined by the RAS.
Transparency	People who need support and their families should understand the rules that are in place that affect them.	It is easy for those administering the system and those using a Personal Budget to understand the decision reached using the RAS.

Criteria	Rationale	Measure of success
Outcomes	The RAS should allow people to concentrate on things that are achieved rather than things that are done.	The RAS features a simple and explicit set of defined outcomes. These outcomes are used to approve Support Plans.
Transaction efficiency	Self-Directed Support requires that those who operate the system spend more time helping people plan and less time assessing needs.	The Self-Assessment Questionnaire is simple to use. Any accompanying means-testing is straightforward. Charging and RAS operate as one integrated system.
Rationing	The RAS is a means of rationing. This should be explicit.	The RAS is used to allocate resources fairly. There is no rationing by service type.
Family support	The role of the social care system should be to support positive family caring relationships.	The RAS creates a reasonable deal for family carers. No one is left without a Personal Budget because they have an active carer. The RAS considers the impact of caring on family members as well as the amount of support offered.
Collaboration and partnership	RAS is a key part of any reformed social care system. Local people must have an opportunity to take part in its creation and application.	There is active involvement of local people in developing reviewing and revising the RAS.
Innovation and flexibility	The system supports creative and flexible use of resources. It encourages people to find the best possible means of meeting their needs.	People regularly make use of support other than traditional service solutions. There are numerous examples of people making a wide range of decisions about how their support needs are met.
Equity	The RAS treats all individuals fairly.	
Integrated	The RAS operates as an integral part of a wider system of Self-Directed Support.	Support to plan is available, as is a range of options to hold the Personal Budget. Reviews are outcome-focused.
Local	The RAS reflects the local economic situation, local prices and changes over time.	There is a review and recalibration system in place that draws intelligence from people who have Personal Budgets.

Criteria	Rationale	Measure of success
Portability	People who need support should be free to move home without undue cost, complication or uncertainty.	Those people wishing to move into the area have existing Personal Budgets honored by the responsible authority.
Prevention	People need access to support at the right time to minimise the risk of their coming into crisis.	The RAS allocates resources at low level to those with even modest needs.
Rights-based	The RAS recognises and defines needs in the terms of rights and entitlements.	Needs are not defined or measured in terms of service types or hours of support. RAS provides a set of guaranteed outcomes.
Just	Any fair system must be operated with discretion.	There is a simple and defined exceptions process. There is a clear and accessible route of appeal.

Figure 12: Design critieria for Resource Allocation

MA – Hertfordshire

MA is a man who originally came from the Islamic republic of Pakistan. He lives in Hertfordshire with his family. He had been an inpatient in a local NHS assessment and treatment unit for a number of years but had been discharged from his section for quite a while. He has complex needs, is deaf and unable to speak. However, he knows what is important to him and is able to communicate with support.

We established MA's indicative budget by completing a Self-Assessment Questionnaire, and then held a number of ***Planning Live*** events with MA and his circle of support. His circle included his family, social worker, nursing staff and psychologist. The information gathered was used to produce his person-centred Support Plan.

Once the plan had been made and we all understood what was important to and for MA, we arranged to meet with a number of providers.

The support package was jointly funded by PCT Continuing Care and the Local Authority. MA and his family wanted to manage part of the Personal Budget as a Direct Payment so a User-controlled Trust was established. They wanted his social worker to directly commission other elements of the support.

The support package consisted of outreach support from a specialist autism provider. The outcomes they specified were focused on maintaining MA's mental health to prevent readmission; supporting MA to continue to live with his family; and enabling him to participate in a range of activities and develop skills so that he could be more independent.

The package included additional support for a transitional period to enable MA to reorient himself to community living. This included a large element of two-to-one support to help him to access community-based resources.

Other elements of the package included:

- the hiring of a lease car
- the commission of an arts, crafts and agriculture-based service
- a visit to Mecca to visit family and pursue religious needs.

The overall cost of the package was considerably less than the NHS campus services and also less than a traditional residential service. These would have been the only option for someone with MA's needs.

MA and his family were much happier. The family was able to stay together. The Direct Payment gave them choice and flexibility where it really mattered.

END

Support planning and review

Support Planning is an essential element of Self-Directed Support. The Support Planning process offers most people the opportunity to build on the assessment they have been involved in. The Support Plan is a clear plan of how to achieve what people really want.

Review is the seventh step in the process. All those involved reflect on what has happened and decide what to do next. Though it is the seventh and final step, Review should be an on-going part of the process, a conversation between all concerned about how things are progressing and whether any changes are needed.

Many people with Personal Budgets know what they want and are able to make it happen – either by themselves or with information and guidance. Some have families or friends who can help. People who need assistance look for someone to help them who has passion, commitment and knowledge. They are unlikely to be concerned about whether the person is a care manager, a provider or an independent broker, as long as the outcome is right.

Experience in working with the local authorities that have allocated Personal Budgets has taught us a good deal about what is important in planning and arranging support. In Control's *Total Transformation* Members tested *The New Support Infrastructure for Self-Directed Support*[1]. We also learned much through those who took part in our *Partners in Policy Making* and *Our Futures* programmes about what really matters to people with Personal Budgets in planning and arranging support (see Chapter Four for more on these programmes).

During this period, it has become clear that, if we overcomplicate these processes, a number of problems can arise. There is already quite enough complexity in the task of transforming social care, and some authorities have tried perhaps too hard to specify and define what seems to be needed in Support Planning – sometimes using a traditional contracting approach. They have found that they have then struggled to find local organisations with the necessary focus.

It may be tempting to put our energy into professionalising Support Planning and brokerage, to invest in *the one right way* of doing it, or create new roles and professionals to be experts (who then need accreditation and monitoring). In Control's evidence

continues to suggest that the focus must remain on finding the means to change the way we all think and work. Our communities are full of people and organisations that can help one another to plan and arrange support, and the leading local authorities are discovering that they now have an important role in modelling, inspiring and empowering these people and organisations to do just that.

In many places, people with Personal Budgets are already able to get the advice or help they need from a Citizen's Advice Bureau, a Centre for Independent Living or a One Stop Shop, as well as from a provider, day service or a care manager – or from someone who already has a Personal Budget. No amount of structural, role or system change can replace the need for people working in social care and in the wider community to truly believe in the rights of older and disabled people to direct their own lives, and to work with them to achieve that direction.

In Control insists that many people with Personal Budgets and their families are capable of planning and arranging their own supports. We also believe that the best and most efficient processes for planning are the ones that are simple and uncomplicated. The local authority has an important role in making available information, advice, support and training to enable people to do these things for themselves. There are a growing number of courses and events designed to support authorities to deliver that information and support.

In 2009, *Pass it On*, a two-day course was launched for individuals, families and others supporting people at a local level. The course works by mobilising local people to use their Personal Budget to get the life they want and pass it on to other people and families. The *Our Futures* programme has also been set up to support family carers to plan.

shop4support is another major development. **shop4support** is an online catalogue that enables people with Personal Budgets to seek out and buy the support they want. It also enables people with Personal Budgets (and people who fund their own support) to plan and manage both the budget and the support. There is more on **shop4support** in Chapter Three of this report.

Experience during this third phase of In Control's work suggests that a much greater emphasis is needed on the review process. Traditional review systems often focus on what has been **delivered** rather than what has been **achieved**. They also have a focus on the relationship between the commissioner and provider. They often don't work well because they are target-driven and are carried out primarily for the purpose of meeting performance indicators. Person-centred reviews should identify where people need more help to plan and move on from situations that are not working for them.

If outcomes are set early on in the process, alongside the Resource Allocation System, they can be the focus of the review. It becomes possible to identify whether the money allocated has done what is needed. There must be a simple set of systemic, evaluation measures that capture changes in quality of life[2]. A framework of this kind can then be used by an individual to think about their life and to focus their planning for the period ahead. This type of information can also be used in an aggregated form to give providers and commissioners useful information about what is and isn't working.

Good support planning and review are essential to the success of Self-Directed Support. There is now a wide literature covering this area and a number of individuals and organisations across the country are able to provide advice and assistance to local

authorities and others. In the last two years, the tools to help people have been adapted to meet the particular needs of different groups. Much of the best practice continues to be developed by Helen Sanderson Associates (HSA). In Control and HSA now host a dedicated Support Planning and Review web-site with background and guidance[3].

The key lessons from this phase of In Control's work are:

- Be clear about the basic elements that a Support Plan needs to contain.
- Ensure that a process to set clear outcomes is at the heart of support planning.
- Review the plan in a person-centred way.

Support planning and brokerage in Kingston

The Royal Borough of Kingston upon Thames is a small London Borough that has been developing Self-Directed Support for three years. The Borough's early focus has been helping people with learning disabilities get Personal Budgets. Around a third of people with learning disabilities in Kingston now have a Personal Budget.

Marie is a young woman just leaving college and home. She wanted to share a house with three local friends and they chose to set up Individual Service Funds with a local provider. (An Individual Service Fund is all or part of someone's Personal Budget, held on their behalf by a service provider in a restricted account and used to fund a bespoke support service.)

Kingston had appointed a team of four in-house support planners and brokers whose role was to develop plans with people who had budgets, their families, providers and other direct supporters. The team had experience in person-centred planning and applied these principles to support planning. Their approach was very practical – do what it takes to help people take control of their plans by working with the person and those around them. There has been a deliberate strategy to get a wide range of people in the Borough to understand how to plan and arrange support through a training and awareness-raising programme. The support-planning team works alongside families, care managers, providers and voluntary sector organisations to encourage them to take part in the planning and arranging of support with people. The team withdraws as much as possible from the planning process but acts as a quality control mechanism to ensure the plans are person-centred, achieving outcomes and managing any risks.

After sharing a house for a year, Marie decided that she wanted to move on. The support-planning team and the provider had in place a process of regular review with Marie and supported her to plan her move. As she had an Individual Service Fund that she could take with her, it was not complicated. The structure of Individual Service Funds allowed the provider to focus on helping Marie get what she wanted rather than protecting the service from change.

Kingston's approach to support planning and brokerage has resulted in a wide range of people in the Borough including disabled people, families, care managers and providers who, at the very least, understand the mechanisms of support planning and brokerage and, in many cases, know how to do it themselves.

Kingston is now offering Self-Directed Support and Personal Budgets to all groups and is developing a range of support planning and brokerage options through a third sector Consortium which is hosted by Kingston's Centre for Independent Living.

END

Direct payments and Personal Budgets

One of the questions often asked about Self-Directed Support is: *Aren't Personal Budgets just the same as Direct Payments?* In Control's definition of a Personal Budget (see above) helps to provide an answer to this question: definitely not. While the definition talks about control of money, there is no suggestion that the money is necessarily passed to the person who needs support in the form of a cash payment, as would be the case with a Direct Payment.

Receiving a Direct Payment often requires the individual or their representative to act as an employer, and always to hold and account for the money they have been allocated for their support. Some people would find this responsibility burdensome and they choose not to take a Direct Payment. This does not mean they should not benefit from having the choice and control offered by a Personal Budget.

In Control is committed to a universal system of Self-Directed Support, so we have tried to ensure that Local Authority Members allow people to hold their Personal Budget in a variety of ways. It is helpful to think of Direct Payments as just one form of a Personal Budget.

A Personal Budget can be beneficial even for those who already have a Direct Payment. The greater flexibility and focus on outcomes associated with In Control's definition of Personal Budgets was important in Rotherham, for example.

Converting Direct Payments to Personal Budgets in Rotherham

Following the introduction of new legislation in 1996, Direct Payments became legal but were often seen as an add-on to the default system and were made *in lieu of services*. Many local authorities placed restrictions on how money made available through Direct Payment legislation could be used.

Work in 2007 in Rotherham demonstrated the beneficial impact of offering the greater flexibilities associated with Personal Budgets. The Local Authority undertook an initiative with people who had been allocated Direct Payments due to their having experienced serious mental health problems. The work involved re-framing existing Direct Payments as Personal Budgets.

In practice, this involved three simple but important steps:

- The Local Authority reviewed its local Direct Payment policy and removed any unnecessary or inappropriate restrictions on how money could be used.
- The existing Direct Payment recipients were reminded of their allocation and told about the new flexibilities, effectively becoming Personal Budget recipients.
- Personal Budget recipients were encouraged to review how they spent their allocation.

To judge the effect of the initiative, Rotherham undertook a simple review with each Personal Budget recipient using a simple standard questionnaire that considered the impact of the change on key areas of their life.

Category	Worse	Same	Better
Health and well being	1	9	6
Being with people you want	0	7	9
Quality of life	0	9	7
Being part of community	1	9	6
Choice and control	0	7	9
Feeling safe at home	0	5	10
Dignity in support	0	11	5
Economic standard of living	0	11	5

Figure 13: Rotherham's questionnaire: results gathered from people with mental health issues

These reported improvements were observed in a service area, mental health, where Direct Payment uptake has, traditionally, been low. It is also a service area in which aspirations to increase choice and control have often been frustrated: service providers have struggled to balance the desire for increased choice and control with the complexity of risk management, compliance with medical treatment regimes and a clear duty of care[4].

END

See the chapter summary on the following page.

Summary: some of the things we have learned about basic tools for change

Good Practice	Avoid
Base the Resource Allocation System on the principles of conditionality and sufficiency, as defined in this chapter.	Avoid Resource Allocation Systems that are partial and which do not take account of the family contribution.
Make sure there is a range of options to help people plan and arrange support.	Avoid sticking rigidly to pre-defined local rules for Resource Allocation. Manage the system dynamically.
Agree clear and specific outcomes from the start. If outcomes are clear from the start, the rest follows on more easily. Planning is more focused and plans form the basis of the review process.	Avoid a process that assesses for services. Focus on making the process genuinely needs-led.
Make sure that there is plenty of information, training and resources so that people can plan and arrange support themselves.	Avoid unnecessary complexity in Support Planning. Keep the requirements of the process simple.
Do person-centred reviews. If outcomes are set early on in the process along with the Resource Allocation, then outcomes can be the focus of the review and it is easier to identify whether the money allocated has helped to achieve the outcomes.	

Figure 14: Good practice and things to avoid when using basic tools for change

NOTES

1 This paper can be downloaded from: **www.in-control.org.uk/TT/supportsystems**

2 For more detail about such measures see Part One of: Hatton, C., Waters, J., Duffy, S., Senker, J., Crosby, N., Poll, C., Tyson, A., O'Brien, J., and Towell, D. (2008) *A Report on In Control's Second Phase, Evaluation and Learning 2005-2007*, In Control, London.

3 **www.supportplanning.org.** See also **http://helensandersonassociates.co.uk/**

4 For more on this topic see: In Control Yorkshire and Humber Forum, *Building on Direct Payments as Key of the Wider System of Self-Directed Support*: available at **www.in-control.org.uk**

Chapter 3

Changes in the commissioning and provision of support

miEnterprise

miEnterprise is a social enterprise in Herefordshire. It was set up to enable **earning disabled** people to plan, set-up, run and develop micro-enterprises – businesses that are as small as people want or as big as they can make them. This is self-employment – it is proper work but very flexible. One member said recently that being in work made him feel like a first class citizen.

miEnterprise is a business club. Its members own it and it runs as a marketing co-operative.

It is a one-stop shop that makes running a business as easy as possible. It has been planned with the Government departments that look after benefits and tax.

It has been designed to work really well with Individual Budgets and people can pay for membership using their Individual Budget.

Members' businesses that are running, or being planned, include:

- selling second hand books
- carrying out environmental conservation work
- selling art
- making ice cream
- offering a personalised home shopping service to people unable to get out
- making cakes
- running a small nursery.

There is more information at: www.mienterprise.org.uk

END

Individual Budget Minder, Embrace Wigan & Leigh / Wigan Council

The *Budget Minder* Pilot was set up to establish independent support mechanisms for disabled people who have a Direct Payment or Individual Budget from Wigan Council.

The pilot was designed to benefit people who have no one in their life to help them manage their money. People helped by *Budget Minder* were either about to start receiving their care through a provider or had been doing so for some time. Concerns surrounding the protection of vulnerable adults with Direct Payments or Individual Budgets and potential abuse from relatives or providers of care had been raised and a solution was needed to address this concern. Wigan Council asked Embrace Wigan & Leigh to provide a broker service to these people that would manage their Direct Payment or Individual Budget.

The main activities of Embrace during the pilot scheme were:

- Managing money: as an independent body, Embrace would receive Direct Payments on behalf of individuals and hold them in a designated account; to ensure timely and accurate payment of invoices for social care support; to provide full and accurate information for audit purposes.
- Checking quality: to ensure quality of services to people – services had to be delivered on time and to the correct standard according to the person's wishes and best interests.

- Statutory reviews: to provide independent advocacy for people at statutory reviews.

Embrace Wigan & Leigh used *shop4support*, a web-based tool developed by In Control and Valueworks to administer the back-office processes of the *Budget Minder* pilot. The core purpose of *shop4support* is to enable the creation of a marketplace for health and social care that allows an individual or broker such as Embrace to order services. The back-office processes of invoicing and payment are then automated to create cost and time savings to the person, broker and service provider. Reports can be produced from the system to help the local authority in auditing monies spent. (You can find more information about *shop4support* below.)

An example of people helped by *Budget Minder*: a single-parent family in which the mother has a learning difficulty

There are four children in the family, three of whom have learning difficulties. One has presented some serious behavioural challenges. The mother and two of the children each have a Direct Payment – from Adult and Children's Services. Budget Minder has enabled Adult and Children's Services funding to be pooled – to the benefit of the whole family. Initially, each Department commissioned different providers. This created chaos and further distress to the family. A change to using just one provider has produced consistency of care and provided help with personal finances and other essential functions. Using one provider has also protected the family from exploitation by other family members.

For the first time, the mother has been able to afford clothing and good quality food for her family. The young people have been able to take advantage of new opportunities and take part in wider activities through education and the services of Embrace Wigan & Leigh.

Before this pilot, there was a real threat that the children would be taken into care. This threat has now receded. *Budget Minder* has reduced the level of social worker involvement and ensured that the family stayed together. The mother described the service as *the best thing that has ever happened to me*.

The local authority has benefited from a number of efficiencies: reduced social worker time, cost savings created by the use of a single provider, and reduced management costs. There was also a risk of much higher costs if the situation had deteriorated and the children had been taken into care.[1]

END

Changes in the commissioning and provision of support

Some of the examples in earlier chapters of this report suggest that, if personalisation is to gain ground, there are implications far beyond the narrow world of adult social care. There are implications that extend further than a simple changed service specification, job description or set of council-approved procedures. Real transformation entails a radical change in the way each and every one of us thinks about him or herself as a member of the local community and as a citizen who has rights and obligations – and how we express that changed understanding through our work and also in our lives outside work.

This chapter concentrates on what we have discovered in trying to make these changes during the last two years:

- What have been the really difficult issues for local authorities and others?
- What solutions have been tried?
- Which approaches have worked, and which haven't?

We concentrate here mainly on positive examples, but will also try to highlight problem areas.

The chapter focuses particularly on core issues for authorities:

- commissioning and provision of support services
- issues for the workforce, in particular social workers
- helping people using the new system to stay safe
- changing in-house services.

The stories in this chapter come from a number of sources but, as in the last chapter, they draw particularly on the work of In Control's *Total Transformation* programme, which ran between 2007 and 2009. This programme was designed to support those local authority Adult Service Departments which committed to making rapid changes to their organisational culture, systems and procedures so that Self-Directed Support would become the normative model by (it was hoped) 2010. The twenty authorities that participated in this programme were supported in various ways. These included on-site visits and participation in a series of projects that sought to make headway in areas that presented particular blockages. The authorities involved and the programme areas are summarised in the table below.

Local authorities participating in the *Total Transformation* programme, 2007-2009	Total Transformation projects
Cambridgeshire, Croydon, Cumbria, Essex, Hampshire, Hartlepool, Hackney, Lancashire, Leeds, Lincolnshire, Newham, Newcastle, Northumberland, Oldham, Richmond, Sheffield, Southampton, Tower Hamlets, West Sussex, York.	1. Support systems 2. Conversion of in-house services 3. Stakeholder engagement – elected members 4. Care management and social work 5. Developing community capacity 6. External provider development 7. IT systems 8. Workforce development 9. Safeguarding 10. Outcomes for citizens

Figure 15: Total Transformation Members and projects

This chapter focuses on the role of both the local authority and that of its close partners providing support. It is sometimes very difficult to generalise in these areas, because history and current arrangements vary so much across the country: in some places the local authority has developed a role as a strong community leader and as a commissioner of support services; in others, the authority retains a significant role as a direct provider of support. In some places, there are well-established partnerships with NHS and other agencies; in other places these are lacking. In some places, there is a strong citizen or user-led third sector; in others, this sector is less-developed. What follows, therefore, needs to be read while bearing in mind the local situation. The conclusions about what action could be taken need to be adjusted accordingly.

Local authority commissioning: the relationship with service providers

The term *commissioning* is widely used but means different things to different people. The chapter starts with commissioning because many people think it is the foundation for what follows.

We have spoken in the past about commissioning *oiling the wheels* of Self-Directed Support. In Control adapts a 2006 definition of commissioning by the Commission for Social Care Inspection:

> *Working together with citizens and providers to support individuals to translate their aspirations into timely and quality services which meet their needs, enable choice and control, are cost effective and support the whole community.*

Sometimes, people who support personalisation and Self-Directed Support are hostile to commissioning because they believe it locates control with someone other than the citizen at the centre. This is not the way In Control uses the term[2].

The Department of Health *Commissioning Toolkit* proposes that we adopt three levels of commissioning, as follows:

- **Strategic commissioning** is at county or regional level. It often operates across agencies such as health, social care and housing. It helps to set the broad conditions so that Self-Directed Support can become established. It does this by trying to ensure that all agencies work together to a common agenda, that the right third-sector organisations and user-led organisations are funded and that information and advice services are available to ordinary people.
- **Operational commissioning** usually covers part of a city, town, or larger rural area where population is more thinly spread. It works to get universal services like schools, colleges, health centres, libraries and commercial outlets to deal with people in a more personalised way (rather than treating them all the same). It might also help to co-ordinate specialist services (for example, day centres, home care and equipment services), so that they *join up* when people use their budgets to buy them.
- **Citizens' commissioning** is the level at which citizens direct their own support using Personal Budgets or their own funds[3].

Importantly, all three levels of commissioning in this definition are multi-sector. That is to say commissioning is seen as part of a broad approach to creating stronger communities, one that includes both **universal services** (those that are available to everyone regardless of eligibility) and **targeted services** (services such as most health and social care services, where people need to pass a pre-defined eligibility test).

Underlying this approach to commissioning is what Clive Miller of the Office of Public Management[4] refers to as a *continuum of co-production*, that stretches from *fully serviced* support, reliant on the resources of organisations, through *equal co-production* between citizen and organisation to *self-help*, where citizens make use of family, friends and other community resources (and not of formal organisations). This approach is premised on

people making best use of their individual capacities and *social capital*, in order to learn, grow and make community connections.

What does this mean in reality for local authorities working to develop plans that seek to *commission for personalisation*? In Control suggests that local authorities adopt a framework for the production of their commissioning plans drawing on the key principles articulated above.

These plans need to reflect:

- the important dual role that local authorities now have in legislation and guidance in **place shaping** and **community leadership**, important levers in the commissioning process
- the need for an organic and dynamic relationship between commissioning plans across the age-range. It is particularly important that plans for adults have such a relationship with the Children and Young People's Plan, and that this relationship is an active and on-going one that extends into the operational delivery phase
- Joint Strategic Needs Analysis and other demographic, socio-economic and public health considerations
- pre-existing local policies, plans and patterns of services
- the expectations of other statutory stakeholders
- the views of local citizens and their representatives as expressed through the political process, and through formal bodies such as Local Involvement Networks (LINks), and through the newer approaches to participation including deliberative forums, citizens' summits and citizens' juries.

There are a number of more specific tools that have been developed to support the commissioning of personalised health and social care services, and authorities should make use of these to provide information about the expectations of citizens.

These approaches (which we might call citizen-market intelligence tools) include:

- *shop4support*, a developing web-based technology, to enable Individual Budget users to access information and purchase local support services. Commissioners can use reports from this system to determine how they should influence the market. (See the next page for an account of the introduction of *shop4support* in the London Borough of Harrow.)
- *Shaping the Future Together*, a tool to collate information from assessments and reviews to assist commissioners. This was originally designed specifically for, and has been used successfully in, services for people with learning difficulties.
- *Working Together for Change*, a new tool available on the Department of Health website to make use of person-centred information to shape commissioning plans. This centres on a process to engage with groups of local people, establish and clarify what they say their needs are and analyse the data for commissioning purposes.

Drawing on the information produced by these tools and technologies, In Control proposes that local authorities develop commissioning plans using a model framework that In Control developed with partners and published in early 2010[5]. The process that

authorities use to develop commissioning plans may differ, but all must reflect the principles of co-production – they should be produced with, not for people.

No judgements are made here about whether or not authorities produce plans for specific groups of citizens (for example, people with mental health issues or people with learning difficulties). However, people at different points in the life-cycle (children, working-age people, older people) have different requirements and this fact needs to be recognised. In any case, the underlying philosophy must be one of equal citizenship regardless of *label*. If individual commissioning plans are produced for specific groups, it is important that an effective process is in place so that the plans are developed and implemented together rather than separately.

It is critical that commissioners involve and work with local providers in this process. Commissioners need to respect the expertise of providers and build on providers' day-to-day contact with people who use services. This applies particularly to those providers who signal a desire to break new ground and develop more personalised services: in some places, close contact with people who use services has encouraged providers to lead the way. Commissioners need to be responsive to and appreciative of providers' leadership.

The London Borough of Harrow and **shop4support**

In December 2009, the first phase of Harrow's *shop4support* portal went online, helping Harrow to achieve the recent Association of Directors of Adult Social Services (ADASS) / Department of Health *Information and Advice Milestone* six months early. *shop4support* is a major technical step towards making Self-Directed Support happen on the ground for large numbers of people. The following account summarises Harrow's experience.

The London Borough of Harrow made a strategic decision to implement the *Putting People First* agenda by April 2011, ensuring the majority of the Borough's citizens who have social care needs will have a Personal Budget and will direct their own support. The key aim within Harrow's three-year Transformation Programme is to enable people to have real choice and control in a very practical sense while ensuring it is affordable. **shop4support** provides a major part of the technical solution that will enable this to happen.

The **shop4support** solution

In March 2009, Harrow Council engaged **shop4support** to undertake a planning project.

This involved the shop4support team working closely with the Council on a number of key developments:

- **An integrated solution:** a bespoke online marketplace that would complement Harrow's transformation plans for adult social care and help them to achieve their objectives.

- **A benefits case:** the development of a financial model to quantify the expected efficiencies, and a framework for identifying non-financial benefits.
- **An implementation plan:** a fully costed, phased plan to deploy and embed the solution.

Delivering financial efficiencies in Harrow

While the main aim of personalisation is undoubtedly to improve outcomes for citizens, **shop4support** is also able to bring market efficiencies. As local authorities and service providers move from a wholesale supply model to a retail model, there is a need to re-think and re-configure operational and back-office processes.

Under a system of Self-Directed Support, service providers will now deal directly with people needing support and those acting on their behalf. As a result, local authorities will have reduced administrative responsibilities as these are taken on by service providers and citizens themselves, as individuals and their families start to become commissioners in their own right. Local authorities remain responsible for the public funding of social care, however, and the current economic climate has made the delivering of financial efficiencies more necessary than ever.

shop4support provided Harrow Council with a business case, created in partnership with service providers and In Control, to demonstrate achievable efficiencies. This business case was based on the finding that 40p in every pound expended on social care is actually spent on transactional, administrative and other activities which add no value.

As the social care sector is in a state of transition, it is important that we compare like with like – make a meaningful comparison.

In assessing shop4support's impact on efficiencies, we can compare:

- the current situation
- the future situation (in which personalisation is implemented) using the generally accepted premise that costs will justifiably increase as a result of an improvement in outcomes
- a future situation in which *shop4support* is used (shown inclusive of the costs for *shop4support*).

The planning project demonstrated to Harrow Council that **shop4support** can create overall market efficiency alongside an improvement in outcomes for people. It showed conclusively that **shop4support** will be a self-financing, integrated technology that will meet the requirements of the citizens of Harrow, and will bring efficiencies. The project also provided Harrow Council with a valuable appraisal of its work to date and of its future plans.

Following the success of the planning project, the Council and **shop4support** agreed to work together to adopt and develop the system. Councillor Barry Macleod-Cullinane, Harrow Council's Portfolio Holder for Adults and Housing, said *We believe that this pioneering partnership with* **shop4support** *will play a critical role in ensuring our service users gain the full benefits from personalising social care.*

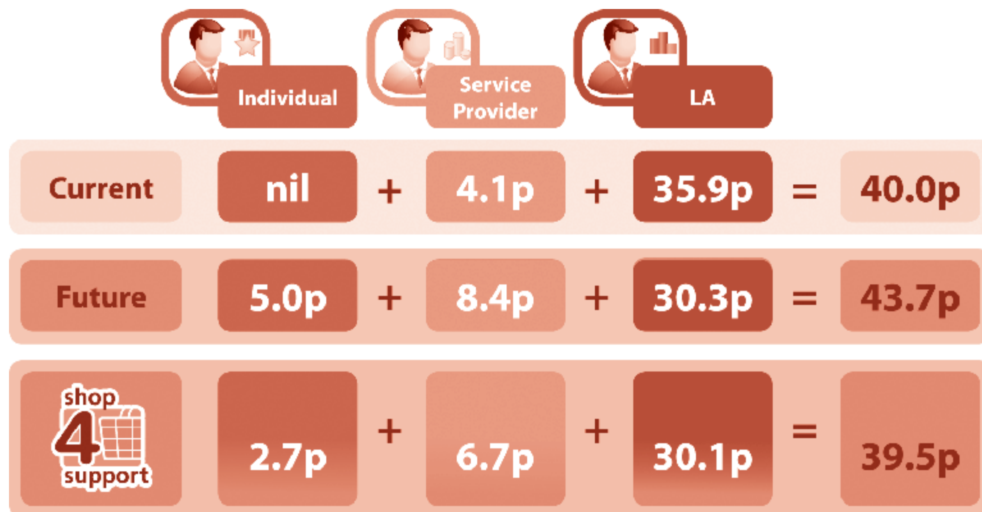


Figure 16: shop4support's efficiency model

Bringing communities together, creating social capital

shop4support also offers a *Community Catalogue*, an online, tailor-made portal to give Harrow residents up-to-date information about local community services, voluntary groups and other free resources. The system will also provide the Council with reports that offer the latest information on usage and trends, thus assisting planning and strategic commissioning.

Launch of the programme

As part of Harrow and shop4support's launch programme, several events were held to tell Harrow stakeholder groups how shop4support could benefit them:

- Through the *Community Catalogue*, Harrow's community and voluntary organisations would be supplied with a completely free online marketing channel and an effective way of communicating with their customers.
- Through the *eMarketplace*, Harrow's service providers would gain access to more customers via their own online stores – without significant investment.
- And, most importantly, people would have a greater choice of social care services and better control of their support, their money and their lives.

Feedback was positive. Deven Pillay, Chief Executive of Harrow Mencap, said **shop4support** *is an excellent idea and will provide individuals and their carers with a simple method to access and choose from a range of potential services to meet their needs.*

shop4support becomes a reality in Harrow

Using **shop4support**, Harrow achieved the ADASS / Department of Health *Information and Advice Milestone* six months early. This milestone states:

> *When it comes to dissemination of information, each council must have a strategy in place by April 2010 covering universal advice services. By April 2011 authorities must be able to prove that the public is fully informed about where they can go to obtain such information and advice.*

In January 2010, Harrow Council's preferred service providers had their own online public catalogues (which are available to all service users) and private catalogues (which reflect Harrow's previously agreed rates that are passed onto people funded by the Council).

Some practical examples of actions to date include:

- The conversion of day service users to Personal Budgets: *shop4support* has been used as an interactive tool to showcase the alternative services that are available in Harrow, in order to encourage service users to consider taking a Personal Budget. To date, ten individuals have been identified who will convert some of their existing day services to new services using a Personal Budget.
- The stimulation of new services: *shop4support* and Harrow Council have developed a commercial partnership proposition that encourages service providers to develop new services. *shop4support* offers a means of promoting these new services. This is especially important, as it relates directly to the ADASS /Department of Health *Local Commissioning Milestone*, which states that, by October 2010: *local authorities must have commissioning strategies which address the future needs of their local population and which evidence the fact that all stakeholders, including third party providers, have fed ideas into them.* Again, Harrow Council has achieved this milestone well in advance of the target date.

Examples can be seen at www.shop4support.com/harrow

shop4support: implemented

Through the implementation of the **shop4support** system, Harrow Council has demonstrated a commitment to personalisation, to building communities and helping individuals direct their own support. The online marketplace has given citizens greater access and choice in the products and services available to buy with their Personal Budgets.

In addition, Harrow's *Community Catalogue* encourages individuals to participate in events and activities in the local area and so to lead fulfilling lives. **shop4support**'s social networking and support planning functions have given people further avenues to take control of their lives.

In early 2009, David Behan, Director General for Social Care, Local Government and Care Partnerships, said of **shop4support**:

> *Technology is transforming the way we conduct our lives. As a society, we expect much more from public services. We demand that services are tailored around our needs, and help to support the way we wish to live our lives. People who use services use them to remain in control of their lives, helping them to work, to learn, to shop, to relax, to live independently, to meet family and friends, in short to do what we all do – to live a life. This development seeks to combine technology and an approach to personalised services in an innovative way, with the purpose of ensuring people are helped to live their lives and are supported to do so.*

Harrow Council's **shop4support** pages can be found at www.shop4support.com/harrow. For more information about **shop4support**, please call 01942 614 088 or email info@shop4support.com.

Commissioning in Hartlepool

Local authority commissioning is in part a process to define and plan the support services required to meet the needs of local people. Under a system of Self-Directed Support, citizens themselves identify the specific arrangements they require – whether these arrangements include services or not. This is sometimes described as a shift from a **wholesale** model of supply to a **retail** model. Chapter 6 of *A Report on In Control's Second Phase, 2005-2007* [6] defined many of the issues this brings for providers, and illustrated these with examples of initiatives from Castle Supported Living in Lancashire, KeyRing in Newcastle and using Adam's story from Cumbria.

We will not repeat these lessons here, but rather reflect further on the experience in Hartlepool. Before doing this, we should remember that Self-Directed Support finds many of its roots in initiatives from provider organisations. In Glasgow and North Lanarkshire, for example, organisations pioneered Individual Service Funds (ISFs): existing traditional contracts and blocks of funding were split into Personal Budgets to be managed by the provider, guided by the Support Plans of the individuals concerned[7]. It is becoming evident in some places, especially where organisations work across local authority boundaries that such provider-led transformation can be very effective.

Hartlepool Borough Council was a *commissioning organisation* some time before Self-Directed Support appeared on the agenda. Commissioning activity there did not – for the most part – define services as large blocks, numbers of beds or places purchased at a single rate. The fact that services were already purchased individually, rather than in blocks, helped to create an environment that enabled providers to begin to think about their culture and their practice. Without this helpful environment, providers may think they face a frightening set of imperatives from Government, local authorities and newly empowered citizens.

In Hartlepool, while conditions seem relatively favourable, experience suggests there is need for further work. Core costs for some contracts have had to be re-structured as they move to ISF-style arrangements. Inevitably, new gaps in the pattern of provision have surfaced. Needs have become apparent, for example, for a broader based peer-support service and for a new advocacy service.

The Council has led three *personalisation events* with providers. Much detailed work has also happened outside these events to shift the roles and expectations of all concerned. This work has focused on service level agreements, contracts and monitoring arrangements that now review how individuals use their Personal Budget allocations. As a result of the changed expectations, providers' views of the best way to offer support have shifted. A small number of schemes have decided to move away from Care Quality Commission registration – a positive change for the tenants concerned (but one which needs to be carefully managed, and *is being handled in pragmatic little steps*).

Work is also in hand to rationalise the different funding streams – particularly Supporting People (SP) and Independent Living Fund – which contribute to the commissioning of services, and all of which currently operate to different rules and monitoring regimes. This has involved a good deal of painstaking work to unpick the different funding contributions that make up each individual's budget. This process has been helped by good working relations with other agencies, and has now begun to bear fruit.

Sarah Ward, the Social Care Transformation Lead reports:

We've done great assessments with SP people. We asked a lot of hard questions about use of Supporting People. End users don't need to know some of this detail around finance, and the make-up of packages. What they are concerned with is how it affects their life. So we don't necessarily share all the detail.

Many of the mechanisms to manage this new set of commissioning arrangements are only now being developed or made available. The Authority has commissioned a new contract management and financial assessment management information system as part of their overall ICT operating system. The system, called *Controcc* (Oxford Computer Consultants – OCC), can generate graphical reports to show commitments, costs and outcomes. Further work is underway in partnership with OCC to develop a fully interactive Personal Budget monitoring area which will allow Individual Budget holders access via a customer portal. The Authority is also considering a Quality Rating system by individuals that will encourage and gather feedback about specific services. Managers interviewed in summer 2009 were optimistic about these developments but had some reservations. There are still unresolved issues and concerns. One manager commented:

We now need to create the market place, with sufficient choice for everyone to live the life they choose. It's still difficult to free up money, and there is still something of an over-reliance on residential care.

Small Providers

Another challenge in the transformation process concerns the style, focus and – importantly – size of the support services that are available to people.

Since the 1990s, the social care market in the UK has become increasingly dominated by large enterprises. These are often backed by City money and offer service models focused less on choice and control than keeping costs down through traditional economies – large numbers of standard units that offer little scope to regard people as individuals who have a unique perspective and can make a personal contribution.

This is, perhaps, something of a caricature and is truer in some market segments (probably especially in services for older people) than in others. But there is little doubt that a need to control costs using contracting models (some of which have been promoted by Government) has encouraged many local authorities to welcome providers under large block arrangements delivering high volume at low unit costs.

While the worst of such arrangements are obviously antipathetic to personalisation, In Control has never been opposed to large provider organisations as such. Bigger organisations may bring with them new capacity and resources to develop services. There are many examples of large third-sector and other not-for-profit providers that embraced Self-Directed Support from the beginning, and can now demonstrate significant progress. The Individual Service Fund model is being used in many places to de-construct block arrangements, with great benefits for individuals.

Nonetheless, In Control takes the view that, if personalisation is to succeed, the balance of provision in social care markets is too strongly in favour of large providers. Many people using Personal Budgets opt for solutions that are highly personal to themselves, their circles and networks. Support Plans often contain solutions that draw on the capacity of local communities and do not depend on traditional day care or home care services. An important part of the commissioning task for local authorities is, therefore, the promotion and stimulation of small services that can meet these emerging needs. These services are sometimes referred to as *micro provision*.

The organisation NAAPS[8] which has researched the barriers and opportunities in this respect suggests that:

> *Micro social care and support enterprises established and managed by local people are in a good position to deliver individualised services and are vital elements of a diverse market. Micro social care and support providers are independent of any larger or parent organisation and often deliver the service themselves without employing staff, or have a small number of paid or unpaid workers. Most providers of micro services see their operation as being an ideal size and are not aiming to develop their enterprise in order to support more people or to expand into a different area.*

NAAPS goes on to point out that:

> *Every local authority has existing micro providers in their area but they can be hard to identify and engage; they face growing regulatory, legislative and other barriers and in general their numbers are falling. In every area there are entrepreneurs who would be willing and able to set up new, innovative and highly personalised service options if only they knew what people needed and had the information and support that they need to do so with confidence. There has been a view that new services will simply emerge and existing services adapt and thrive in response to the growing number of people with their own budgets. Evidence suggests that this does not happen so easily and in most areas the local market is becoming less rather than more diverse*[9].

In summary, In Control sees an important and continuing role for local authorities in ensuring that local support is available for people to purchase their Personal Budgets. That support must reflect what people want and need, and its delivery must demonstrate robustly personalised values. Under Self-Directed Support, the old role of the local authority commissioner as an intermediary who stands between citizen and support service is disappearing. It is important that it should do so: all needs and all circumstances are different. The individual is the best person to plan, specify and *procure* the services they need.

shop4support and other similar systems exemplify the crucial role that information technology can now play in bringing providers and citizens together. These IT solutions need to complement local arrangements that enable individuals to identify and manage their support (including the arrangements for **financial brokerage** that are considered in Chapter Two). In short, if Self-Directed Support is to prove effective and efficient, if ordinary people are to get good lives as a result and if the market is to remain stable, commissioners and providers need to re-think their roles and redefine their relationships such that the citizen is firmly at the centre of all they do.

Workforce development and the role of local authority social workers

In the course of the last two years, many authorities have moved from a belief that major changes to the workforce will be required *at some point in the future* to a view that this issue is pressing. This is an important advance.

In Control will soon publish a *Workforce Framework* based on the results of its *Total Transformation Workforce Development* programme.

Key messages from this work include:

- Workforce transformation extends beyond the local authority and, indeed, beyond the social care sector. It needs to include staff in universal services.
- A very broad understanding is needed among staff that the person and those closest to them are the experts on the person's needs.
- There needs to be a broad understanding of the Self-Directed Support process. In particular, staff need to know about the full range of funding streams, person-centred approaches and what is meant by *an outcome*.
- A transparent information system is needed to support personalisation – one that is accessible to the whole workforce.
- The workforce needs to be skilled in helping people to complete their Supported Self-Assessment.
- There is a need for skilled individuals and groups who can undertake the functions needed to help someone to plan and get what is in their plan: support planning, service design, and co-ordination.
- The workforce needs to include people people who are skilled in scrutinising and signing off plans. These people need a good understanding of **risk enablement** and safeguarding issues.
- Staff are needed who have a strong, broad-based understanding of what is available in specific communities to provide the full range of support for individuals.
- There need to be staff who understand employment law, tax and insurance issues, and who can signpost people to experts.
- The workforce needs to include staff whose focus is building capacity in the community – for all ages and across all areas of life.
- There needs to be a broad understanding of the importance of reflection and review as a central part of the process of Self-Directed Support.

Registered social workers form a key group of professional staff within local authorities. Under the system introduced by the *1990 NHS and Community Care Act*, professional social workers often became care managers – in effect, gate-keepers who make assessments and ration scarce resources. Many were dissatisfied and left the profession or, at least, the local authority sector. They complained that their core professional values had been compromised and they were no longer asked to make use of high-level skills or fulfil the role they had been trained for.

In Control's *Total Transformation* project on social work set itself the task of determining whether there was indeed a role for this group of professionals under a system of Self-

Directed Support and, if so, what might be distinctive about that role. This task was approached by following In Control's seven steps and asking what (if any) role there might be for social workers at each step. An abbreviated version of the results of this exercise is produced below.

Step	Tasks, skills and knowledge required	A role for professional social workers?
Step one: My money, finding out how much 1	*Inform people / explain / FACS screening / supported self-assessment / financial assessment / benefits advice / income maximisation / manage expectations.* *Communications.* *Active listening and support.* *Provision of accurate, straightforward and timely financial and benefits information.* *Sensitivity to crisis, and ability to access short-term resources.* *Problem-solving and signposting.*	Professional social workers have a role in helping some people understand and complete the assessment process; and in coming to terms with the emotional impact of life changes and their need for support. Social work training encourages a more holistic view of the person in their social and economic environment, and this perspective is often crucial at this stage. Local authorities (LAs) will need effective systems for ensuring that social workers are called upon when they are needed.
Step two: Making my Plan 2	*A plan which sets out what is important, what will make life better / is safe and sustainable and affordable / meets needs / is likely to be signed off by LA / and considers risk to LA.* *Interpersonal skills.* *Knowledge of person-centred planning / Support Planning techniques and resources.* *Facilitation skills: ability to lead the process.* *Imagination and creativity.* *Information about community resources.* *Knowledge and skills about accessing networks and services beyond the local community.* *Manage risk.* *Agree outcomes.* *Manage conflict.* *Financial planning.*	The skill set and interests of many professional social workers are ideally suited for this set of tasks, and, in some instances, the social worker will be the best person to do them. Social workers are, for example, trained to help people to assess, manage and take appropriate risks, and as LAs move away from excessively risk-averse policies and procedures, social workers are well-placed to assist with more person-centred ways of managing risk. Professional social workers should also possess the skills to support and facilitate other people to make best use of their own interests and skills, including technical skills with IT, photos, drawing etc.

Step	Tasks, skills and knowledge required	A role for professional social workers?
Step three: Getting my plan agreed 3	*Ensuring that the plan is safe / Does it meet needs? / If so, which needs? / Ensuring the plan is within RAS allocation / Ensuring the plan is sustainable.* *Analysis and evaluation: ability to consider whether a plan is comprehensive, coherent, realistic and achievable.* *Coherent framework for sign-off.* *Understanding of safeguarding and risk.* *Local knowledge.*	Social workers should be effective and experienced in challenging Support Plans when these are not completely fit for purpose, and in so doing helping people to make real, informed choices. Local authorities need to be very thoughtful about the checks and balances they put in place at this stage of the process, as there is a tremendous temptation not to let go. The focus then, needs to be on attitude and aptitude, perhaps more than skills as such.
Step four: Organising my money 4	*Ensuring all options for managing the money have been considered / A clear understanding of the contractual obligations each entails / Specific issues for providers and in-house services understood / Ensuring social workers are themselves in a position to manage the money for someone.* *Knowledge of the full range of options to manage money: the six routes to managing the money each need to be clearly understood in principle and in local practice.* ***This requires a range of skills:*** • *Interpersonal and influencing* • *Financial management* • *Contractual (including arrangements to deploy Budgets with Independent Living Trusts and with other legal bodies)* • *Legal (including scope of Direct Payments regulations, and use of Well Being powers of the local authority.* • *Understanding of provider culture and practice* • *Understanding principles and practice of Individual Service Funds.* **Where a social worker is nominated to manage the money this will require additional skills:** • *Hands-on financial skills and knowledge (including knowledge of costs of in-house services and how these are dealt with locally)* • *Awareness of employment law, payroll issues, HR issues, awareness of IT solutions.*	Social work core skills will be highly relevant for many of the decisions required for someone to complete this step. Social workers are often in a good position to mediate between the person at the centre and the local authority as commissioner, and this role will be just as important in the transformed system. Social workers may have important specific roles in relation to arrangements such as ISFs, where there may be a need to advocate on behalf of the person, as providers get used to a new way of delivering support. In the longer term we expect that the reliance on social workers as advocates will diminish, as person-centred thinking becomes more pervasive.

Step	Tasks, skills and knowledge required	A role for professional social workers?
Step five: Organising my support 5	*Ensuring each disabled person has the support they need as a customer / ensuring that a full range of types of support are available locally / ensuring that direct help and assistance with service design is available for those who need it.* *Empowerment and organisational skills.* *Communications.* *Overcoming disability discrimination.* *Direct work: some people need direct, practical help to organise and manage their support. This requires a range of life skills and management skills, including time management, financial planning, negotiation and advocacy skills and general awareness of mental and physical health and wellbeing.* *Individual service design: some people will need help to actually design and build a service around them.*	Professional social workers have broad-based skill sets, which are responsive to both individual and system, and which should be particularly well attuned to these complexities. This may be particularly important where someone has no one else in their life to provide help. But there is no doubt that this is a challenging area for social workers, many of whom have not been asked to work in the very broad-based, lateral-thinking manner required. If local authorities do see a role for the social work workforce here, social work staff need the development opportunities, remit and time in their work schedules to take on this set of tasks.
Step Six: Living Life 6	*Ensuring that people have the fullest range of support options available to them locally / ensuring that they have the information and means to access these and use Personal Budgets to purchase what they need to achieve the goals in their plan.* *A means to take an overview of the local market for support and to act to plug gaps.* *Skills in engaging with the full range of service providers.* *In relation to service design and tailoring of support: where someone has a particularly complicated life, or is very significantly impaired, unusual arrangements are sometimes necessary.* *Ability to contingency plan / respond to crisis. There is a need to be flexible and responsive when things don't go to plan*	Social workers are often well placed to take roles in terms of the provision of market intelligence and in service design and with individual Personal Budget users. They should know both the individuals the local community, and be in a good position to provide a form of on-going quality check of what is in place.

Step	Tasks, skills and knowledge required	A role for professional social workers?
Step seven: Seeing how its worked 7	*Ensuring that people have the opportunity to check whether things are going well, to learn and to make adjustments where necessary / ensuring that the wider community sees money well spent / ensuring that other disabled people can learn from the person's experience.* *Energy, enthusiasm and openness.* *Negotiation skills.* *Ability to evaluate the total situation.* *Conflict resolution where this arises.* *Assertiveness and confidence to follow through on conclusions where different views prevail.* *Financial management where budget issues arise.* *Belief and confidence in the values of person-centred approaches and citizen-led solutions.*	Professional local authority social workers will often be the leaders, and, in the early days of SDS, many local authorities will want their staff to lead the process. Professional social workers bring skills in guiding people through life changes: the journey to make effective use of a Personal Budget over time is all about such changes, and social workers are well placed to help. See the paper Reviewing Progress on the In Control website for further guidance on this step.

Figure 17: Possible roles for social workers in Self-Directed Support

A fuller version of this table appears in the paper, *Self-Directed Support: Social Workers' Contribution*[10] which can be found on the In Control website.

The paper concluded that there was no task in the process that could only be done by social workers. But it does appear that, in many instances, social workers are best-placed to undertake particular tasks. The education and experience of professional social workers should be seen as a valuable resource for local authorities.

Social workers themselves are generally enthusiastic about Self-Directed Support, seeing a convergence between the values it promotes and those of the profession. One social worker from the London Borough of Newham said:

> *The introduction of Self-Directed Support in 2008 challenged me in various ways. I thought there would no longer be the duty of care by local authorities. I thought the system would be open to abuse. I also felt that I would be disempowered as a social worker and that the new way of delivering services might promote conflicts between social workers and service users. Today, having completed a few cases, I feel differently about SDS and my role. I have realised that I am still relevant in the scheme and that service users have become involved in their own affairs and that the conflicts I had perceived are non-existent.*

Ensuring that people are safe

Some people worry that Self-Directed Support fails to keep people safe. In Control's experience, however, is directly contrary to this worry. All the evidence In Control has collected suggests that people feel and are safer when they are In Control of their support and their money and they can determine what happens around them on a day-to-day basis. Of course, this does not mean that there is nothing to worry about. Personalised support services cannot magically eliminate risks. That would not be desirable: risk is an important aspect of a full life.

In Control believes that personalisation makes people safer because it:

- is focused on strengthening citizenship and using the most appropriate measures, balancing freedom and control to help people stay safe
- improves the current care management system by the use of Self-Directed Support, which provides a comprehensive approach to risk management
- enables people to move away from ineffective and institutional systems of control, which create a dangerous illusion of safety but which have proved inherently risky
- provides an ideal model for responding to complex cases of vulnerability and abuse where careful risk management and person-centred practice are essential
- creates the best possible framework for preventing abuse by strengthening communities. Connection with friends, neighbours and other local people who know and care about us are usually by far the best way to stay safe, and we should do everything we can to strengthen these connections.

Finally, and most importantly, personalisation makes life safer by helping people to take back responsibility and thereby get control of their life and move away from harmful environments.

We have written in previous reports about the concept and practice of **risk enablement**, a part of the Support Planning process that helps people and those around them to develop plans that include risks they can assess, understand, and mitigate. The local authority can agree the plan as it stands, suggest amendments or turn it down depending on its view of the mitigating measures included. Risk enablement is now an important part of the Self-Directed Support process in most local authorities.

Risk enablement in support planning is not the only means of helping people to stay safe. We need to make available a range of simple, accessible tools and resources to people with planning and decision-making through all seven steps of the process. (See the section on support planning and brokerage in Chapter Two). Local authorities also need to review their formal safeguarding procedures with these issues in mind as they think about the role and remit of their workforce.

In Control recommends that local authorities:

- clearly define the role and responsibilities of professional social work staff and others in terms that reflect the positive role they play in risk enablement for individuals, and for the detection and prevention of abuse
- make it clear that it is the responsibility of all staff to be aware of adult and

child protection procedures, and to provide alerts through the agreed channels with appropriate urgency

- make it clear that suspected or actual incidents of abuse will be investigated and potentially prosecuted by the police and criminal justice system
- set out the important role that professional social workers have in many situations, especially in instances where criminal prosecution is viewed as inappropriate. Social workers are well equipped to work alongside the police to resolve complex social and family issues of risk and responsibility, and to bring into play gentler measures through the planning and problem-solving approaches outlined in the table above
- play a part in the creation of a no-blame culture – one which provides a collective response to abuse and does not scapegoat individual members of staff.

In Control's *Total Transformation Safeguarding Project* has taken this thinking further and the local authorities involved are now developing a series of policy and guidance documents to support positive risk-taking. These documents include a template with model terms of reference for a Risk Enablement Panel and a model policy framework to support choice and control. The group has also reviewed the processes that support some of the ethically contentious issues that local authorities face when people appear to lack mental capacity to make decisions, or when they regularly take decisions in ways which seem reckless of their own safety or which put those around them in danger. We will publish more on these important issues in the coming year. [11]

Changing in-house services

People using local authorities' own services have, historically, had little choice and control. Most have had to accept the offer of a particular in-house service, or they simply did not get any support. With the introduction of Personal Budgets, there are already strong indications that this is changing.

Many of the local authority Members of In Control have a significant investment in in-house services including day services, short breaks, residential care, home-care and supported housing.

As local authorities have offered Personal Budgets to more people, the implications for in-house services have become clearer. Some of the issues necessitate changes in culture and thinking – in similar ways to commissioners and external providers – but others are particular to in-house services.

Future demand for in-house services

As part of the *Total Transformation* programme, In Control worked with the Housing and Support Partnership[12] to develop a simple model that could measure changes in patterns of expenditure in services, based on how individuals with Personal Budgets choose to spend their money. The results show the potential financial impact of this change over a five-year timescale for in-house services, as well as for those services which are externally commissioned.

The results show that:

- some people opt out of buying in-house services altogether and create an arrangement that meets their own particular needs by employing Personal Assistants or commissioning a bespoke service from a provider, using, for example, an Individual Service Fund
- others opt to purchase in-house services but only if the service can meet their particular needs. There are many examples of how people reduce their use of in-house services and create a bespoke service using the remainder of their Personal Budget.

In all cases, a Personal Budget allows people to take their money elsewhere if they choose. For people whose need for support services is new, there should now be a real choice: they will not simply have to accept what is on offer – going to the local council day centre or making use of the council respite service. This, of course, poses a problem for local authorities that cannot rely on in-house services being taken up in the future.

Some people will want to continue buying in-house services as an entire package of support because the service is good and meets their needs. In these cases, people know and trust council services, there may be little else on offer, and they do not wish to create anything different.

The important questions that local authorities must ask themselves and local people who need support include:

- What do current and future users of support want and need from in-house services?
- Do in-house services satisfy these needs and wants?
- Are in-house services sustainable and competitively priced in the market?
- What is the local market (competition)?
- Are in-house services sufficiently flexible to enable people to take their money elsewhere if they choose?

In Control worked with the consultancy organisation, Paradigm[13] and other partners to develop an IT-based package, *Reach*[14], to support local authorities to change day services within the context of Personal Budgets and ensure that change is based on what people who use the service want.

The nature and scope of change for in-house services

The nature and scope of changes implied for in-house services varies from one local authority to the next, but a common requirement will be the need to make these services attractive and responsive to what citizens want and will buy. Services will also need to be affordable and priced competitively with similar services in the independent sector. They will need to be sustainable and be structured and managed in such a way that there is flexibility to tailor support to meet individual needs.

These changes may include the reduction or closure of some services. Others may adapt to meet new needs or gaps or niches in the market – specialist support for people with very complex needs, for example, or providing help with support planning, brokerage or community bridge-building.

A new activity for many in-house services will be positioning and marketing. Services will need to think about the most effective approach to positioning and marketing the service they provide. Most in-house services have limited experience of market research, promotion and communication.

Personal Budget holders will want services delivered in a way that suits them. In-house services will need to develop new and more flexible ways of delivering services and move away from single-product services. Some services may need to develop a menu-based approach based on the identified preferences and likely purchasing decisions of current and future customers. This approach must include prices that are linked to the menu of options and reflect real costs.

Costing and pricing in-house services

In-house services will need to attach a chargeable unit to the product they are selling and must take a transparent and realistic approach to the costs of delivering the service, including management and overhead costs. This has been difficult for in-house services so far because the inclusion of directorate and corporate costs can produce a price for the service that cannot compete in the wider market. In-house services will need to analyse their costs and consider how direct and indirect costs and overheads can be reduced.

In some local authorities, the favourable staff salaries and conditions (compared to the independent sector) may mean that a unit price is higher. This does not mean that a particular service is uncompetitive if staff conditions lead to a service of exceptionally high quality, or one that fills a gap in the market that other providers struggle with. Services will, however, need to consider changes in working practices to remove any non-essential or bureaucratic activity, or they may simply need to do more.

One standard way of deriving a unit cost is to divide the overall budget by a chargeable unit, such as an hour or day or service user. This method is unhelpful in Self-Directed Support, mainly because a price is needed that reflects the actual delivery of the service and is not dependent on a fixed volume (as in a block contract). Sheffield City Council have worked with the Housing and Support Partnership and NAAPS to develop a series of pricing tools to enable in-house services to calculate unit prices based on activity[15].

Local authorities also need to analyse and understand the link between the components of the Self-Assessment Questionnaire, Resource Allocation System and the future role for in-house services to ensure that costs are competitive, and to understand how any necessary efficiencies in the cost and organisation of in-house services can be made. If cost exceeds market price, the options for the authority are to cease activity, carry on with a subsidised service, or change the service in one of the ways outlined above.

Newcastle – Care at Home

Newcastle City Council's in-house homecare service, ***Care at Home***, analysed its position and viability in the market. The unit costs were £32.81 per hour compared to other similar services provided in the independent sector which were between £11.65 and £12.64. ***Care at Home*** could not compete in this market and so the Council could not sustain the service. The Council made a decision to focus on early intervention and prevention and only provide in-house services to people requiring palliative care or who had complex support needs. All mainstream long-term care packages will be provided by the private sector. ***Care at Home*** will provide a free re-ablement service for up to six weeks for all new service users. The benefits will include an enhanced focus on re-ablement, no redundancies and the meeting of some complex support needs in the community.

END

The experience of transformation

Many of the stories and examples in this and other In Control reports feature the words of ordinary people – Personal Budget holders, family or other community members who share In Control's values. This is deliberate, and In Control believes these testimonies are the best measure of success.

This chapter and the preceding one have concentrated on the experiences of paid local authority and provider staff who are now charged with re-thinking what they offer. This is a considerable challenge, one that should not be underestimated. Where this challenge is tackled head-on, the outcome should be celebrated. The twenty *Total Transformation* local authorities made significant progress in the two years of the programme and worked together to find solutions to many of the challenges we identified at the outset. By the end of the programme, more than 13,000 people across the 20 authorities were in control of their budget and many more were in process.

This chapter concludes with the words of paid staff from two of the leading local authorities. The first is John Dixon, the Director of Social and Caring Services in West Sussex County Council, who also has a warning – that personalisation should not turn into a *cuts exercise*. The second is a social worker from the London Borough of Newham, who highlights both the positives and some of continuing concerns about the implementation of Self-Directed Support.

John Dixon, Director of Social and Caring Services, West Sussex

In local authorities the penny has started to drop that this is a major opportunity to address underlying problems. There's a bit of a domino effect and this is encouraging. At the same time, we must pay attention that this doesn't simply turn into a cuts exercise. Overall, the transfer of control and a policy of personalisation is fundamental to the future of public services. The tide of expectation can't be held back. It's a social phenomenon. The people who are becoming older now won't be pushed around. We professionals will have no choice but to change our ways.

END

Newham social worker

I sometimes felt that I was limited in what I could do to bring about the desired change in vulnerable people's lives by resource-driven service provision and delivery. Managers had become more like finance controllers. I was, therefore, thrilled by the introduction of Self-Directed Support as a more flexible alternative to the existing Direct Payments – especially in leaving users in control of how services are delivered and in the assessment of their own needs.

There is a worry though: this flexibility has sometimes been hampered by the use of systems such as performance indicators and target-setting in the work environment and these limit the time we can spend with service users.

END

Summary: some of the things we need to do to change the way support is provided

Good practice	Avoid
Nurture local business and enterprise, including small social care providers, especially ones that are innovative and responsive.	Avoid traditional block contracts and other off-the-peg solutions. Get out of the block contracts that already exist and develop plans to personalise directly provided services.
Ensure people have support and advice to manage their money in whatever way they want, and to stay legal.	Don't disregard the expertise of social workers and other professionals. Their role needs to change to reflect the seven-step model. They can then become among the best advocates of Self-Directed Support.
Commissioners and providers should work together to develop commissioning plans that are realistic but which also capture the visionary nature of personalisation.	Don't assume that people have easy access to information about local supports or that they will find it easy to use their Personal Budgets to purchase what they need. Instead, invest in an on-line system like *shop4support*.
Ensure that there are mechanisms to help people stay safe through Risk Enablement and through safeguarding procedures that follow the principles of Self-Directed Support.	

Figure 18: Good practice and things to avoid when changing how support is provided

NOTES

1 This summary is adapted with the permission of Embrace Wigan & Leigh.

2 See for example: (2007) *Commissioners and Providers Together, the Citizen at the Centre*, available at **www.in-control.org.uk**

3 These distinctions and other work in this paper draw on the work of Clive Miller at the Office of Public Management: **www.opm.co.uk**

4 Office of Public Management: **www.opm.co.uk**

5 In Control (2010) *A Framework for Commissioning: Model Guidance*, available at: **www.in-control.org.uk**

6 Hatton, C., Waters, J., Duffy, S., Senker, J., Crosby, N., Poll, C., Tyson, A., O'Brien, J., and Towell, D. (2008) *A Report on In Control's Second Phase, Evaluation and Learning 2005-2007*, In Control, London.

7 Organisations working in this way include: Inclusion Glasgow: **www.inclusion-glasgow.org.uk**; Partners for Inclusion: **www.partnersforinclusion.org**; C-Change for Inclusion: **www.c-change.org.uk**

8 NAAPS – the National Association of Adult Placement Schemes – is a UK charity established to represent the interests of all those involved in delivering very small, individualised, community based services such as Shared Lives (formerly known as Adult Placement): **www.naaps.org.uk**

9 NAAPS and Department of Health (2009) *Supporting Micro-market Development, Key Messages for Local Authorities*, available at: **www.dhcarenetworks.org.uk/_library/Resources/Personalisation/Personalisation_advice/SSMSCSEkeymessages.pdf**

10 These results appear in the paper: Tyson, A. *Self-Directed Support: The Social Workers' Contribution*. See also the follow-up paper, *Systems, Practice, and Support of Professional Social Work Under Self-Directed Support*. Both are available at www.in-control.org.uk

11 The *Terms of Reference for a Risk Enablement Panel* are reproduced as Appendix 1 of this report.

12 The Housing and Support Partnership provides consultancy, training, development and research in housing for vulnerable people: **www.housingandsupport.co.uk**

13 Paradigm describes itself as *the leading consultancy, training and development agency in the field of disability:* **www.paradigm-uk.org**

14 This will be published by Paradigm in April 2010.

15 Available on the In Control website: **www.in-control.org.uk/In-house**

Chapter 4

Looking ahead

Lynda and Georgina

My name is Lynda Hicks. I have a daughter, Georgina, who is 26 and who has Downs Syndrome. We both did the first National Partners in Policymaking *course in Loughborough.*

Georgina is a very articulate young lady and has always wanted to be a hairdresser. She did her NVQ level 1 course in hairdressing when she was 16. She has worked in a hairdressing shop ever since she finished the course but has never been allowed to properly pursue her career because of problems presented by the industry.

Firstly, to get Georgina a job in a salon I had to go to every hairdressing shop on the Wirral asking would they take her on as a junior. That was soul-destroying because, sadly, we live in a 'beautiful society' and if you are not one of the 'beautiful people' it's hard to get into. We did eventually find Georgina a job in a salon but she was not paid – it was only voluntary. At first, Georgina didn't mind that because she was doing what she had always wanted to do. But after several years of brushing the floor, gowning the ladies and making them a cup of tea Georgina started to get disheartened.

It was at that point that we went on the Partners *course. I think this changed Georgina's life. It gave her confidence. She has always been a confident young lady (but in a shy sort of a way). Going on the course seemed to open her up to other ideas and she seemed to start thinking for herself.*

Anyway, a consultancy job came up at Paradigm. They were looking for someone with a learning disability to fill the post. I talked to Georgina about it and she said she quite fancied it because her heart wasn't in hairdressing anymore. In all the years she has worked in the business, she has never felt valued or appreciated. So she decided to go for the interview at Paradigm and she got the job! She starts on 1st September. She is thrilled to bits and is looking forward to the new challenges ahead. We have talked about it for hours and, even though she is a bit frightened, she is also excited. As her mother, watching Georgina develop, I definitely know that the Partners *course gave her a new confidence that I don't believe she would have gained otherwise.*

END

Jenny's Personal Health Budget

Jenny has cancer and is in hospital. She needs a hoist in order to move from bed to chair and toilet, so is being assessed to move into a nursing home. She does not want to make this move and would prefer to return to her home. She would need considerable support to achieve this. The nurses think she will be safer in a nursing home.

Jenny now has a Personal Health Budget. This means that she is supported to plan for her future and discuss all the risks involved in returning home. As a result, an OT went to her house to assess what work on the property was needed to accommodate the hoist and electric wheelchair. As Jenny would need her bathroom enlarged to accommodate the hoist, she was asked to consider going into a home while the work was done. She did not want to do this, so a compromise was reached: she would use a commode in the bedroom until the work had been carried out. This approach allowed Jenny full choice and control and satisfied safeguarding issues for all concerned.

Most people, if given the right support, would rather remain at home than go into hospital, a nursing or residential home. Personal Health Budgets will help people to get the right home support so that far more people have the option of staying in their own home.

END

Grapevine

Grapevine is a community organisation in Coventry that connects people with learning difficulties with other local people who share their interests.

Grapevine does this by building on two strong beliefs: firstly, that inclusion is possible for everyone, regardless of personal history, disability or anything else; and, secondly, that belonging is an essential part of a good life, to keep us healthy, happy and safe.

Many organisations claim similar values, but Grapevine's approach has been unusual in the way it works to build on these ideas by really attending to – tuning in to – what individuals and those who know and love them say (and don't say) about what makes the person feel good.

The organisation uses this information to find someone who is right to work with the person – in a way that is genuinely based on shared interests, mutual benefit and real caring. Then there is sometimes a long process of learning by trial and error, while the right connection is found.

There are a number of detailed examples of individuals who have grown and developed through this process in Chapter Ten of *In Community*[1].

Examples include:

- Des who, after months of trying out different experiences, joined a steel band as resident fan and fundraiser.
- Paul, who realised his dream to become a DJ and ended up having his own show on community radio and training to be a club DJ.
- Mark, who became a healthy walks leader.
- Anoop, a keen sports fan, who is now a member of a local hockey club where he recruits new players and takes photos for the website. (He had struggled to fit in elsewhere.)

For more information about Grapevine, contact Clare Wightman:
cwightman@grapevinecoventryandwarwickshire.co.uk

END

Looking ahead

Perhaps the single most important insight from In Control's work over the past two years is that the vast majority of ordinary people do not think about their lives in the boxes that local and central government use.

These boxes – for example, *Children's Services, Adult Services, Community Development* and the boxes within boxes, *Special Needs, Physical Disability, Learning Disability (or Difficulty), Mental Health, Black and Minority Ethnic Services* – were developed for the good reason that it is not possible for everybody to know about everything. There is a need for some specialist knowledge in order to support people well, and sometimes it seems to make economic sense to cluster specialist services together. Also, many people like to be connected with others in similar situations to share experiences and gain peer support.

The problem with the boxes approach is that it pushes our thinking down a road that leads away from family, connections and a whole life, towards default solutions – specialist services, often located in special places away from the mainstream of community life. This approach means that people have to make sense of many different systems and adapt to the requirements of many professionals. If people happen to find themselves in two or more boxes it is common for them to fall through the middle. Then the bureaucracy struggles to bring a range of agencies and departments together and make rational decisions in the interests of the whole person.

Connecting people

If ambitions for personalisation are to be realised, we need to re-think and give greater emphasis to a person's whole life, their family, friendships, community and ordinary connections. We must focus much less on the demands of specialist services. In Control started the move to Self-Directed Support by working with local authority adult social care departments and providers, mainly in services for people with learning disabilities.

During the past two years, however, possibilities have expanded and deepened. We can now see the first prospects presented by a **whole-life approach**, guided by ordinary people – members of a social movement – and supported by professional people who share that

movement's values. This final chapter in Part One of the report begins to describe the challenges ahead as personalisation extends further and deeper.

We have begun to address these challenges by focusing our attention on three dimensions.

Children, young people and families

Paradigm's *Dynamite* programme and In Control's *Taking Control* programme have demonstrated that the principles of personalisation and Self-Directed Support apply just as much to children, young people and their families as they do to adults.

To achieve genuine personalisation, we need to think about the whole of a person's life from the time before they are born to the time they die. We also need to see the person in all their aspects – with family and friends, learning, working, having fun, staying healthy. The work with young people that Nic Crosby wrote about in the *Report on In Control's Second Phase* has developed rapidly in the last two years and has become a cornerstone of In Control's work. Many of the examples given in this report are about young people and their families.

Health

We have learned that we need to give special attention to people's mental and physical health, partly because this is so important for older people and for disabled people of all ages, but also because the ways we approach health and health services has a particular history, and brings a particular set of challenges.

In Control's work on Health, *Staying In Control*, began early in 2008, predating Lord Darzi's report[2], which made the idea of piloting Personal Health Budgets the legitimate business of the NHS. This initial work produced the first discussion paper on Self-Directed Support in Health: *Citizenship in Health*[3]. We must now test out how Self-Directed Support in Health can work best for the people directly affected; for the professionals and clinicians who support them; and for the communities around them. The Department of Health is now leading a *Personal Health Budget Pilot Programme*. In Control is a strategic partner and a member of the Programme Board. The second phase of In Control's Health programme complements the Department's work, and brings to bear In Control's experience and value base.

Community

Community deserves special consideration. In particular, we need to pay attention to the great diversity of our communities, particularly in regard to: rural and urban, prosperity, age-profile, cultural and ethnic mix and a host of other ways. We need to ensure that our focus extends beyond the individual to whole communities so we can find ways to encourage communities to welcome and sustain all their members. In 2009, Carl Poll and others produced an important book, *In Community, Practical Lessons in Supporting Isolated People to be Part of Community*[4], and In Control launched its *Stronger Communities* programme, led initially by John Gillespie and now by Alicia Wood.

Diversity and Equality

Underpinning In Control's work is a set of fundamental beliefs. These include the perspective 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.*

Since In Control began work in 2003, we have understood not only that personalisation is an approach for all, but also that, to make a real impact, the models we develop need to be flexible so we can meet the needs of all cultures and groups within society. As we look ahead to broaden what we do, this feature of In Control's work becomes more prominent.

This issue has begun to be recognised elsewhere, for example by the Social Care Institute of Excellence (SCIE), whose *Signposting* project aims to help identify how products such as their recent series of *Personalisation Guides*[5] are relevant to Black and Minority Ethnic Communities.

Many local authorities and service providers are now starting to think through ways in which they can adjust how they implement Self-Directed Support to ensure equality of access. The two stories below illustrate this direction: the first is from Oldham and features Bridging the Gap, a support agency that works with the local Asian community. The second features a piece of research commissioned by the Department of Health.

Bridging the Gap in Oldham

Shazia is a young Muslim woman from Oldham who has used mental health services.

Shazia and her family were asked about their hopes of being able to take control of her support. They wanted a more flexible service, one that took account of the things that were important to her.

Shazia said *I wanted my support to be truly flexible. This was not always possible when I was supported by traditional services.*

Some of the concerns held by Shazia and her family were about gender issues and respect for her religion and culture. Her supporters also needed to be bi-lingual. The hope was that this would improve her life at home and her access to the community. Nothing of this kind had been offered to the family before.

Shazia and her family described what was important about having control of her support:

To be able to choose the staff that support my daughter, not having services deciding for me who should support Shazia. To have staff who understand my daughter's needs and lifestyle and support her accordingly. Not having to explain and justify why I do things differently. Not to worry about staff bringing non-halal food into my house with the risk of Shazia eating it.

In the past, things had not been right for Shazia and her family. The stress had resulted in her being admitted to hospital with mental health problems.

Before In Control, it seemed difficult to imagine things could change for the better. We almost believed, as we were told by the professionals, that this was part and parcel of Shazia and her mental health problems.

Fortunately for Shazia, Oldham had adopted Self-Directed Support for all eligible adults. Shazia and her family attended awareness days to hear about others'

experiences. This gave them the confidence to work on implementing a plan and recruit Shazia's staff. They took the decisions, rather than have a care manager decide things for them. The assistance of Bridging The Gap made a positive difference too as it helped them make sense of the whole process. The family said:

Traditionally services make these decisions for you. It was a bit scary to get used to the idea of having to make all these decisions ourselves. Having a good agency gave us the confidence.

The individually tailored support worked well for Shazia. The consistency of staff led to a significant improvement in her mental health. She became very settled and soon began, for the first time, to make use of resources in her community.

Everyone involved has seen a big improvement in Shazia. The family concluded:

Give it a try and find a good local provider to help.

This account was provided by Shazia, her family, and a member of the support agency, Bridging The Gap.

END

The Personal Advocacy and Story Telling Project (PAST)

The British Institute of Learning Disabilities (BILD) has been funded by the Department of Health to discover how well the process of accessing support using a Personal Budget is working for people from Black, Asian, Minority and Ethnic (BAME) communities with learning disabilities.

It is widely acknowledged that barriers exist that can prevent individuals from BAME communities from gaining equitable access to advocacy services, hence also from gaining equal access to health and social care[6]. The aim of this project is find examples of excellence in advocacy.

We have called the project *The PAST Project, Personal Advocacy Story Telling*. Our main aim is to share the stories which we hope will enable advocacy groups, people from BAME communities and professionals involved in personalisation and Individual Budgets to learn and develop better ways of working and engaging with people who have learning disabilities and are from a variety of Black and Minority Ethnic communities.

Sondra Butterworth has been employed by BILD to lead the project.

The project has three key objectives:

1. To gather stories from people with learning disabilities from BAME communities.
   - The process will be carefully thought out with the needs and wishes of those willing to share their stories taken into consideration. The necessary consent will be obtained before the stories are shared.
   - These stories can be shared in whatever format the story-tellers wish: for example, a visual recording, story book, written word, pictures, or through an advocate.
2. To gain stories from advocates who have had experience of working with people who have learning disabilities from BAME communities.
   - We plan to hold three consultation events in Liverpool Birmingham and London in the Spring of 2010. The title of the events will be *Personalisation and BAME Communities: Finding the X- Factor.*
   - The main objective of the events will be to discover what advocacy groups,

and the individuals who self-advocate think about Personal Budgets and personalised support.

- We want to discover if advocacy groups have learned key lessons from their experience of working with people from BAME Communities.
- The responses from the advocates who attend the events will be collated into a report, which will inform the direction of the PAST project and hopefully provide us with valuable information about why people from BAME Communities have not yet always made full use of Personal Budgets.

Clare Roberts, Project Worker from In Control, met with Sondra Butterworth recently to discuss how BILD and In Control can work collaboratively. Clare will co-facilitate one of the consultation events and will contribute to the short report.

3. To gain information from health and social care service providers with regard to how they engage with people from BAME communities.
   - The aim of this part of the project plan will be to identify what barriers health and social care service providers think exist, which may prevent individuals from BAME communities from gaining equitable access to advocacy services and Personal Budgets.
   - An on-line questionnaire is being developed, and representatives from health and social care service providers and advocacy groups will be invited to complete the questionnaire. The responses from the questionnaire will be collated and written into a final report.

Details of *The PAST Project* can be found on the BILD web site at www.bild.org.uk

If you would like further information or you would like to be involved: s.butterworth@bild.org.uk ; telephone: 07702 369 092.

END

The final word on this subject goes to Rackhee McNulty from Leicester, the mother of Liam, 21, who has both learning and physical disabilities. Rackhee talks about some of the cultural barriers her family has faced:

In our culture you don't ask for help. You just have to get on and do it. This can be really hard.

Children, young people and families

In Control believes that personalisation demands a fundamental shift in the relationship between individual citizen and the state. This shift has certain technical aspects – hence In Control has worked with local authorities to develop Self-Directed Support that includes Resource Allocation Systems and Personal Budgets.

Chapter Two describes this work but also makes clear that there is a more fundamental challenge in creating personalisation: to understand what people have a right to expect when they need various kinds of state support.

At the centre of this new relationship are the needs of children, young people families, working-age adults with a disability or a mental health problem, and older people. Our hope is that all of the individuals concerned will now come to see their needs defined and met in new, more individual ways; and that the re-designed processes are built on the view that each individual has the potential to become an active, contributing member of their community.

The public profile and reputation of our children's services is, at best, mixed. This reputation was further damaged by the recent Baby Peter case in Haringey. It often appears that almost all of the media profile (and hence the public attention and most of the resources) is on child protection and rarely on those children who are in need of support due to disability or impairment.

Nevertheless, some local authorities continue to provide good support for the latter group. Sefton is one example. In Sefton, the Council clearly defines the different needs of the two groups and avoids the very common issues that families have to deal with if they have a child with a disability – namely that they cannot get support unless their child is deemed to be *at risk from some level of abuse*.

A mother from another area told In Control *Ah well, I have been told once he reaches 18, he will get the right support then for his disability, but, until then, it is expected mum does all the support. That's lovely for me, but he hates having his mum helping him at activities where no one else's mum stays.*

Situations like this one arise because of a service mindset that says *His family love him a lot. He's not at risk. He doesn't need protection. Therefore, no resource is needed.* Supporting people using good social work and community support can prevent many young people ending up in out-of-borough or out-of-county placements. Most of these are triggered for frustrated young people who didn't get the modest amount of help they needed in their early teenage years.

Families frequently talk of being made to feel *grateful* for any support offered, whether or not the support is chosen or actually meets their needs as they perceive them. Changing this experience lies at the heart of personalisation. Parents live busy, hectic, often chaotic and stressful lives. Their support needs and those of their children have to be met in a way that supports them to maintain emotional well-being and activity.

We know from our own experiences as family members that if we can meet these needs and offer children a stable and secure home, they can thrive. The personalisation agenda, the use of Personal Budgets, the emerging role of the Budget Holding Lead Professional and lessons from work in the adult world have now begun to help us think through how we can support families to take control.

Until very recently, the Government considered personalisation as relevant to working-age adults. More than two years ago, the *Taking Control* programme had begun to pioneer an approach to personalising the relationship between children, young people and their families, and the state. In 2010, we are still not in a position to offer a complete picture – it is certainly not a question of *job done*. However, we can draw on learning from across the country to identify the fundamental changes needed to deliver personalised support to a child or young person and their family.

This work in progress draws on learning from In Control's own programme and also from the Department of Children Schools and Families-funded Budget Holding Lead Professional work[7], the work of the Commissioning Support Group[8] and of the Office of Public Management (OPM) to outline the beginnings of an approach to personalisation for children, young people, their families and the services they use.

Children's Services – and families and children themselves – need time, space and opportunity to make sense of and develop this agenda from their own perspective. It is not simply a case of picking up the work done in adult social and health care and transferring it to the children's world.

There are a number of fundamental challenges:

- The subtleties of supporting a child in a family that is struggling to offer the child the support they need.
- The demands of paying attention to what children are saying and, at the same time, ensuring that parents feel they are respected and retain their right to decide how their children are brought up.
- The importance of helping children stay safe in a world where staying safe is seen as increasingly problematic, and those employed to ensure children's safety are portrayed as both intrusive and ineffectual. This is a very different context from that of adults, who are encouraged to plan their own lives.

This section of the report sets out how we are beginning to address these challenges in order to develop a personalised approach to supporting children, young people and families. This approach must include how we begin to promote best outcomes for any child living at home with their family, and also offer personalised solutions for those no longer living with their family.

Government policy and guidance

Since 2007, Government policy for children and families has tried to catch up with the policy shift in adult social care.

Aiming High for Disabled Children: Better Support for Families[9], sets out an ambitious three-year programme of work to transform Disabled Children's Services. In many ways,

it builds on the work of the Budget Holding Lead Professionals, which were piloted in sixteen areas of the country from 2006.

The *Aiming High* programme contains a set of work areas:

- Extending the current offer of short breaks
- The *Transition Support Programme*
- Childcare
- Palliative care
- The *Core Offer* and *National Indicator*.

The Government has also committed to piloting Personal Budgets. These pilots were launched in March 2009 in six areas[10]. Four of those six sites are members of the *Taking Control* programme: Newcastle, Gateshead, Gloucestershire and Essex.

The *Aiming High* agenda is focused on delivering a *Core Offer*[11] that covers:

- information and transparency
- assessment
- participation and feedback.

Taking Control **Members see Personal Budgets as critical to the delivery of this *Core Offer*:**

- making available good information
- involving families in the allocation of their resources
- good assessment (most efficiently using the Common Assessment Framework)
- giving families the tailored support they need
- delivering participation with immediate feedback.

Family members are active in taking the pilot work forward and are key members of Steering Groups and Project Boards in all *Taking Control* local authorities. To be successful, this approach must continue to be developed from the roots up. Families are leading the work through practical action. They are now seeing the benefits of their pioneering involvement: there are improvements to their quality of life and the health and well-being of children.

In Control's work with children, young people and families is influenced by the learning from its work with adults and by the undertakings given in the *Putting People First* Concordat, published in December, 2007. *Putting People First* sets out a vision for personalisation beyond Self-Directed Support and the technology of Personal Budgets. It describes how public organisations must assist people to access universal services in their communities. This approach is vital to the design of supports that children, young people and families need to live good, healthy, well-connected lives – and, in many ways, it sets the benchmark for our programme.

What we have learned from *Taking Control*

Taking Control[12] began in 2007. It supports a growing network of Children's Services in developing Personal Budgets for children and young people. By August 2009, 35 services were Members. There were 85 live budgets for disabled children (including one for a

three-year-old child) and three set up and managed on behalf of children in the care of the local authority. In the same month, Gloucestershire County Council decided to nominate all their Budget Holding Lead Professional budgets as Individual Budgets. This decision took the total of Personal Budgets for children and young people in the country to over 750.

There are four areas of work being undertaken across *Taking Control* sites:

- The Front Door / Initial Point of Contact
- Resource Allocation
- The Support Plan
- Living my life.

The Front Door/Initial Point of Contact

The **Front Door** covers the first contact between services and a child or young person and those caring for them.

Member sites identified the following key actions[13] to be completed at this front door:

- completion of the Common Assessment Framework (CAF)
- ensure equity of access – the front door is open and accessible to all
- universal / mainstream services are available to the family
- eligibility for further support is established.

If we give attention to what people need at this first point of contact, we begin to appreciate how personalisation and our approach to Personal Budgets can start to have an impact in many areas of life, and not just in terms of people's long-term support needs. Adding in a small Personal Budget often means that the support a young person gets from universal services can be made more effective and more tailored to their needs and circumstances.

The London Borough of Newham

Newham joined *Taking Control* in January 2008. The Borough has 16 live Personal Budgets for children who are supported by Disabled Children's Services. They have started to explore how they could use a simplified approach to resource allocation alongside the Common Assessment Framework (CAF).

They have tailored their allocation system, including the outcomes set out in The Children's Plan, and, in the case of their *Mini-RAS*, limited the funding available to £3,600 based on their current CAF-linked spend on children and families.

The *Mini-RAS* allocation system is used as one of the tools available to the lead professional in setting an outline allocation to support the child or young person. This approach is viewed as extending the use of a Personal Budget to the **Front Door** as one way of meeting the support needs presented by the child.

END

Resource Allocation

The method of resource allocation is sometimes described as one of *participatory allocation*. It differs from those assessment processes that are focused on information-gathering. In *Taking Control* sites, most children and families have been receiving or would be expected to receive support from the specialist Disabled Children's Team. Hence, the funding distributed using the Resource Allocation System is usually managed as part of the budget allocated to Disabled Children's Services: some authorities have added to these resources, using monies from *Aiming High Short Breaks* funding.

The basis of the approach is a simple set of statements that enable families and professionals to identify how much support the child or young person needs to achieve the agreed outcomes. Taking Control has used the *Every Child Matters Outcomes* (ECM) as the basis of these statements.

Each statement relates to one of the outcomes set out in the *ECM Outcomes Framework*. These are:

- Stay safe.
- Be healthy.
- Make a positive contribution.
- Enjoy and achieve.
- Achieve economic well-being.

This approach aims to ensure that support needs are met with an appropriate allocation of resources, as in the model developed in adult services. This is an **indicative allocation**, which means that, where necessary, the amount can be challenged and amended.

Major learning points from this process include:

- Both professionals and families report how this process appears to be a first step in radically changing the relationship between person and professional. Most regard this as a positive change. (A few professionals have struggled with the adjustment in role and relationship.)
- Most families report that there is now much less need to *battle* to get the support their child needs, as they did under the old system.
- Across all sites, reports suggest a zero-cost impact on budgets. However, there have been changes in distribution of resources and sizes of allocation.
- These changes in allocation relate to a number of factors, which reflect learning from early adopters in the adult world, particularly: families who in the past have not used all or even part of the support offered but now do so; families who in the past have not come forward with eligible needs due to the restricted options available but are now doing so.

The last point indicates that these experiments with personalisation in children's services are gradually uncovering **unmet need** and meeting **eligible need**. All participants take a positive view of these changes. There will be a budgetary impact. However, all suggest that it is better to know about the need than it should remain hidden.

The approach has also been piloted outside Disabled Children's Services – with children in care and young people with substance misuse problems through links with the work of Budget Holding Lead Professionals. This work has incorporated careful consultation with

a group of young people who have experience of the care system as well as many different groups of parents. The exercise has identified challenges in the process of agreeing the real costs of support for this group as well as questions about how the allocation fits with the high costs of current services.

However, there has been extremely positive feedback from young people. There is broad agreement about using a set of common outcomes as the basis for resource allocation for this group. Further work is needed to set and agree these. The long-term intention is to have a common allocation system that works for all children and young people.

A version of this allocation system for the national Learning and Skills Council[14] is now complete. Although its introduction is still under discussion, it is being used in two local authority areas: Sheffield and Essex to allocate an Individual Learning Support Fund (ILSF). The example that follows is from Sheffield.

Developing integrated funding – using social care, Health and Learning and Skills Council funding

Sheffield City Council has been involved in a ground-breaking piece of work which points the way to integrated Personal Budgets (that draw together funds from different sectors).

The work in Sheffield involved students leaving Talbot School who combined different funding streams and made a single Support Plan that delivered a common set of outcomes. This was the first year that all students from Talbot School pursued their further education in Sheffield. (In the past, some have had to go outside the City.)

Social care money was allocated by the Sheffield Adults' Service Resource Allocation System. The Learning and Skills Council funding (currently allocated using a matrix system) was decided using a prototype *Every Child Matters* allocation system mirroring that being used across the *Taking Control* network. The Learning and Skills Council funding focused on delivering *learning support which enabled a student to participate in learning activities with identified learning outcomes*.

The next challenge was to develop a single Support Plan that evidenced the delivery of learning outcomes pertinent to social care funding and, in two cases, Health funding.

Gerry Kelly worked as the broker on this project and explains:

Young people only have one life, so having only one plan to support them just made so much sense. The planning process allowed the voice of the young person to be clearly heard. It also gave those involved in supporting the young people and families a general understanding of what was needed and when.

The issues that arose, such as getting the timeframes right, were worked through with a view to improving the experience and making it easier as time went on. This was empowering for the young people and their families and will prevent another culture of dependency being created in the future. The obstacles that arose felt surmountable by virtue of having 'the money issue' resolved. For the first time ever, I did not have anxious and frustrated families phoning me during the summer holidays.

END

The Support Plan

Creating a robust, child-centred Support Plan is essential. The Support Plan sets out how all the resources available (not just the Personal Budget) will be used to provide the support the child and those caring for him or her need. It should include how any resources provided by Children's Services will be used or spent. This section covers four steps from In Control's seven-step model: Making my plan, Getting my plan agreed, Organising my money, and Organising my support.

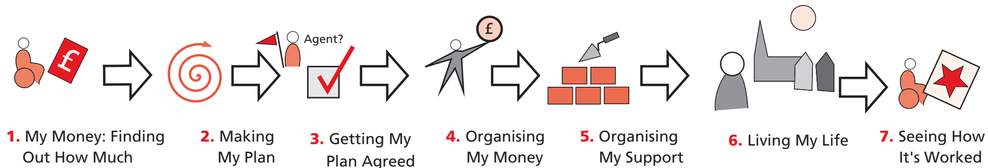


Figure 19: In Control's Seven Steps to Self-Directed Support

Making the Plan

Every Support Plan is individual. The process for each person is different. But new insights and profound changes are common outcomes in support planning. Ryan's planning process below gives an indication of how the Plan can trigger significant change.

Ryan – Middlesborough

Ryan is 17. He lives at home with his mother, father and two younger sisters. Ryan's family has struggled to use short break services and saw an Individual Budget for Ryan as an opportunity to get support that works and is flexible.

Completing the Resource Allocation questionnaire proved both challenging and enlightening for Ryan's family. They came to appreciate how much support they give Ryan and how he is completely dependent on them. They found completing a plan quite confusing to start with. Understanding rules around spending the budget and thinking *outside the box* were initially quite difficult. However, they have completed the plan and it has been agreed.

Ryan's parents think the Individual Budget has completely changed their life and Ryan's. They have been able to get support when they want it. Ryan has been on holiday twice this year. He has begun to speak and his school has reported a big improvement in behaviour. Ryan is less anxious and much more relaxed.

The whole process has encouraged Ryan's family to think deeply about Ryan's support needs and how they can plan for a more adult life for Ryan in the future. They want to use the Individual Budget to help them begin to plan for the future and for the transition to the adult world.

END

Getting the plan agreed

The local authority needs to agree a process for signing off the completed plan.

In agreeing to sign-off a Support Plan, the local authority is making a statement that it believes the plan delivers its duty of care and provides a positive and clear approach to keeping the child safe. There is a clear expectation in agreeing the Plan that concerns and needs identified within the CAF or other formal assessment are acknowledged and acted on. Local authority managers report greater confidence in the delivery of their safeguarding responsibilities through the child-focused Support Plan than previously. They say they feel better informed about how the resources and support will work for the child.

Managing the money

Family life can be busy, chaotic and demanding – especially if you have a son or daughter with an impairment or additional support need. Families need a full range of support options that reflect their choices and circumstances. It needs to be clear that there is no assumption that the family will take responsibility for managing the budget. So far in *Taking Control* local authorities, there have been few examples of new services developed to help families to manage the budget.

One option is for the local authority Children's Service to manage the money on behalf of a child or family. This example illustrates how this can work.

Carrie and Jo

Jo is a Service manager in a Children's Service participating in the *Taking Control* programme. Jo and colleagues have been supporting a young woman, Carrie (16 years old), to think about how she could use her Personal Budget from Disabled Children's Services.

Carrie attends a mainstream school and has physical impairments. She needs a lot of support to get up and go out and about. Her mother does not agree with some of Carrie's ideas about how she wants to be supported. For example, they disagree about the number of showers Carrie should take in a week. Such disagreements prevent Carrie's mother from effectively managing the budget. Jo has taken on the role of managing the budget. Jo hopes that, in the long-term, Carrie will manage it herself.

Carrie now has a shower every morning, with help from her own support staff (people she knows well and trusts). She also has pamper sessions each month. She is supported to go out with young people she knows from school, including to support their local football team. From Jo's and Carrie's points of view, the plan is working very well. Carrie is leading the life of a young adult and feels more confident being out and about. Jo sees one of the major outcomes as the massive increase in Carrie's self-esteem.

END

Organising support

The next step is to find appropriate support. This account from Halton describes one approach.

Halton – Piloting Children's Individual Budgets

In Halton, eleven families were part of the pilot which began at the end of 2008. Five families had a child under the age of five years old and the other six were over ten years old. The pilot was one of a number of initiatives funded by *Aiming High for Disabled Children*.

Halton Children's Services commissioned Barnardos and Halton Speak Out to complete the Resource Allocation questionnaire and to support families to develop their support plan. Barnardos runs a Children's Centre in Halton. Its offer of support was centred on this facility. Families were very positive about support from people working in the voluntary sector. They said they felt more able to open up to non-statutory agency professionals.

Families liked the support:

- *We had it very easy. My son's community nurse put our names forward for the pilot and a lady from Barnardos was very good in giving us all the information we needed. We had our assessment and within two weeks things were up and running.*
- *Barnardos have been brilliant with us. They have given us loads of information. They have also found us a nursery to try out over the summer. We had a letter from the nursery inviting us to come along and see them and they asked me to leave Stuart with them the following week. I was very nervous about it because I don't like leaving him with people he doesn't know, but he absolutely loved it.*
- *I would most definitely recommend it to other families. The flexibility of it, and that it benefits Noah directly is just fantastic and there are no restrictions. You can totally personalise it to your child.*
- *We've had a summer like no other. Usually we would have to pay for everything ourselves, which means that we couldn't have done all these things together as a family. On top of it all, our other children would normally have got upset because we could only ever afford for our son to go to these things.*
- *My son was clear from the very start that it was his money and he didn't want to share it with anyone else. When Mal came to see us, he said to her clearly that he didn't want to do anything with his brother.*

The pilot has been very positive and the commission for Barnardos to expand their offer of support is being confirmed. Individual Budgets will continue to be offered to disabled children and young people in Halton.

This case study is an extract from a full evaluation of the Halton pilot carried out by Pippa Murray of ibk initiatives.

END

People need a menu of support options – one that includes, at one extreme, the capacity to recruit and train a team for a child or young person, and, at the other, a range of in-house support services that offer good value for money and are competitively priced with private and voluntary providers. Adult services have demonstrated that part (or all) of a young person's Personal Budget can be left within the service to fund in-house provision and children's services can follow their example.

Living life

There are now many stories about children, young people and families making good use of a Personal Budget so that they achieve what they want in life, are happier, healthier, safer, get a better education and are better connected with others. A number of these stories are used as illustrations through this report. Another one follows, told this time in the words of the young person himself. It is stories like this that provide the real inspiration and drive for our programme. Hence, we conclude this section with Kieran's words.

Kieran has a Personal Budget and support from a Budget Holding Lead Professional (BHLP)

My name's Kieran and I want to say how the BHLP programme has made a difference to me.

As a young person who has moved round a bit, it hasn't always been easy to settle at anything much. Sometimes being able to ask for help has been difficult. The BHLP programme has changed that. I was able to choose my own rep and have total input into deciding the things I need and how to achieve personal ambitions.

It's pretty cool being able to ask for things and sometimes actually getting them!

But that's how it works and it really makes you think carefully about using the service to ground you and think about what's important to you. I don't always get what I want and sometimes it's a disappointment, but I'm never scared to ask and when things are really tough I know I can ask my rep and they'll look after my basic needs too!

I'm working now. I've passed my bike test and I'm living in my own flat. There are still changes to be made and things I want to achieve. The biggest difference to me though is feeling much more confident and able to decide my own future.

END

Beyond Personal Budgets: a whole-life approach

The move to personalisation is principally about increasing the choice and control people can exert over the support they receive, whether health[15] or social care. In Control and its partners are convinced that we need to go further and deeper and adopt a **whole-life approach** across ages and support needs. We also need to take into account the contribution of all the other elements that people must draw on if they are to live full and active lives. For some, this may mainly mean having a Personal Budget. For others, financial resources may consist of other elements.

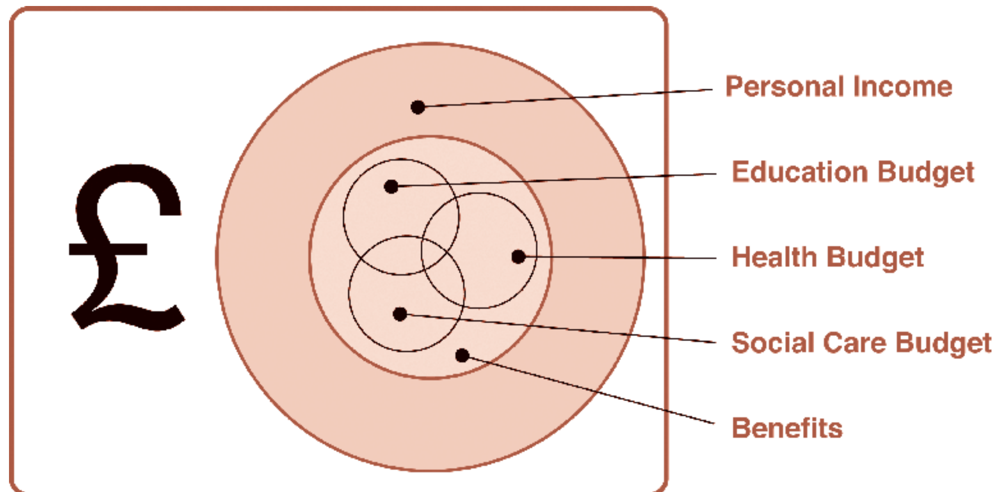


Figure 20: Financial resources available to an individual or family

A Personal Budget adds to the resources available to an individual or family. These resources can be used in the everyday life of the community – whether using the bus, getting to the library, going to the sports centre, joining a youth club, going to the cinema, watching a football match or going on holiday.

However, the financial assets we have are far from the only determinants of how we decide to do things, who we spend time with and what we choose to do in our day-to-day lives.

Real wealth

Nic Crosby and Simon Duffy suggest that every individual, family and child draws on a range of sources of **real wealth** in order to shape and lead the life they choose.

When we, as citizens of our community and the wider world, make decisions, choices and plans, we make use of the whole of this real wealth.

The elements that make up real wealth are:

1. Understanding

What we know about the world and ourselves is fundamental to what we can achieve. Having a rich understanding of the world and what it can offer us is the first dimension of real wealth. However, if we lack important information about the world, our communities, our bodies or ourselves, we will struggle to achieve what we want.

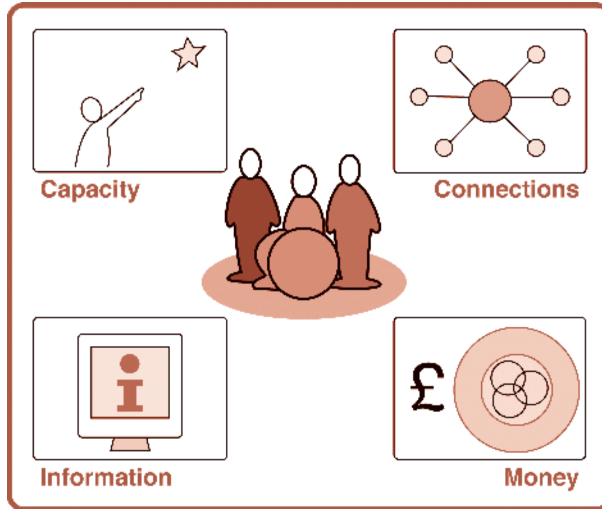


Figure 21: Real wealth

2. Connections

Who we know – our family, friends, colleagues and neighbours – is vital to our lives. Almost everything we do in life is with or through others. If we are rich in connections we can quickly access opportunities, resources or information. However, if we are isolated we will struggle.

3. Assets

Money, capital, property and other financial assets are also vitally important in the modern world, both to our sense of identity and our ability to be independent. If we are rich in assets we can pay for things, employ people or commission support. However, if we are poor we become reliant on others. We then lack the means to achieve our goals.

4. Strengths

Each one of us has a combination of strengths or abilities – not just formal skills but the full range of human gifts. It is by developing and expressing these gifts, by using our skills (however extensive or limited they may be) that we construct our lives. If we are lacking in ability or our gifts go unrecognised by others, we will feel trapped and incapable.

5. Resilience

Our resilience is forged by many factors: our genetic make-up, our mental and emotional health, our physical health and history, our whole-life history, experiences both positive and negative, achievements and losses, our sense of who we are and our own value, our ability to learn.

Resilience is likely to vary over time and will be affected by the impact of life events, good and bad. This is one reason why the timing of our engagement with the Self-Directed Support process is so important and why sensitivity to each person's unique situation is necessary, People unused to or out of practice with being in control and making decisions may need more support and time to successfully grow those skills and gain confidence. (Re-ablement services, which have proved very popular in the last couple of years, are in part a means to defer this engagement to the right moment.) There is growing evidence, of the importance of not underestimating people's ability to take control (if they have appropriate support) and the transformative effect of such self-reliance on their lives. It is this flame of inner resilience that is the central and most important dimension of our real wealth.

In Control's *Taking Control* programme is one way in which we are now working beyond adult social care to embrace the whole of life. Another is a programme to help families with a disabled member plan for the long term, particularly to plan ahead for a time when parents have died or are no longer able to provide direct support. This programme, *Our Futures* (previously Plan UK), is outlined below. A further very important aspect of In Control's whole-life approach is our Health work, which is described in the next section.

Our Futures UK

Our Futures UK (formerly PLAN UK) is a project serving and supporting small local family groups around the UK. This model of support for families who are caring for a disabled relative is influenced and inspired by the work of PLAN Canada.

Our Futures supports families to make and implement long-term plans to provide peace of mind about *what happens when I am not here?* It does this through helping families to make practical preparations including building a circle of support for the person who will need long-term care, and committing to support each other – as much as is necessary and no more than is needed. It has hospitality and reciprocity at its heart.

The core values are:

Family leadership – recognising the vital and indispensable role of families, and that we don't always need a professional solution or input to make things work.

Safety and security through relationships – *An individual's health and safety is directly related to the number of relationships in his or her life.* (Philia Project)

Relationships make our lives rich and meaningful. Belonging is paramount.

A core aim of the model is to help families ensure that the person they care for does not have only paid people in their lives. Good services are not a good life: that requires relationships of choice and friendship and love.

Self-sufficiency – The model promotes reciprocity and equal relationships with funders, based on give and gain. It promotes social enterprise, particularly the development of micro-enterprises to support people with a disability to be able to support themselves and to contribute.

Contribution equals citizenship – To be part of one's community one must give to gain. Everyone has a contribution to make. *The health, wellbeing and strength of our society require the presence and participation of all citizens.* (Philia Project)

Over the past year, the project has been delivering a programme to set up new local groups and creating a national resource. It has also insisted on the need to be a family-led project. As a result, families have chosen the new name and a partnership arrangement with Embrace Wigan and Leigh has been formalised. Embrace is now managing the programme into its second year, and working in partnership with In Control to develop a long-term plan for *Our Futures UK*.

***Our Futures* is an In Control Project**

END

Health

The importance of relationships in the health transaction: Dr. Paul Hodgkin

I think that there's already evidence that having control makes you healthier. Feeling trapped – learned helplessness – makes you unhealthy, so how we do this is really important. It's not just what NICE[17] tells us is effective, it's also how we do it.

I think what's happening in the New Neuroscience is really exciting. Over the next five or ten years, it will become apparent how you give statins is as important as the fact that you give the statins. All these arguments will get overlaid progressively with an understanding that it's the relationship as well as the transaction that matters. People are absolute experts at spotting insincerity in relationships, so you can't fudge it. You can't do little tricks of looking them in the eye or whatever. It has to come from the heart. So I think this is about a renewal in the next decade of putting professional practice right at the heart of things so that people understand this and can integrate both the really important bits of evidence that come out of NICE and the New Neuroscience, which says how we do things with people is absolutely crucial.[16]

END

Patient or whole person?

Dr. Hodgkin sums up what many people have said to In Control about health. We believe that we must see individuals as whole people, individuals who have a range of complex interacting needs but also the potential to make a contribution – to contribute and creatively engage in change, often in ways which amaze and confound our traditional ways of seeing doctor-patient or practitioner-client relationships. Our focus is on whole people in their social context.

We recognise and value the fact that people are members of networks made up of their friends and family, and are part of whole systems. This applies both to people requesting help and those seeking to provide that help. A change in one individual has a knock-on effect. For instance, if someone becomes ill, their partner will worry, and that state of anxiety will have consequences. Much of our work in this area is, therefore, focused on supporting people to recognise and sometimes to renegotiate their relationships. It is about designing and modelling new ways of sharing power between commissioners, providers and professionals, and those seeking support and treatment.

The aim is to adjust the balance of power so that it moves further towards people directly affected by ill health, to enable them to be more actively engaged and have their personal experience of illness respected as an essential component in decision-making. How someone reacts to illness and to changed life-circumstances is specific to them, their personality and previous life-experiences. This remains true no matter how much we learn about an illness, its prognosis or the likely effect of a range of treatments.

We cannot assume we know, for example, that an individual would always rather be pain-free, regardless of the impact of the medication on their whole life and priorities. We need, therefore, to actively seek out the individual's sense of what is happening to

their body, their thinking and emotions, and the impact that these changes have on those around them. We need to initiate a dialogue that might support shared decision-making – where personal, lived experience joins with and enhances professional wisdom.

A new relationship

There will always be health situations, in which we would best leave power and decision-making with expert professionals. Some people may never want to change this arrangement. Of course, some situations and some medical conditions are more reliant on clinical interventions than others. In Control's view, based on its work in social care and on its commitment to people's right to an ordinary life as full citizens, is that, over time and with sufficient information and support, most people will want to take more control of their own health. The key aim is to create a changed relationship between the NHS and the people it serves: people take more responsibility and clinicians share decision-making.

Citizenship and health

For some people, the experience of living with a health-related condition leads to a sense of grief and loss as well as a reduction in self-esteem and self-confidence. While the intent remains that people lead ordinary lives as full citizens, those experiencing the losses that may result from a degenerative disease may find that they have changed priorities, so sensitivity needs to prevail in planning their support. Individuals should not feel judged if their Support Plan is less about playing an active citizen role and more about feeling understood, safe, cared-for and comfortable.

Self-Directed Support is a whole-system approach specifically designed to enable better decision-making, and to make best use of public money by shifting information, power and control closer to people. A social movement is now forming, driven by disabled people themselves who demand these changes. This is true of both health and social care. Our health is affected by many things, including social and economic factors such as poverty, isolation, unemployment and poor housing. As Simon Duffy has shown, these are the factors that, in part, constitute **citizenship**[18], and this sense of citizenship matters in the way we think about our health. A society that excludes people from citizenship guarantees poor health, as evidenced, for example, in the early death rates of people with mental health problems.

Over the last couple of years, and with increasing momentum, the ideas underpinning Self-Directed Support have been expressed in thinking within the NHS. Often, different words are used but the same themes are present: shifting power and control closer to people who are experiencing an ongoing illness.

These ideas have also found expression in several Government policy initiatives. For example:

- The work on *Rethinking long term conditions* by the Centre for Clinical Management Development at Durham University
- The *Co-creating Health* three-year demonstration programme by the Health Foundation
- The *Expert Patient Programme*
- The latest Department of Health *Personal Health Budget Pilot Programme.*

It seems that there is an emerging consensus that the principles that underpin In Control's work on personalisation can and should be applied to important areas of the current health care system. At the same time, most people acknowledge that there is much more thinking and experimentation to be done.

As we have seen, a central element of Self Directed Support is the use of a Personal Budget. In Control's working definition of this concept as applied to health is as follows:

> *A Personal Health Budget is an allocation of resources made to a person with an established health need (or their immediate representative).*

The purpose of the Personal Health Budget is to ensure that the person is able to call on a predefined level of resources and use these flexibly to meet their identified health needs and outcomes.

The person must:

- know how much money they have in their Personal Budget
- be able to spend the money in ways and at times that make sense to them
- agree the outcomes that must be achieved with the money.

The budget must be:

- used in ways that help the person achieve predefined outcomes
- targeted towards individuals with specifically defined needs.

As we have seen in Chapter Two, Personal Budgets can be held in a variety of ways: notional, real budget held by a third party, or (when legislation is in place) healthcare Direct Payments[19].

Our experience suggests that – just as in social care - Personal Health Budgets will only work if there are also:

- opportunities to meaningfully plan and shape treatment and support – in a flexible way
- effective systems of support, information and advice
- a range of effective options
- appropriate systems for professional input and monitoring
- a shift in the power between an individual and the NHS. In practice, this means a move away from the worst aspects of the stereotypical patient-doctor relationship.

As our work in social care demonstrates, if these other factors are not in place, people will struggle to make Personal Budgets work for them. Money alone is insufficient.

A personalised approach is one that involves improved decision-making and a more equal and helpful relationship between individual and the state. It is much more than *giving people money*. Sometimes people are poorest when they are using their own money because they may have no information, no connections, no confidence, no knowledge of other possibilities and no one to help them plan. In Health, just as in social care, knowledge of someone's **real wealth** (see above) is central to understanding what they may need in order to make best use of their financial resources – whether those resources

come through a Personal Budget or not. For some individuals, the major driver for change may be provided by their loved ones or others in the local community who push or encourage them. Simply offering someone control over money is rarely sufficient and may even be pointless without involving this broader context. For people to have control of the necessary resources for active citizenship we need to see them as whole people in their whole context – their real wealth, not just their illness and finances.

In practice, seeing people's real wealth means:

- increasing people's understanding of risks, options and good strategies
- strengthening people's skills and confidence
- helping people to stay connected to each other.

While we move towards outcomes and processes that are as simple as possible, we must be clear that this new approach will also sustain current good professional and clinical practice. This new perspective is based on a dialogue between people. It is about recognising that the person who experiences a health issue has a contribution to make alongside the contribution of the professional *expert*. We want to make sure that the person's voice and their sense of what works for them is taken into account alongside the clinical perspective.

To ensure the person's perspective is taken into account, we must have:

- a clear process for authorising plans so that the person is healthy and safe
- expert clinical input alongside an individual's own views and ideas
- continuous appropriate monitoring and review of an individual's health condition over time.

The Planning Together diagram captures these essential features:

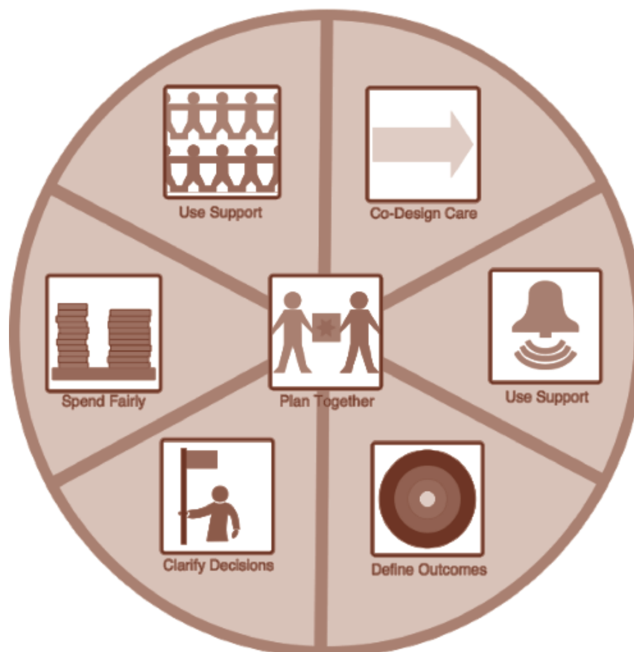


Figure 22: Planning together

Personal Health Budgets and the NHS

The creation of the NHS was one of the great achievements of the twentieth century and, in the UK, we are rightly proud of it.

In Control supports the NHS in:

- providing the highest quality care
- offering universal and equal access
- being free to those who need it.

These are important principles and any reform should be underpinned by them and seek to enhance and improve them.

The Department of Health is now taking forward the Government's proposals for piloting Direct Payments for health care. Subject to Parliamentary approval, the Health Bill provides power to make regulations allowing Direct Payments in authorised pilot schemes. This is an important development because it is a very significant step for Government to give even a few people more power and control over their health support needs.

The latest policy document for the NHS has many references to personalisation including:

> *By putting power in the hands of people we have created a powerful engine for reform. Where once we had to rely on national targets to drive improvements, we can now drive change through the influence of patients. This will be the basis on which we renew our vision for the future*[20].

Self-Directed Support and Personal Health Budgets are not a universal panacea. They will not be appropriate across the whole of the NHS, nor will they resolve the financial constraints of a limited NHS budget. Self-Directed Support, based on a transparent system of Resource Allocation, will necessarily bring to the fore an open public debate about health priorities and how to connect provision of resources to need in the most efficient and effective ways.

The evidence from social care shows that people themselves have the highest vested interest in getting best value for their money, so long as it is made clear that it is indeed their money. In considering **efficiency**, we must factor in the wasted resource represented by services that are provided but which people do not want or use. We must also take into account the effect on efficiency when people are cut off from natural community supports and their dependency on services increases as are result.

Self-Directed Support in Health must now be carefully evaluated. Any move towards Self-Directed Support in Health must demonstrate value for public money and sustainability in the long term. But it is important to think about effectiveness alongside efficiency. It is essential, in other words, to evaluate not simply the savings made through different purchasing arrangements but also the changes these arrangements bring about in people's lives from the perspective of the individuals themselves, their family and friends, and of the professionals involved with them. An evaluation must also address the wider strategic issues of resource use across the whole public health and social care system. Learning in the health system is at an early stage but already suggests an exciting future.

Translating key messages into action

The following section was written by Jo Fitzgerald, who is the parent of a young man using a Personal Health Budget. At the end of each section, Rita Brewis, In Control's lead on Health, suggests how the ideas can be translated into action.

Key messages

Key messages are already emerging from people and families based on their direct experience of Personal Health Budgets which accord with the points already discussed. As the parent of a young man with a Personal Health Budget, it is reassuring to hear that, even at this early stage, people and families are being heard.

The importance of listening to people and families

The process of developing Personal Health Budgets so far highlights the need to listen closely to what individuals and families have to say. Being listened to and understood very early on in the process of developing our son's personal health plan was especially transformative for us as a family. It enhanced our self-belief, enabled us to clarify our thoughts and crystallised our vision. I know this to be true for other families too, and this suggests it is an integral part of the process that cannot be negated or hurried.

It is widely acknowledged that clinicians and services will need to embrace a huge culture shift as Personal Health Budgets are introduced. This is also true for those using these budgets. After years of being *done to* by services, having the opportunity to talk intimately about their experiences will help people explore what a Personal Health Budget could mean to them and to unlock their full potential. From the dark place we were in four years ago, the biggest shift in our family's process occurred when we began to see that there was an alternative to the way we were living. Suddenly, there was a light at the end of the tunnel.

> **Rita Brewis comments:** In Control intends to support individuals and families to share learning about support planning. This planning process starts with an exploration of what is important **to** someone, as well as considering what is important **for** them in terms of their health. Support planning differs from care planning in that it starts by identifying someone's hopes and dreams – how they would like their life to be. The planning process then goes on to explore how those hopes may best be realised by understanding what is important to and for that person. Personal Health Budgets enable this process to make best use of information about the public money available and the person's own real wealth.
>
> Jo Harvey of Helen Sanderson Associates has worked with colleagues in West Midlands Primary Care Trusts to create a draft set of criteria and a workbook to support people developing their health plan[21]. In Control will work with individuals and families and also with decision makers in PCTs to share such good practice about what criteria are useful when signing-off a Support Plan.
>
> These criteria include how risk is managed and what training needs to be undertaken to support a person and meet their health needs. This may include complex clinical tasks. Hence, careful consideration must be given to the role and development needs of clinical staff. It will be essential to ensure not only that

clinical tasks are performed expertly and safely, but also that the way in which the tasks are carried out conforms to the person's Support Plan.

We need to invest in people and families

Not only do we need to listen to individuals and families, we also need to invest in them. Investing isn't simply about acknowledging people's own innate resources. It's also about investing in innovative mechanisms to support people to take control. For example, there will be people who want to set up a social enterprise as a third party mechanism to manage their budget and provide them with support. Or, pooling their resources may give people what they need in order to manage complex packages of care using local knowledge and expertise. We also need to think about toolkits for families. People must be empowered and supported to find their own solutions.

A good example of this is a family in the north west of England who have negotiated their own third-party arrangement with a third-sector organisation. This arrangement has been agreed by the commissioner and will start in January 2010. So, we need guidelines that help people to negotiate what they want and need from such a third-party arrangement. And we will need to train and support the people brokering their own arrangements and recognise that, in essence, they are citizen commissioners.

Rita Brewis comments: In Control will work with four key groups to co-create a toolkit that will make Personal Health Budgets a reality for the maximum number of people. The four key groups are: people wishing to use a Personal Budget; professionals; commissioners responsible for agreeing and monitoring the plan; and service providers who wish to have a role – either in terms of direct input, or a support role in *holding the money* or employing staff on someone's behalf.

This work is both urgent and important, especially since it appears that, for several years to come, legislation to allow Direct Payments in Health will only apply to a few Primary Care Trusts; and also that many individuals and families may not immediately wish to hold money themselves or employ staff directly but will want control over their health plan and over how resources are used. We need a suite of flexible options, backed-up by effective information and support systems so that people have the degree of direct control they want (and they do not feel that responsibilities are imposed on them). This is the way to ensure that personal health plans can be used equitably across diverse communities by people in a range of different circumstances, including those who lack capacity.

Transfer of power to people must be genuine

It isn't enough to choose whether to go shopping or where to go on holiday. Sharing power means much more than involving people in support planning. Our family learned this lesson when we entered into a third-party arrangement based on a false set of assumptions. We assumed that what we (the family) meant by being *in control* was not the same as what the organisation we had appointed to hold our son's budget meant. Sadly, within two or three months, it became clear we were talking a different language. As the third party, the organisation was responsible for the budget and for all important decisions. We did not experience any shift in power. What we got was no different to the service we had left behind. We have since brokered a new arrangement based on shared values and aspirations and this is now working as we had always imagined.

Rita Brewis comments*:* In Control intends to work with its Members to find effective ways of measuring whether the transfer of power is real. These measures will be created by individuals and family members working with provider organisations to agree the framework for a useful set of criteria that can be developed over time and through actual use. We will also work to connect people who want to link together locally, regionally and nationally, to advance a movement towards power-sharing by finding collective solutions and providing mutual support.

Timing is crucial

While there are many similarities between Personal Budgets in social care and Personal Health Budgets, there are also significant differences. I believe timing is one of them. People with long-term or complex health conditions often experience many peaks and troughs in their life. There can be a huge variation in how people experience their condition at any one time. This suggests to me that we need to think carefully about timing.

As people start to be offered Personal Health Budgets, we need to ensure the process is not prescriptive. We must refrain from offering a Personal Health Budget only on discharge from hospital, for example. Again, I am drawing on our family's initial feelings of relief when our son was discharged from hospital after twelve months. At that stage, we would not have wanted or been ready for a Personal Health Budget. However, things felt very different two years down the line. Those involved in offering budgets must be sensitive to where people are in relation to their health condition. They need to remain open to the fact that people change their minds, and that should not be a barrier to having a Personal Health Budget when the time is right.

Rita Brewis comments: In Control will work with its Members to find simple ways of ensuring that a Personal Health Budget is made available to people in timely, accessible ways, not offered as a tick-box exercise (which will prevent take-up). We will also be alert to the threat that any targets put in place by Government may unintentionally impede real choice in whether and when someone wishes to take control over their health plan.

Having a Personal Health Budget is not '*all or nothing*'

Having a Personal Health Budget does not mean cutting all ties with existing services. It should afford someone the opportunity to take control of whichever aspects of their life they choose, and should not lead to the loss of services which provide helpful and timely support.

Rita Brewis comments: In Control intends to work with all its Members and through public presentations and publications, to share a clear approach to health support planning which emphasises the importance of a changed dialogue between individuals and health professionals. This dialogue will enable integration of the best clinical knowledge and professional contribution to health outcomes with the individual's own personal priorities.

Urgent: some people need a Personal Health Budget as soon as possible

There are a number of people who, having had a Personal Budget for social care, have been reassessed for Continuing Health Care funding, and their budget has been taken away. Those people are experiencing a profound loss of choice and control. They had built strong relationships with Personal Assistants only to be told that arrangements that had been working so well could not be continued due to a change in funding. This can be immensely distressing.

Sadly, some of the people most keen to have a Personal Health Budget do not live in a place which is part of the In Control or Department of Health programmes. How do we support the people who aren't in the best place emotionally or geographically at this time? How do we support those people to have a dialogue with commissioners and to articulate their sense of urgency? There are people who simply can't wait for us to work everything out. We need to have opportunities to learn through practice.

> **Rita Brewis comments:** In Control aims to join with citizens and those who support them to demand change and to communicate the distress which some people feel.
>
> At the same time, In Control seeks to work constructively with policymakers and Government to support strategic decision-making and sustainable developments. We remain committed to building confidence and resilience throughout public services, as well as with individuals and communities, and, by doing this, producing the shift in power that people need. Since we all use health services, we all have a big stake in developing the NHS and sustaining its best qualities. We will continue to link people so that they can share ideas about what is possible and we will publicise the new solutions they find. We will continue to share stories of how people can and do transform their lives when power and decision-making are shared.

Community

Since In Control began in 2003, it has emphasised the critical importance of connection with others in our community. What exactly do we mean by this? What does it mean to *take part in community life*? This is not a straightforward question. For each person, the answer is different, and it can be extremely difficult to pin down exactly what we mean when we make general statements about *inclusion* or *community involvement*.

Sue Bott, Director of the National Centre for Independent Living (NCIL)

In Control is working with NCIL to make sure that people really do have choice and control over their lives and are part of their local community. Sometimes people can leave an institution only to become institutionalised in their own home.

This can happen when the support needed to take part in everyday activities in the community is not recognised or when the value of the support is so limited it provides little more than help to get out of bed in the morning or a meal. This is not independent living. This is living confined within your own four walls.

END

Communities are made up of family, relationships, friends, informal associations, groups, clubs and societies, places of worship, education and learning services, voluntary sector initiatives, health and social services, housing, transport, elected politicians, emergency services, shops, businesses, entertainment, sports, leisure and other services.

We can crudely divide this mass of activities and participants into three elements of community life: public services; community businesses; and natural relationships and activities. In order to really take part in community life, people need these three elements of community to be working for them.

Public community services

In some aspects of community life – for example, council-run services, health, emergency services, transport – we tend to have a passive relationship with *the service*. We generally accept what we are given because what we are getting is in some way essential to us, and / or there is no-two way transaction. We are receiving and not giving back.

If we only receive services in this way, we are simply service users and our lives are restricted by this single role. Many disabled people are called *service users* by professionals even outside the context of the service. (By contrast, all members of the public are not consistently called *patients* even though we have all been to see a GP at least once.)

Nevertheless, deciding on a helpful definition of the roles of the service provider and user is important, particularly with essential services. We need to focus here on getting the power balance right and on making these public services directly accountable to people. In Control continues to urge that **all** public services become genuinely accountable in these terms.

Community businesses and services

In other aspects of community life, such as shops, entertainment and businesses, we are customers with the power and control to take part or not. If we think we are not getting what we want, we can go elsewhere or even start our own business or initiative if we see a gap and we have the right skills and energy. These types of relationships are usually transactional (we give money and we receive a product or service) and they provide us with some of the essentials and extras to live an ordinary life.

If we are only consumers, however, we go through life making transactions for goods and services and our life is empty of real connections to others. Much has been written about the fact that shopping centres have replaced churches in the nation's consciousness.

Nevertheless, being a consumer gives people power, choice and control. We buy goods and services for life's essentials, for the things that help us to take part in ordinary life, the things that help us feel equal to others and the things that give us pleasure. Businesses expend much effort finding out what the customer wants, rather than simply overwhelming people with choice (an approach that has proved ineffective). Commercial business aims to build a trusted brand for its customers. This demonstrates that people who have full choice and control in this way still need information about what is available to buy. Reputation by branded value is more powerful now than ever.

The principles of consumer choice, power and control should, therefore, not be dismissed. They have been used to develop *shop4support*[22], a social enterprise company that has developed web-based tools to enable people with health and social support needs to take on the more powerful role of consumer of support. *shop4support* also provides a social networking facility so that people are able to discuss what works and does not work for them. Customers can *vendor rate* services; and citizens can be encouraged to develop more informal ways to share their expertise and time (see the *Timebanks* example below). In Control has also promoted micro-enterprise as a means by which people can launch their own organisations to provide the support they need[23], or run their own businesses to earn a living.

Natural networks and activities

When it comes to family, friends, groups, networks, places of worship, clubs and societies and local voluntary sector organisations, the power relationship is more equal. We both give and receive in order to make the relationship, group or activity work effectively. This type of relationship is the most equal in that we have an opportunity to give something important from ourselves and to have our needs met. Hence, many people talk about these experiences as their main source of meaning and true support.

If we live our lives only as service users and consumers, and do not have these other relationships that are independent of financial or service transactions, our lives lack the qualities that can make life rich. If we make real connections with those around us in our community through family, friends and people who share our beliefs, passions and interests, then we find ourselves surrounded by others who reflect and confirm our identity – who we really are.

In Control's main work in this area has been in the promotion of community capacity building and using social capital in the process of support planning, with a clear

expectation that Self-Directed Support, if done well, will enable people to take part in community life.

In Control's community development programme has involved the promotion of ways in which organisations can help people who are excluded or marginalised to play a more active part in community life. We are also in the early stages of a piece of work with the Department of Health on social capital which is linked with our new *Strengthening Communities* programme with a small group of local authorities. *Strengthening Communities* promotes community development within local authorities' personalisation work, and helps them to experiment and test tools to do this effectively. A number of In Control's other programmes are built on the expectation that strong, inclusive communities that welcome the contribution of all their members either exist or will be nurtured. This applies to the *Partners in Policymaking* programme and its associated courses (see below) and to *Our Futures* (see above), and particularly to the *Public Membership* programme.

Community development needs different approaches for different people

In Control is working with many groups of people who, because of their life circumstances, have different views about what they want or expect from their community.

Historically, services deliberately removed disabled people from communities. More recently, society has provided disabled people with homes and services that are physically located in communities but still segregate them from the mainstream of community life. Many staff in residential services are still encouraged to view taking part in community as a trip out to the pub or bowling alley, for example. Many disabled people have not been encouraged to expect communities to offer anything to them – or indeed that they have anything to offer in return. Many still describe how they feel confined within *homes in the community*.

For people with mental health problems and people with learning difficulties, *developing community* has come to mean finding places to get away from the institution or service, identifying places and activities where people can mix with others in the community. In the last few years, community development on behalf of these groups has focused on professional interventions, mapping community resources and then devising ways to improve access.

For people with physical disabilities, *developing communities* has been based on demands for physical access; asserting the right to access buildings, transport and public areas, or the right to support in a job or housing. *Community development* for these groups has been largely about removing barriers to access so that people can have a good opportunity to get on and lead normal lives.

For older people, people with chronic health conditions and families and children there are yet other issues. Most have experienced life-changing events, often trauma, that have seen them take on the status of Health or Social Services *user*. Before this, fulfilling a role and taking part in community life was natural and taken for granted. For people in these circumstances, community development has been about efforts to maintain or restore their relationships in their community. We now see many older people supporting one

another to maintain their connections and stay out of residential and nursing homes – a trend we want to support and encourage.

We are also beginning to think about and explore issues for other groups, such as homeless people and others who may have had little opportunity in their lives to experience positive aspects of community life; or for those, like many people who have been institutionalised or spent long periods in prison, who have not been able to learn how to take an effective part in an open community. Another set of tools is needed to respond to their needs and potential contribution.

Our experience of community is changing, particularly as many people have moved away from the church. Many people no longer have a natural spiritual home and place to connect with each other. The people who make up our local communities are also changing as mobility increases and we move around the country and world more, and come to rely more on electronic communications and the virtual world. The rapid growth of social networking sites bears out our fundamental need to be connected with others.

It is undeniable that disability, ill health, ageing and the effects of institutionalisation are not the exclusive reasons that people are disconnected from their communities. The need for better connection with one another applies to us all, and this implies that the thinking and learning now beginning within the disability movement will be of benefit to all of us.

Principles of In Control's community development work

In Control's work on community will become a major focus in the next phase of work and will be underpinned by the following principles:

- Community, citizenship and connectedness to others are central to all of the work of In Control.
- In Control believes that all citizens, including those at risk of exclusion, have something important to offer their communities: profound changes can happen in society when ordinary citizens take the lead to transform their lives and their communities.
- In Control's approach to community development will be based in the experience of ordinary people and will use language that most people understand.
- In Control believes that community and connectedness matter to everybody, but developing opportunities for those most at risk of exclusion provides a good marker of our success in work with communities. In Control will, therefore, focus on developing communities with those most at risk of exclusion, though, in doing this, we must ensure that the whole community perceives the work positively.
- In Control's approach to community development involves ordinary citizens doing small or big things to make a positive difference to their communities. We need to create conditions that make this more achievable through community development activity and through developing technologies that make the most of **social capital** and **real wealth** (see above).

In Control will work in partnership with its Organisational and Public Members and with agencies concerned with community development on specific projects that meet these principles. We are not *experts* on community development: our role will be to facilitate learning, networking, sharing and evaluation.

The specific objectives of In Control's community development work will be:

- To facilitate community development at the grass roots level with public Members and *Partners in Policy Making* graduates through regional networks by mobilising energy and enthusiasm and securing funding where needed.
- To understand, by conducting research and evalution, the conditions needed for successful community development and what people need in order to develop community for themselves.
- To facilitate system change with our Organisational Members that allows community development to flourish.
- To evaluate whether initiatives have made a difference in the community and in people's lives through our evaluation work.
- To use In Control's website, publications and networks to share learning and stories in ways that inspire others to start their own community development initiatives.

Connected Care in Hartlepool

In reflecting on progress in Hartlepool, Sarah Ward, the authority's Social Care Transformation Manager says *We are facing the larger Putting People First agenda now. We need to think about the impact on community. There is a real community spirit in Hartlepool with 500 plus community organisations. Our work with Connected Care has meant we have had to consider all of this. We need to give some thought to how we make the most of it.*

The *Connected Care* initiative is an important example of what can be achieved. It is based in one ward in the Borough, Owton, which has a population of 7,000. Levels of deprivation are high. *Connected Care* is led by the national organisation, Turning Point. The project had as its central driver the notion of building capacity from the ground up.

The initiative was funded by the Borough Council, the Primary Care Trust and the Working and Neighbourhoods Fund.

It was described at its start in 2006 as comprising a number of major elements:

- A special team of navigators. This team will listen to the residents of the community to identify their problems and concerns, guide and support them and help link services to meet their needs. Team members will be recruited from the community.
- The development of a range of low-level support services that focus on maintaining independence.
- A **social enterprise vehicle** to deliver the above – this enterprise to be managed by residents and local community organisations, with statutory agencies as stakeholders.
- A service co-ordinator to manage the service and ensure it meets the needs of residents. This person to be recruited locally.

The project sought to address some of the barriers that local people saw as holding back their community. These barriers were identified and specified through a Community Audit which asked people about how services might be better organised to meet their needs. Themes that emerged included: information, choice, access to services, continuity and communication between services, and issues in relation to the workforce.

Ray Harriman, a Connected Care navigator, says *We often read about joined-up services, but the reality is that they are often poorly delivered. So a big piece of work is with partners to look at how we better align budgets.*

Another comment was: *Connected Care is not separate from the wider social and economic contexts in which people live their lives: Connected Care in fact needs to be delivered within this wider context. Initiatives that tackle poverty and create employment and prosperity are an important component of Connected Care.*

Ray Harriman gives the example of a family he has been working with, where there are real issues around the children. *The elder sibling has had frequent run-ins with the criminal justice system, the youngest has problems at school. There are issues around benefits advice, real issues of poverty and debt. We often see neighbourhood disputes and the consequences of a dire lack of suitable housing – seven people in a three-bedroom house.*

Housing Hartlepool introduced a new system so that families can now bid for a house. Providing a culture where local agencies – the Housing Department and others – think laterally has been one of the major successes of *Connected Care*.

Another example involves a young woman who came to see Ray with her mother. She was twenty-four and had four children – three of whom were in care. *She was coming off the top of very bad heroin addiction, no house – horrendous. Now she's got a three-bedroom house, her children back. We provide ongoing support, advice and guidance, She's off drugs, works for a local residents' association, has done a level 2 youth work qualification and will go on to do a foundation degree next year. She now gives advice to young people about drugs and alcohol abuse and has a solid relationship with her partner.*

Ray attributes these successes to having cultivated good working relationships with partners. *It wasn't all down to the level of support we were able to give here. We didn't do it on our own. We pulled in other agencies. A lot of what it's about is helping people know what's available – getting people in as part of the solution, providing joined-up services.*

The Borough Council is now beginning to think seriously about prevention. As Principal Finance Manager, Jeanette Willis, puts it: *We're starting to ask everybody, as part of our standard assessment, what support could have prevented them from needing social care.*

The Community Audit showed that it is often the smallest things that are the most important. Ray Harriman describes this as *about changing a light-bulb so the older person doesn't go on to have a fall and end up in hospital. We're talking about low-level services.*

Connected Care aims to develop services at a community level. This has meant working with many of the smaller local organisations and commissioning them to deliver the services that people say they want. It has also meant providing the advice and support that makes this possible for small organisations – including help with drawing up contracts and with back-office support.

To this end, *Connected Care* has recently set up *Who Cares*, a Community Interest Company (CIC), which is now beginning to commission services directly. The CIC's directors are representatives of community organisations. Ray Harriman says that *this is because we feel very strongly we should keep ownership in the local community. This is about empowering local community organisations and ensuring that these are still there*.

Gerard Wistow, researcher and local councillor in Owton has written widely about *Connected Care*[24]. Many challenges have been encountered, perhaps not surprisingly, given the ambition and the determination to find solutions that are local and which go with the grain of local community.

For Sarah Ward and her colleagues in Hartlepool, the challenge now is to build a stronger relationship with the *Connected Care* pilot: *We could be making better use of having the pilot there. For instance, it's not uncommon for local social work team members to have to 'pend' certain situations – and in those cases if we let* Connected Care *know, at least while there's a backlog within the system they could keep an eye on the person.*

Ray Harriman also sees this as a challenge: *We don't want to be another cog in the wheel. We've got to be something different from the Local Authority. We need to be able to respond to what people need. We need to be inside the system but in our work we have to be able to stand outside it. We've seen a massive change and we're working to produce a big change from people in the voluntary sector too. The question now is how do we align what we do better with the system?*

Sarah Ward and her colleagues working on Self-Directed Support know that they now need to look more closely at lessons from *Connected Care* in Owton, and from elsewhere: *A while ago, we got a group together including everybody with 'community' in their job title. Hartlepool is a tiny authority but that was still a lot of people. We began by conducting a mapping exercise to look at who's doing what. Now we've got to see what else is going on and how we can be better at linking together what we're all doing. There are a lot of meetings happening around planning, regeneration, neighbourhoods and community.*

END

Idea Stores in the London Borough of Tower Hamlets

Idea Stores are the Tower Hamlets equivalent of libraries but combine a range of traditional services with amenities going beyond those usually associated with libraries. Each of the six principal ***Idea Stores*** dotted around the Borough contains a crèche, dance space and area for complimentary health activities. ***Idea Stores*** have been established as places people go to have fun. They are a great success. Judith St John, ***Idea Stores*** manager, notes that there were a total of 2 million visits to ***Idea Stores*** last year by the Borough's 280,000 residents.

The fact that the Stores are located in busy places where people go anyway means that it is easier to meet the needs of vulnerable groups. To this end, they have weekly activities such as a *golden time* for over-50s. They also run a range of partnership activities, for instance, with a firm of solicitors that offers free legal advice. Many people come through the door to borrow a book or for some other specific reason, but when they are there they have the opportunity to explore the full range of activities and opportunities that might enhance other areas of their life. Judith St John says she is particularly keen that the Stores attract older people and other

potential users of social care services, and that these developments fit with the changes within social care.

There are several other projects in development that suggest that ***Idea Stores*** will come to play an even wider role in future. One is a new transport service that will bring people with restricted mobility to the library rather than relying on the home delivery service. Joytun Akther, the project manager, is confident that this will result in people accessing a broader range of activities than with home delivery and make possible the kind of outcomes that come from social interaction – outcomes that are impossible if people can't get to the Stores.

Another project with great potential is a live information database and networking website that will enable community and voluntary groups to publicise their events and activities. The database could also provide information on services, and even provide a route into ***shop4support*** where people can use their Personal Budget to buy care and support services. Judith is currently considering a piece of technology that will allow the platform to utilise the personalised Web 2.0 technology and solve the problem of information becoming out of date. The site could allow people to offer up their services or skills in an informal way, facilitating the kind of exchanges of skills and support options made possible through time banking (see below).

Sarah Ford, the Borough's Personalisation Lead, adds *What we're interested in here in Tower Hamlets is community change. Personal budgets are one different method for buying support, but what we're asking is 'What is transformational activity?' as opposed to something which just affects an individual. Idea Stores are one example of this.*

END

Time banks

Time banking is one of the most exciting initiatives in the UK (and internationally) and it is underpinned by an inherent faith in the capacity and good-sense of individuals and communities. Below, Martin Simon, Chief Executive of Timebanking UK, gives a brief outline of this straightforward community-building tool.

The problem: not so long ago we knew our neighbours and who to ask for a favour if we needed one – and our neighbours knew if we would do them a favour in return. But life is different now. Our family and friends do not always live nearby and it is not easy to ask a stranger for a favour, particularly if we do not know if we can ever pay them back.

The solution: time banks: for every hour you help out locally you earn one time credit, a community loyalty point. You can then use time credits to buy an hour of shopping, pet care, gardening, a music lesson, a lift, a language lesson, or salsa dancing – almost anything. You will feel useful, have fun and make new friends. We guarantee it! Time banking is free, owned by local people and runs on their energy – so it is completely recession proof!

A few of the things people have done for each other in time banks:

- Accompanying people to appointments
- Doing errands like collecting prescriptions
- Woodwork
- Cleaning and clearing
- Helping with reading
- Shopping
- Typing
- Driving a car
- Gardening
- Storytelling and reading out loud

- Computer skills
- Washing and ironing
- House sitting
- Cooking
- After school care
- Emergencies.

For more information: www.timebanking.org

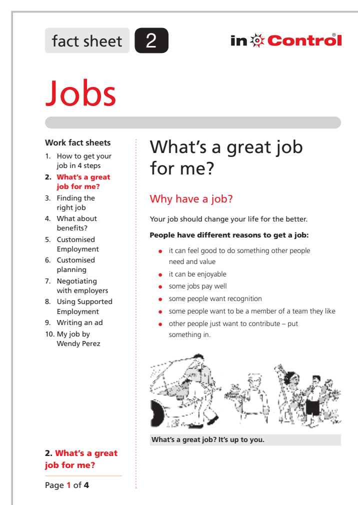
END

Jobs and economic regeneration

One aspect of life which most people say makes them feel good about themselves is having a paid job. Paid work enables us to have an income earned through our own efforts. It gives us a sense that we are making a contribution beyond our own individual needs and preoccupations. It gives us a broad sense of status – in the workplace and outside. It provides us with access to a world of connections, relationships and sometimes friendships and emotional support that wouldn't otherwise be there for us.

Employment and unemployment figures are major indicators of the economic health of the nation. With a faltering economy, there are huge political and social policy imperatives to get more people into paid work. Yet the employment rate for disabled people remains low, particularly for people with learning difficulties, and evidence from In Control's earlier phases of work shows that having a Personal Budget made little difference: with a few exceptions, people either could not or chose not to use their budget allocation as a stepping stone to work.

The right kind of information?



fact sheet 2 — in Control

Jobs

Work fact sheets

1. How to get your job in 4 steps
2. **What's a great job for me?**
3. Finding the right job
4. What about benefits?
5. Customised Employment
6. Customised planning
7. Negotiating with employers
8. Using Supported Employment
9. Writing an ad
10. My job by Wendy Perez

What's a great job for me?

Why have a job?

Your job should change your life for the better.

People have different reasons to get a job:

- it can feel good to do something other people need and value
- it can be enjoyable
- some jobs pay well
- some people want recognition
- some people want to be a member of a team they like
- other people just want to contribute – put something in.

What's a great job? It's up to you.

2. What's a great job for me?

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In Control believes that this has been a gap in its work to date. We made our first efforts to remedy this more than two years ago, as part of the second phase work, when we commissioned Anne O'Bryan to develop some pages for the In Control website and fact sheets to help people use their Personal Budgets to get a paid job. The fact sheets led an individual through the process of thinking about their ideal job; planning how they might go about identifying a job opportunity; analysing the impact of paid work on their welfare benefits; negotiating with potential employers; and finally, putting in place the support they might need to survive in the job once they have it. The webpages also include Wendy Perez' story about finding and holding down a job.

Figure 23: An In Control factsheet about getting a job

The webpages and fact sheets were well received, but we did not have a process for finding out how much difference they made to people actually getting into the job market. We think the impact was limited. Some people said that they needed direct advice and support, not information on-line.

In the meantime, the Government has said it would give priority to addressing the low levels of employment among disabled people. This had already been a major theme in the important document from the Cabinet Office (and other Government departments) in 2005, *Improving the Life Chances of Disabled People*[25], and it was underlined in 2007 by *Public Service Agreement 16*, a requirement that local authorities and their partners work to increase the *proportion of socially excluded adults in settled accommodation and employment, education and training.* This was followed in 2009 by another major policy document, *Valuing Employment Now*[26], which set targets and proposed a number of measures to help people with learning difficulties to get work.

Many of these initiatives and measures were aimed at local government as the leaders of Local Strategic Partnerships and the lead commissioners of services for people with learning difficulties. Many of In Control's leading local authority Members have been uncertain about how to respond. Adult social care departments have commissioned or provided daytime activities for some disabled people – often in day centres, occasionally in sheltered workshops – but, despite councils' wider remit for economic and social regeneration, they have rarely given any real focus or priority to helping people (or helping people back) into the paid job market. As already noted, very few disabled people were found to be using their Personal Budgets to get paid work, and, in cases where they did indicate that this was what they wanted, most care managers in the majority of local authorities lacked the specialist knowledge or expertise to help them achieve it.

It was for these reasons that In Control developed the *Real Jobs* programme in 2009. We defined a *real job* as one in which someone is employed by a company or organisation, or is self-employed. The person is paid.

In addition, a real job is one that:

- helps the person to meet their life-goals and aspirations
- is valued by managers and colleagues
- gives the person a chance to progress (if they wish to)
- has similar hours and times of work as other employees at the company or in similar jobs
- gives employment rights and the other benefits accorded to colleagues and others in similar jobs[27].

The main aim of the *Real Jobs* programme is to work with local authorities and to assist as many Personal Budget holders as possible to get and keep a real job.

Secondary aims were:

- To tell stories of great jobs and inspire more individuals and families to want them.
- To ensure that we develop practice that is inclusive of everyone, in particular people with high support needs, care leavers and other traditionally excluded groups. To ensure that the practice we develop is culturally sensitive.
- To influence the wider world of work, and initiatives from the Department of Work and Pensions, the Office of Disability Issues and third- and private-sector organisations.
- To enable people to make best use of all available funding streams to help them get a job.

- To assist young people who are planning their future by linking with related initiatives with families and schools.
- To influence the implementation of the *Valuing Employment Now* strategy.

The programme begins in 2010. The intention is to work alongside local authorities and their partners to analyse where their strengths lie and where they need assistance.

Hence, we will begin with a piece of detailed diagnostic work as we have found, in all areas of In Control's work, that every locality is different and each needs an individual focus and type of support. The second part of the programme offers localities a range of specialist supports based on their identified need and on the input of national experts like Anne O'Bryan, Keith Bates and Wendy Perez (an expert by experience) who together can offer help in developing local support for self-employment, family-led jobs, customised employment, job-coaching and much more.

At the time of writing, the programme is at the development stage. Those local authorities which take the issue seriously will need to identify this or a similar programme if they are to make significant headway in guiding disabled people into the workforce.

In Control: a social movement

In the Introduction to this report we outlined the beginnings of a new social movement, bringing together young and old, disabled and non-disabled people, family members and professionals – all united by the belief in values that promote rights and responsibilities, choice and control and connection with others in our community.

In the first three chapters, we described In Control's work over the past two years in helping local authorities and their partners to make a success of the operating system called Self-Directed Support through the vehicle of Personal Budgets, and in assisting local people to take control of their money, their support and their lives as active citizens.

In the first part of this chapter, we have focused on some of our more recent work to expand the vision, to bring attention to the whole of a person's life experience including their emotional and physical health and the contribution they can make to community and in the workplace.

We now need to bring these strands together and reflect in particular on the experience of ordinary people who have taken leadership roles in this process, and to set out some of our ideas for the shape of this new social movement.

Partners in Policymaking

Partners in Policymaking had its origins in the United States in the 1980s. It began with the recognition that, while all disabled adults and children and their families share many challenges and difficulties, in practice they are often divided and demoralised and lack any sense of community or of direction.

They also lack leadership. Often, disabled people or family members would *just talk about their problems, not about what would make things better*[28]. The recognition of this failing led to the development of the first *Partners* courses in the United States. The early courses were designed by and run for parents of disabled children and adults. Their aim was to provide information, to enable people to gain skills and to equip them with the emotional support to grow in confidence. The courses in the 1980s and 1990s were enormously successful and were inspirational for many of the leaders of the American disability rights movement.

Chris Gathercole and Lynne Elwell brought the model to England. The first *Partners* course in the UK was held in Oldham in 1996. Since then, similar courses have been held in most regions of England, Scotland and Ireland. Courses are also planned for Wales and the Isle of Man. The programmes have been cited in Government documents and were highly praised in a House of Commons debate on *Life Chances of Disabled Children* (January 2007).

Professor Chris Hatton of Lancaster University carried out an evaluation[29] of *Partners* and associated courses that have run in the north west of England. Professor Hatton reported that the findings were amongst the most positive of any programme he had evaluated. They showed a range of impacts: directly building the ability of people and their families to direct their lives, enabling people to engage more positively and effectively with services, and building local and, in some cases, national organisations to further the interests of disabled people and families.

The *Partners* model has grown and developed in the last couple of years, and this now forms the hub of a network of active, involved citizens across England.

The programmes on offer now include:

- *Sharing the Challenge*, designed for parents who have disabled children over the age of 16, and for disabled adults.
- *Kindred Spirits*, designed for families of disabled people, and for people who work in education, health and local government.
- *Tomorrow's Leaders*, specifically designed for self-advocates with learning difficulties who are in a position to influence and shape local and national policy.
- *Sharing Knowledge*, for parents of children aged 14 to 19, to help them think about and plan for the future.

The latest programme, *All Together Better* is funded by the Department of Health. The program has the specific remit of identifying, training, supporting and sustaining a national network of champions, all of whom have first-hand experience of the issues of disability and / or old age that affect family carers and the people they support. This network includes people representative of all major disability groups, including older people and those with sensory impairments, physical impairments, mental health issues and learning difficulties. It also includes people with long term and / or life-limiting conditions. This network includes disabled people, their families and allies, both professional and otherwise. At the time of writing, the programme is underway. 47 members are participating.

These members were selected from a much larger group of applicants, on the basis that each would:

- have a clear understanding of disability and of the barriers faced by disabled people, older people and their families in the modern Britain
- understand and hold to the values of personalisation and the need to respond to each person as a unique individual
- have a particular understanding of the issues for family carers
- be familiar with the main legislative and policy context which affects disabled people and their families; and have some understanding of the way local government, the NHS and the Third Sector work together to provide services
- be able and prepared to actively promote the needs and wishes both of individual disabled people and their families and the wider needs of disabled people in local community life
- be able to create peer support locally
- be able to promote the need for further champions and opinion leaders in this area
- be able to become citizen leaders and translate policy into practice.

Government funding for such a radical and ambitious programme represents a significant endorsement of this movement. Government has made positive statements about empowerment, co-production and building community capacity for a number of years now, and *Putting People First* is a remarkably forward-looking document. But to provide funding for a programme of this nature – a genuinely citizen-led initiative with the explicit aim of enabling people to make a more effective and robust contribution to local systems – represents a major breakthrough. It builds **challenge** into the system in a way that is unusual.

How might we now envisage the graduates of this and its sister programmes beginning to influence policy and practice and, more importantly, what can we expect local systems to look like if all goes well in the years to come? In other words, what is our vision for the change process?

Change from within and without

One can observe that most social movements are characterised internally as being **for** something – typically the rights of a disadvantaged section of the population, for example, people from a particular ethnic group, women or gay people; and externally as **against** something, usually some version of the status quo. What is In Control for and against? How do we understand change coming about and exactly what change will it be?

If we are a social movement in this way, then we are an unusual one: although we want to change the status quo, we are clearly saying that we must do so alongside many of those who have been involved in the old system – managers, professionals, care workers, families and ordinary members of the public. We believe fundamentally that the great majority of people have good hearts and want to see a society that is better for all. Therefore, we are all allies, or at least potential allies, in this process.

It is notable that Government policy statements such as *Putting People First* capture our vision and our aspirations well. Senior managers in many local authorities are passionate

about personalisation. Many professionals who implement Self-Directed Support are among its greatest advocates. Ordinary users of social care services, citizens and family members say their lives have been transformed by it.

So, in saying that we are against the status quo, we also say that we are now attempting to change it both from within and from without.

Part of the difficulty for us all is our learned behaviour – responses to issues and situations that are unreflective, and are based on years of experience. Sometimes, this behaviour is based on old ways of thinking from an era that favoured excessive caution and the view that those in need of support from the public purse should respond as passive and grateful recipients of a professional gift. Simon Duffy has written at length about this in *Keys to Citizenship*[30], and elsewhere.

In Control's statement of ethical values makes our fundamental beliefs clear.

1. We believe that every human being has equal dignity and the right to be treated with equal respect, whatever their impairment, age or health status. We are all different, but we are all entitled to be treated with respect.
2. More than this, 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.
3. 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.
4. 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.
5. We all need extra help from time to time, and some of us need that help regularly and throughout our life. This might be as a result of disability, old age or ill health. The fact that this need for extra help exists is both natural and an important opportunity for all of us to recognise our need for support and our mutual interdependence.

In the years to come, we will see communities across England retain much of their diversity and, we hope, their vibrancy: we will not lose the distinction between rural life and city life or between areas where there is a preponderance of people from particular cultural or ethnic groups.

But we hope that:

- all these diverse communities will recognise the above beliefs as worth aspiring to
- communities will welcome diversity and difference, and seek ways to include people who differ from the norm in any respect
- all will seek ways to be helpful and supportive of people who need extra support
- communities will discover or create solutions that are imaginative, ordinary and tailored to the individual
- all will work alongside their elected representatives, professional people and paid officers of the local authority to discover and test ways that individuals

can make their own decisions, have control over their own lives and make a real contribution

- everyone will have some understanding of the experience of others – those in poverty, in pain, suffering loss and other forms of adversity – and all will see it as part of their responsibility as a member of society to respond.

In Control believes that it is the right moment to launch a programme of *Public Membership* to capture and channel the energy that we have described in this report and in other In Control publications.

What will be the characteristics of this programme, and how might we move forward in the next phase of In Control's work towards this ambitious vision?

Reflection

Firstly, the movement will value reflection. From the beginning, In Control has described itself as a *learning community*. We have never believed that we have all the answers to all problems in social and health care. Rather, we recognised that the old system was no longer functional, and that we owned a set of beliefs that were fundamentally at odds with those underpinning this failing system.

We now suggest that we need to go forward to the next level in this process of transformation in a very thoughtful way: we have succeeded in developing some of the technical solutions through the operating system we have called Self-Directed Support; we have identified a group of enthusiastic allies; and we have even persuaded the Government to change policy. But, as the preceding paragraphs make clear, we still have far to go. Our belief is that we can only progress further if, both individually and collectively, we find the time and the tools to stop, think and reflect.

Partnerships and alliances

Secondly, we need to become more serious and business-like about our partnerships and our alliances. In Control has had some success in identifying individuals and organisations that share the values set out above who have energy and ideas to develop and apply these. Our relationships with local authority adult social care departments have been particularly strong, with over 120 Members and twenty *Total Transformation* authorities; and we have sought to transplant these arrangements into our new work with children's departments and with Primary Care Trusts.

We have also developed good working relationships with a number of Government officials, user-led organisations, third-sector groups, provider organisations and consultancies. And, as noted above, we have welcomed citizen and family leaders from the *Partners in Policymaking* programme into the In Control Partnership.

We believe that we need to build on and develop this rather loose federal alliance so that it gains a clearer identity and sense of direction. It is for this reason that we have launched a new set of arrangements for Organisational Members, and the completely new *Public Membership* Programme. We believe that the latter – a voluntary association of citizens who share In Control's beliefs – will form the heart of the organisation's evolving mission. See Appendix 3 for more information about In Control Membership.

Key questions in 2010

Finally, we need to radically review the implications of In Control's values in the light of the changed environment we are operating in. This report has alluded to many of the changes since In Control began work in 2003: Self-Directed Support is now common currency in adult social services and Personal Budgets are set to be available for all; personalisation, more broadly conceived, has become a key dimension in public policy in health, education and welfare reform; thinking about co-production, social capital and empowerment and the commitment to enhance access to universal services have become greater and more sophisticated than early ideas about customers and quasi-markets.

But these positive changes have to be set against the increasingly stark profile of the demographic, fiscal and environmental crises that face us. For all of these reasons, it is clear that *more of the same* is not an option in any area of public policy. The broad question that In Control now needs to reflect on with its friends and allies is: what do these challenges mean in practice for us and for our work?

We conclude the first part of this report by mapping out some of the areas we must address in the next phase of In Control's work. In doing this, we draw on some of the themes set out in *Making It Personal*[31]. This pamphlet says that *Government's role is to shape freedom: getting people to exercise choice in a collectively responsible way and so participate in creating public goods.*

Our questions fall into three broad categories.

A series of questions about the scope and the limits of personalisation – within the domains we have begun working in and beyond:

- Which areas of life is it appropriate to *personalise* and which not?
- What is achievable with other funding streams – Welfare Benefits in particular? (This is an area to be tested further in the inter-departmental *Right to Control* work.)
- What about education and training? Should parents have Personal Budgets for children's schooling, and if so is this a threat to state schools? What about Further and Higher Education?
- What about Health? We have scratched the surface, but health services have many aspects, including maternity services, elective surgery and complementary medicine. Also, what does personalisation mean in NHS hospitals, with all the challenges these present?
- What do we do about those difficult areas where there are high risks of individuals controlling a Personal Budget? These include people who misuse drugs and alcohol and some people with offending histories. In Control's view to date has been that support can be personalised without handing over control of the money. Is this correct and sustainable with every user group?
- A broad question about the role of strategic and operational commissioning within personalisation and the wider context of personalised services[32]: to what extent is there an on-going role for commissioners to plan and procure services in order to advise and assist individuals and to promote personalisation? If there is such a role, how should this be defined?

A series of questions about the nature of citizenship and the politics of participation:

- Have we set our expectations of ordinary citizens as the authors of their own destiny at roughly the right level? How can we check? And does this apply to everyone, regardless of age or disability, in the ways that we have been asserting?
- A parallel question about user-led groups: what can we reasonably expect from these groups, and how should we now go about encouraging and nurturing them?
- What do we now say about the role of universal public services such as schools, hospitals, prisons and the police in relation to citizens who may (we hope) have an increasingly acute sense of their right to a Personal Budget? Is it reasonable and realistic, as *Making It Personal* suggests, to *invite* people to participate more in these institutions, and if so how do we go about this?

Finally, two questions about the nature of community and our appetite for change:

- In Control has made some bold and optimistic statements here about the nature of our communities and the positive energy and untapped social capital they contain. There is of course another view: that our communities are impoverished in many ways and some are hostile places for the old, disabled and lonely. How do we confront negative experiences (as well as negative stereotypes) and enable people to join together and build on their strengths, rather than accept a situation of victimhood?
- How do we sustain the momentum for change when these ideas are no longer fresh and new, when public and private finances are tighter than ever, when there are fewer and fewer people of working age and ever more who depend on them – when, in short, the remnants of the old welfare system are truly broken?

Surely, the answer to this last question is that we must turn to our neighbours to ask for their assistance – and to offer them our assistance in return.

Summary: some things to think about as we look ahead

Good practice	Avoid
Listen to the things that citizens and families say and try to respond positively.	Don't divide people's lives into boxes any more than is necessary. Help people to connect with one another and think whole life (pre-conception to death), learning, work, leisure, friendship and family.
Help people to gain or re-gain and strengthen links with family, friends and community.	Don't assume that all groups and cultures in our society need the same types of support to take control of their lives. Recognise and celebrate diversity and adjust the way we work in response.
Think in terms of an outcomes framework to define what is achieved. The *Every Child Matters* framework is one good example.	Don't assume that Personal Budgets for children and families are only for those with a disabled child or a young family member at transition. Non-disabled and younger children can benefit too.
Develop a full understanding of the real wealth which a child, young person or adult brings, to make the most of their Personal Budget.	Don't ignore the distress or the urgency expressed by some people, especially those who are ill or in pain. Do what you can to help them get choice and control.
Support the National Health Service in transforming and personalising the way health care is delivered.	Don't be simplistic in thinking about community. Think and plan in terms of the three dimensions of public community services, businesses and natural networks and activities.
Find ways to check that, when someone has a Personal Budget, the transfer of power is real: ensure that they can easily change provider if things aren't working well.	
Think widely about community and the need for everyone to connect with those around them.	
Be clear that real jobs are important to everyone of working age. Take some responsibility locally for making real jobs available to all.	
Talk with others about the new social movement, an alliance of citizens, families and professionals. Support it in whatever ways feel right.	

Figure 24: Good practice and things to avoid as we look ahead

NOTES

1 Poll, C., Duffy, S., Hatton, C., Sanderson, H. and Routledge, M. (2006) *A Report on In Control's First Phase 2003-2005*, In Control, London.

2 Department of Health (2008) *High Quality Care for All*, London.

3 Brewis, R. (2009) *Citizenship in Health*, In Control.

4 Poll, C., Kennedy, J., Sanderson, H. (Editors) (2009) *In Community: Practical Lessons in Supporting Isolated People to be Part of Community*, HSA Press, Stockport.

5 For example, SCIE (2008) *A Rough Guide to Personalisation*, available on the SCIE website at **www.scie.org.uk** The Signposting project is described at **http://www.scie.org.uk/publications/signposting.asp?pubID=4232**

6 Richardson, K., Fulton, R. (2009) *Towards Culturally Competent Advocacy: meeting the needs of diverse communities*. BILD discussion paper. **www.bild.org.uk**

7 Office of Public Management, *Report on Budget Holding lead professionals*: **www.opm.co.uk/resources/papers/children_bhlp/BHLP_Final_Report.pdf**

8 Commissioning Support programme **www.commissioningsupport.org.uk/**

9 HM Treasury (2007) *Aiming High for Disabled Children*, London.

10 **www.dcsf.gov.uk/everychildmatters/healthandwellbeing/ahdc/otherareas/ahdcotherareas/**

11 **www.dcsf.gov.uk/everychildmatters/healthandwellbeing/ahdc/coreoffer/coreofferandni/**

12 Taking Control **www.in-control.org.uk/children/**

13 Taking Control (2009) *Whole System Change* Workshop (unpublished report).

14 Crosby, N., and Palmer, M. (2007) *Making Sense of the Money*, and subsequent unpublished work for the National Learning and Skills Council (2008).

15 DARZI Report and proposed Health Bill outline the piloting of Personal Health Budgets.

16 Hodgkin (December 2009) Westminster Health Forum presentation .

17 The National Institute for Health and Clinical Excellence.

18 Duffy, S. (2006) *Keys to Citizenship, A Guide to Getting Good Support for People with Learning Disabilites*, Paradigm, Birkenhead.

19 See Department of Health (2009) *Personal Health Budgets First Steps*, section 3.6, pages 32-35

20 Department of Health (2009) NHS 2010-2015 *From Good to Great, Preventative, People centred, Productive*, page 12 para 1.32.

21 Materials are available from: **http://ifh2.westmidlands.nhs.uk/**

22 See Chapter Three for more information about **shop4support**.

23 See **www.naaps.org.uk**

24 For example, see Wistow, G., and Gallaghan, G., (2008) *Connected Care in Hartlepool Re-visited, Can a Holistic and Community centred approach survive Implementation?* Journal of Integrated Care 16 (2).

25 Cabinet Office (2005) *Improving the Life Chances of Disabled People*, The Prime Minister's Strategy Unit, London.

26 Department of Health (2009) *Valuing Employment Now: Real Jobs for people with learning Disabilities*, Department of Health, London.

27 This may mean things like flexible hours and job shares, but it's important not to assume that disabled people will necessarily want or need these things any more or less than anyone else.

28 Quote from Partners in Policy Making website: **www.partnersinpolicymaking.co.uk/aboutus**

29 Hatton, C. (2006) *Partners in policymaking in North West England : an evaluation*. Working Paper. Lancaster University, Lancaster.

30 Duffy, S. (2006) *Keys to Citizenship, A Guide to Getting Good Support for People with Learning Disabilites*, Paradigm, Birkenhead.

31 Leadbeater, C., Bartlett, J. and Gallagher, J. (2008) *Making it Personal*, Demos, London.

32 See the work of Clive Miller who has produced a number of key publications in this area, notably. Miller, C. (2009) *Social Capital, Co-production and the Delivery of Putting People First*, Department of Health, London.

Evaluation

The impact of Personal Budgets 2005-2009

Evaluation: The impact of Personal Budgets 2005-2009

Personal Budgets: take-up

Personal Budgets are a key element of Self-Directed Support and are central to the Government's policy to reform social care. The Department of Health strategy for the reform of social care, *Putting People First*, requires that all local authorities with social services responsibilities make Personal Budgets available to all those who are eligible for social care support (except in emergencies).

To reflect the significance of Personal Budgets to the national strategy, a new *National Indicator NI 130* was established. This aims to measure the number of people with a Personal Budget. Progress is being closely monitored, locally and nationally.

Monitoring the take-up of Personal Budgets

The take-up of Personal Budgets is perhaps the most reliable and effective way of measuring the transformation of social care. The provision of Personal Budgets represents a significant technical challenge for local authorities. It is one that should lead to a marked increase in choice and control for those in need of support.

For this reason, In Control has invested resources in monitoring the take-up of Personal Budgets over the last three years and has produced a snap-shot of activity each month since June 2006. This regular tracking of activity is published on the In Control

website. In Control's monitoring and definition predate the *National Indicator NI 130* and so operates to a slightly different definition.

In Control's defines Personal Budgets as being held by people who:

- know how much money they can have for their support
- are able to spend the money in ways and at times that make sense to them
- know what outcomes must be achieved with the money.

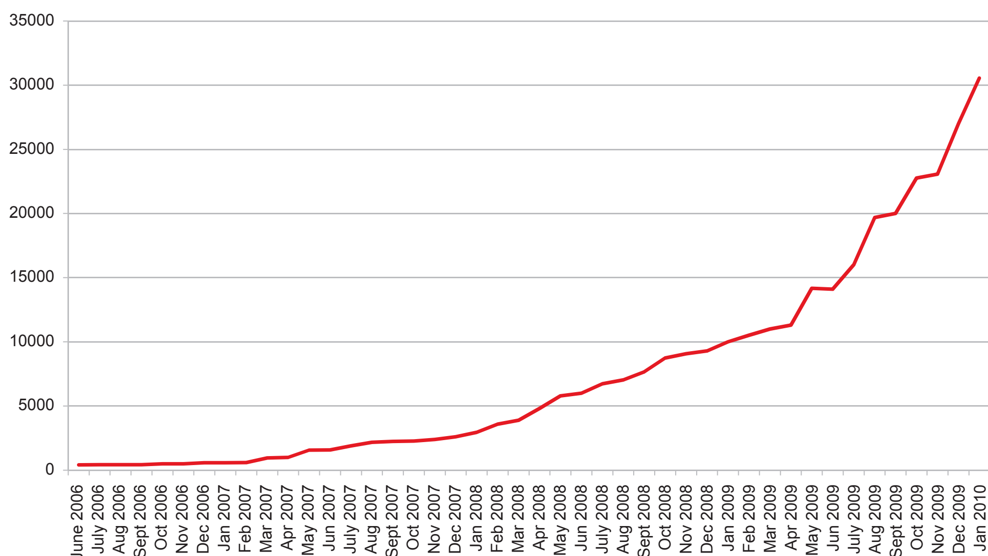
This definition explicitly excludes some people in receipt of Direct Payments who may be captured by *NI 130*. In Control is primarily interested in measuring the transfer of control to individuals who need support and we do not believe that all those individuals who are in receipt of a Direct Payment enjoy control to the level described in the In Control definition.[1]

Collection of data

The information reported here has been gathered from local authorities which have volunteered to share data.

Data is collected using a simple online reporting tool. Data submissions are regularly aggregated and circulated to participating authorities for information sharing and validation. There is no requirement on local authorities to share information and a small number may have chosen not to participate. Therefore, the information below does not present a full national picture. However, given the tight definition of Personal Budget and the significant number of authorities who do report regularly, the figures produced provide a good indication of the pace and level of change.

Take-up since 2006



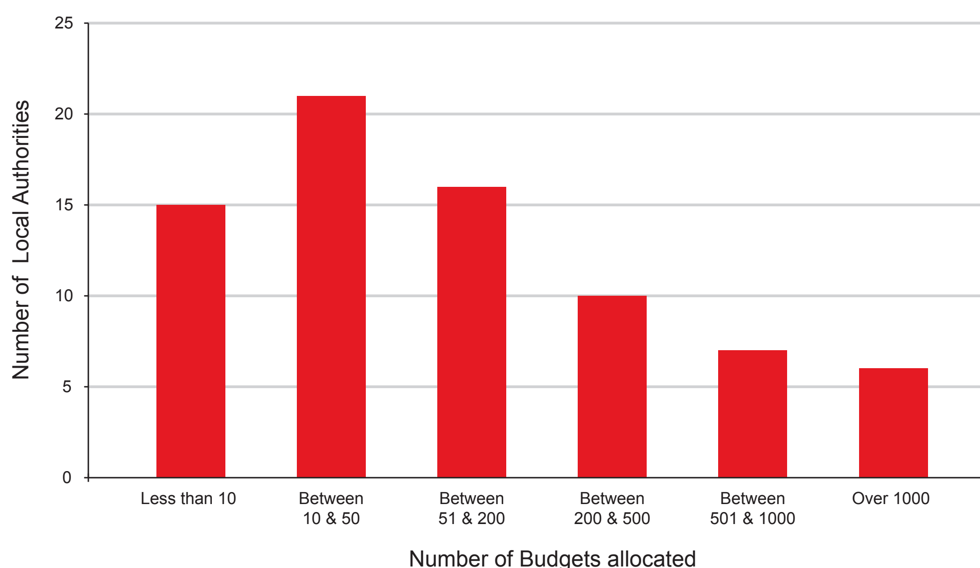
EVAL Fig. 01: Personal Budget take-up 2006-2009

Over the past three years, there has been continued growth in the take-up of Personal Budgets across England.

In 2006, 60 people were reported to In Control as being able to control their own Personal Budget.

Three years later, by the end of 2009, some 30,000 people were reported as having a Personal Budget across 75 local authority areas.

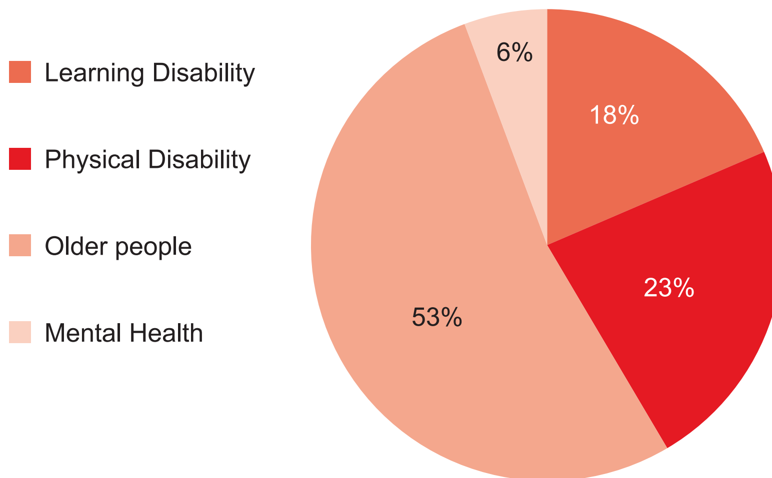
Spread of Personal Budgets across local authorities



EVAL Fig. 02: Number of Personal Budgets allocated by local authorities

Local authorities are at different stages in making Personal Budgets available. The vast majority (92%) of local authorities reported having made Personal Budgets available to fewer than 1000 people. Slightly less than a third (31%) reported that they had made Personal Budgets available to more than 200 people.

Personal Budget allocations by social care group



EVAL Fig. 03: Personal Budget allocations by social care group

Not all reporting authorities have included a detailed breakdown of activity by social care group. Figures for authorities reporting only a total figure have not been included here.

Just over two thirds (68%) of the reporting local authorities included a breakdown by social care group. Just over one third (36%) of these reported take-up of Personal Budgets by all four social care groups. The breakdown showed a relatively modest take-up by older people (53%) while reported take-up by people with physical disabilities was relatively high at 23%. (The overall number of older people using social care is high, hence we might expect even more than 53% of budgets to be taken by older people. The opposite is true of people with physical disabilities.)

15 Local authorities reported making Personal Budgets available to family carers, and eight local authorities have reported making Personal Budgets to children.

Understanding the effect of Personal Budgets and Self-Directed Support

Many of the approaches taken to monitor the performance of social care services have focused on activity happening within the system itself.

Performance management systems tend to focus on how many people are served and the type of service they receive. Some measures capture the cost or length of time it takes to deliver a particular activity. As with In Control's own count of Personal Budgets, the attempt has been to understand what is happening in a complex system by identifying and measuring one key component of that system. The intention is to provide a simple measure that indicates the performance of the wider system.

Such approaches are well established and embedded in the architecture of social services departments. Using approaches of this kind, it has been possible to measure in some

detail what the system does, set benchmarks for performance, and provide essential management information helpful to those charged with running complex systems.

Such approaches have been criticised as they can be costly to operate and have been linked to public judgments on performance. The result is that they can assume an importance beyond their true value. Criticism highlights that the activity of the system itself can become skewed: it begins to focus on what is measured and reported rather than on what is important.

It is difficult to see how approaches that rely heavily on measuring tasks and activity can offer anything other than a very partial account of performance. There is a need to develop better ways of capturing the effectiveness of our social care system. Performance is better understood by measuring directly the impact on the lives of those people the system is designed to serve; namely disabled and older people who need support and their families.

Evaluation of In Control's Second Phase 2005-2007

In 2007, In Control published a report describing its work between 2005 and 2007. This report featured the results of an evaluation project that had included 196 people with Personal Budgets from 17 different local authority areas.

The project, carried out in partnership with Lancaster University, had aimed to develop and apply an evaluation framework that would enable local authorities to better understand the impact of Self-Directed Support on the lives of people who approach them for support. We hoped that the framework would eventually provide the basis of a new way of measuring the effectiveness of the social care system.

The work was underpinned by an aspiration that:

- the evaluation methods should be low-cost (including the costs of evaluation measures and those of collecting and analysing the information)
- the questions asked in the evaluation should be recognised as important by every group involved
- the evaluation methods should impose a minimal time burden on the people 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
- the evaluation methods should be freely available for use by others.

The result was a simple evaluation questionnaire that measured the effect on people's lives of having a Personal Budget against simple three-point scales. The questionnaire also identified what help people had to plan their support and whether they had previously received social care services.

Since 2007, In Control and Lancaster University have continued to work together to develop and apply the framework. Following the *Report on In Control's Second Phase*, the framework was reviewed and amended. An extended framework was developed to include questionnaires designed to gather the views and experiences of family carers and social work staff supporting people with Personal Budgets.

The questionnaire for Personal Budget recipients was revised and a number of further domains were added. Questions in each domain were subdivided to distinguish any reported change from one resulting from having a Personal Budget. A section asking how people had used their Personal Budget was also added. Finally, the questionnaire was amended to include a section that asked people to comment on their experience of aspects of the Self-Directed Support process.

The evaluation questionnaires are available from:
www.in-control.org.uk/researchandevaluationtools

The evaluation framework

Each of the questionnaires captures basic demographic information, such as age, ethnicity and gender, as well as some data specific to each group, such as the number of hours spent in a caring role or the length of time the Personal Budget had been held.

All of the questionnaires ask people to identify how their life or work role has changed in a number of domains since having a Personal Budget, using three-point scales. This simple scale allows people to report whether things were worse, the same or better after the introduction of a Personal Budget.

The exact wording of the scale is sensitive to the context of each question, and in some cases has changed slightly as the framework has been adopted in different local authority areas. This usage has resulted in some variation to the precise wording of each question. In some questions, *more* was used to indicate a better outcome and *less* or *fewer* to indicate a worse outcome. As the questionnaire for Personal Budget recipients was implemented locally, some of the domains were omitted and replaced with other domains.

One area, the City of London, applied the questionnaire before and after the Personal Budget, using a four-point satisfaction scale. To be included in this aggregation, the second application was judged against the first to determine whether the respondent had reported an improvement, no change or a worsening in their situation.

Use of the framework

The framework has been used by a number of local authorities that have written accounts of their work to implement Self-Directed Support. These reports are published at:
www.in-control.org.uk/evaluationreports

Each report features findings resulting from the local application of the evaluation framework.

Aggregated findings

Whilst recognising some local variations exist, it has been possible to identify a set of core domains that have been included relatively consistently in local evaluations, allowing us to add these data from local evaluations to the data collected for the Second Phase report.

In total, between 385 and 522 people using Personal Budgets told us whether their lives had improved, stayed the same or worsened since the introduction of their Personal Budget.

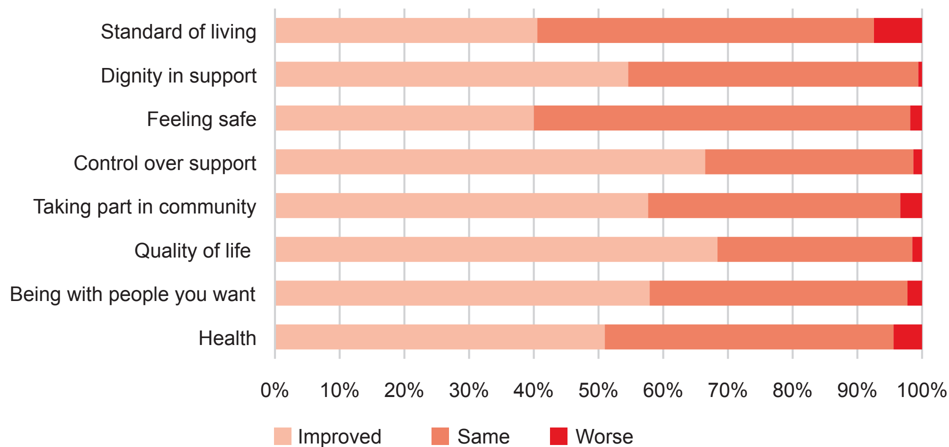
This information was provided about eight domains of people's lives:

- health
- being with people you want
- quality of life
- taking part in their communities
- control over the support they use
- feeling safe both inside and outside their home
- feeling that they are supported in ways that maintain their dignity
- standard of living.

Overall satisfaction

Personal budget recipients	Evaluations (including Phase Two)	Responses
Health	11	522
Being with people you want	8	399
Quality of life	11	528
Taking part in community	7	385
Control over support	11	519
Feeling safe	10	435
Dignity in support	10	513
Standard of living	9	417
Data from: Phase Two Report, Barnsley, Rotherham, City of London, Cambridgeshire, Worcestershire, North Lanarkshire, Richmond (2), Hertfordshire, Northamptonshire.		

EVAL Fig. 04: Satisfaction levels reported in a number of evaluations



EVAL Fig. 05: Satisfaction levels: aggregated findings

More than two-thirds of people using Personal Budgets reported that the control they had over their support (66%) and their overall quality of life (68%) had improved since they took up a Personal Budget.

A majority reported spending more time with people they wanted to (58%), taking a more active role in their local community (58%), feeling that they were supported with more dignity (55%), and feeling in better health (51%) since they took up a Personal Budget.

In the domains of feeling safe (58%) and standard of living (52%), more than half reported no change after they took up a Personal Budget.

In all domains, less than 10% reported that their life had got worse after they took up a Personal Budget.

Family Carers

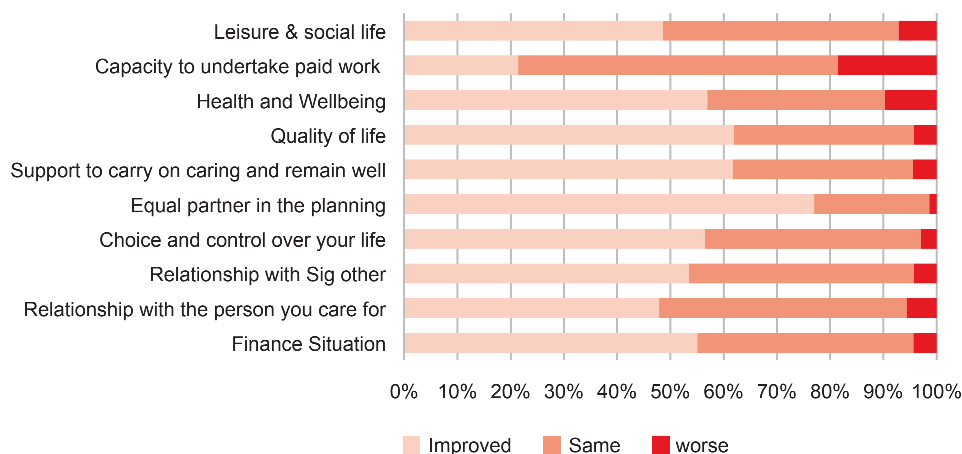
Between 68 and 74 family carers in five local authorities told us whether their lives had improved, stayed the same or worsened since the introduction of a Personal Budget for their relative in ten domains of the carers' lives.

These domains are:

- their finance situation
- their relationship with their relative
- their relationship with a significant other
- choice and control over their own life
- feeling like an equal partner in the planning process
- support to carry on caring and remain well
- their quality of life
- their health and wellbeing
- their capacity to undertake paid work
- their leisure and social life.

Family Carers	Local Authorities	Individual Responses
Finance situation	5	69
Relationship with the person you care for	5	67
Relationship with significant other	5	71
Choice and control over your life	5	69
Equal partner in the planning	5	74
Support to carry on caring and remain well	5	68
Quality of life	5	70
Health and wellbeing	5	72
Capacity to undertake paid work	5	70
Leisure and social life	5	70
Data from : Barnsley, North Lanarkshire, Cambridgeshire, Hertfordshire, Worcestershire.		

EVAL Fig. 06: Number of carer responses by domain



EVAL Fig. 07: Satisfaction levels: family carers

More than three quarters (77%) of family carers reported they had become more of an equal partner in planning since their relative had taken up a Personal Budget.

A majority of family carers also reported improvements in their quality of life (63%), the support they got to carry on caring and remain well (62%), their choice and control over their lives (57%), their health and wellbeing (57%), their finance situation (55%), and their relationship with a significant other (54%).

Around equal numbers of family carers reported either improvement or no change in their relationship with their relative (48% improved; 46% no change); and their leisure and social life (49% improved; 44% no change).

Most family carers reported no change in their capacity to undertake paid work (60%).

In each domain, fewer than 11% of family carers reported their family life worsening after their relative took up a Personal Budget: the only exception was in terms of capacity to undertake paid work (where the figure was 19%).

Professionals' perspective

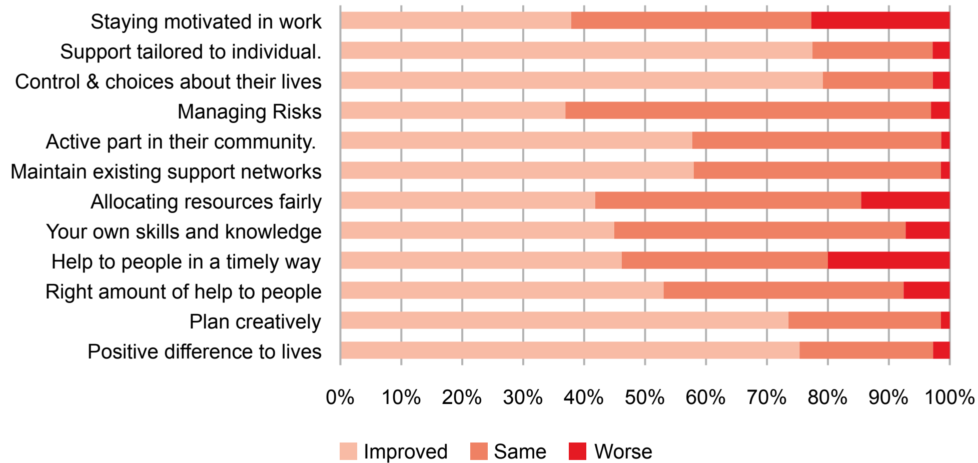
Between 55 and 73 professionals involved in implementing Personal Budgets in five local authorities told us whether their working environments had improved, stayed the same or worsened since they began implementing Personal Budgets in twelve domains.

These domains were:

- making a positive difference to people's lives
- creative planning
- getting the right amount of help to people
- getting help to people in a timely way
- the professionals' own skills and knowledge
- allocating resources fairly
- the maintenance of existing support networks
- the person taking an active part in their community
- managing risks
- people having control and making choices about their lives
- support being tailored to the individual
- the professional staying motivated in their work.

Professionals	Local Authorities	Responses
Positive difference to lives	5	73
Plan creatively	5	68
Right amount of help to people	5	66
Help to people in a timely way	5	65
Your own skills and knowledge	5	69
Allocating resources fairly	5	55
Maintain existing support networks	5	69
Active part in their community.	5	71
Managing Risks	5	65
Control and choices about their lives	5	72
Support tailored to individual.	5	71
Staying motivated in work	5	66
Data from: Cambridgeshire, Worcestershire, North Lanarkshire, Barnsley		

EVAL Fig. 08: Number of professional responses by domain



EVAL Fig. 09: Professionals' views on changes after Personal Budgets

Around three quarters of professionals reported that people had more control and choices about their lives with Personal Budgets (79%), supports were more tailored to individuals (77%), Personal Budgets had made a positive difference to the lives of people using them (75%) and that professionals could plan more creatively (74%).

More than half of professionals reported improvements in people maintaining their existing support networks (59%), people taking a more active part in their local communities (58%) and getting the right amount of help to people (53%).

Around equal numbers of professionals reported either improvement or no change in getting help to people in a timely way (46% improved; 34% no change), their professional skills and knowledge (45% improved; 48% no change), allocating resources fairly (42% improved; 44% no change) and staying motivated in their work (38% improved; 39% no change).

Most professionals reported no change in risk management with the onset of Personal Budgets (60%).

Less than 10% of professionals reported things getting worse in 9 of the 12 domains. More substantial minorities of professionals reported things getting worse with regard to allocating resources fairly (15%), getting help to people in a timely way (20%) and staying motivated in their work (23%).

Local evaluation – **Richmond**

The London Borough of Richmond decided to undertake a local evaluation. The Council believed that it was important to listen to the views and experiences of people who had Personal Budgets, their families and staff who had worked with them. The Council wanted to establish how people had spent their Personal Budget and what effect the budget and the seven-step Self-Directed Support process had on their life. It was hoped this exercise would provide lessons for the Council and for other local stakeholders.

Richmond used In Control's evaluation framework developed in partnership with Lancaster University. The evaluation was intended to highlight, celebrate and share good practice, and identify areas for improvement.

The Council commissioned a local user-led organisation, Richmond User Independent Living Scheme (RUILS), to undertake 20 in-depth interviews with people receiving a Personal Budget. The interviews were carried out by people who had disabilities and by RUILS staff.

The people were interviewed who had had their Personal Budget for longer than six months. This was to ensure that people had had an opportunity to notice any difference the Personal Budget may have had on their life.

During the interviews, people filled out a standard questionnaire which asked a range of questions about the Self-Directed Support process and the impact of Personal Budgets. The questionnaire also included basic demographic information. By asking for this information, the Council hoped to understand what Richmond was doing right as well as what needed to be improved.

For each domain, people were asked to indicate their level of satisfaction on a simple three-point descriptive scale of: worse, no change, improved.

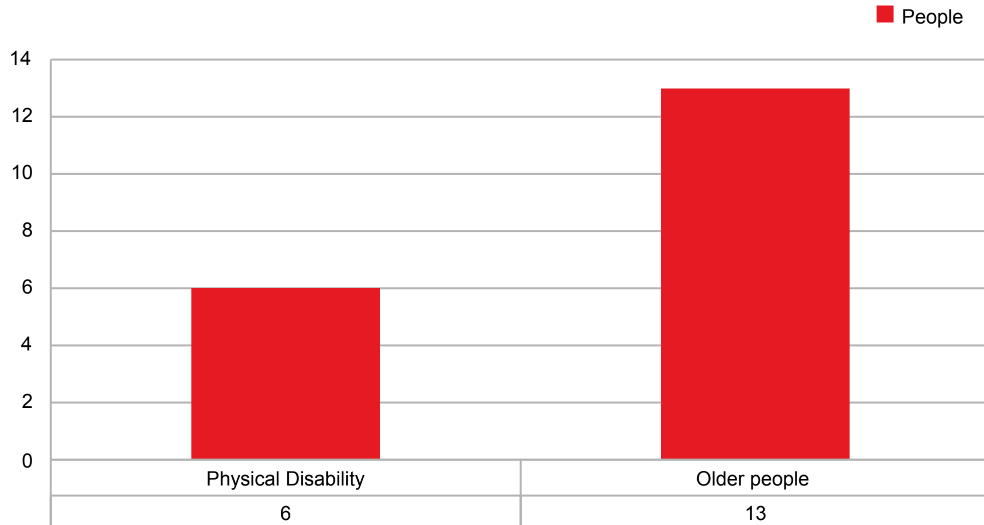
Data were collected from all 19 people taking part. The interviewers were also able to ask a range of open questions and interviewees could talk generally about their experiences of Self-Directed Support. These responses were recorded and reported as individual stories and were published in a local evaluation report. The evaluation also considered people's Support Plans to find out what people were buying and how they were organising their Personal Budget.

In Control acknowledges the work of Cathy Maker (RUILS) and Caroline Tack (London Borough of Richmond) in compiling this information.

The RUILS evaluation

Participants

19 people took part in the evaluation process. The majority (78%) was older people.

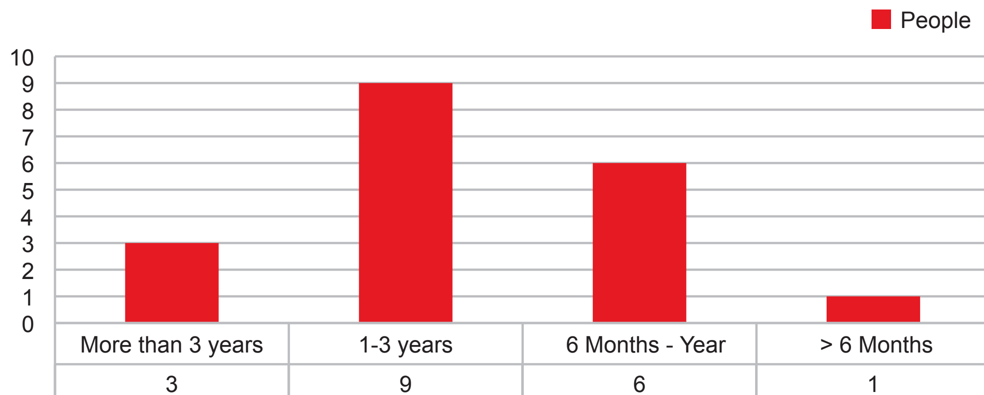


EVAL Fig. 10: Participants in Richmond evaluation by care group

Length of time

People were asked how long they had been using their Personal Budget.

Half the group had held their Personal Budgets for over a year and just over a third (39%) had held their Personal Budgets for less than a year, including one person who had held their Personal Budget for less than six months. Three people (17%) had held their Personal Budget for more than three years



EVAL Fig. 11: Length of time that participants had held a Personal Budget

How people held their Personal Budget

12 people (63%) said they held their Personal Budget as a Direct Payment, and 7 (37%) asked the Council to hold their budget.

The Self-Directed Support process

	Self Asssesment	Find out about SDS	Get the money	Make a plan	Get your support
Not Sure	3	3	3	3	3
Yes	13	11	15	13	13
No	1	5	1	2	3

EVAL Fig. 12: The process of getting Self-Directed Support in Richmond – how easy was it?

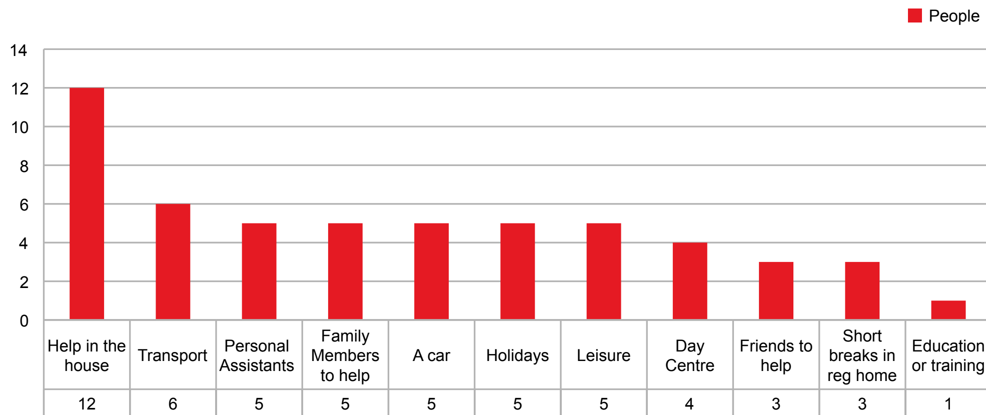
People were asked about their experience of the Self-Directed Support process. They were asked five questions about the ease of the process and were able to respond: *yes*, *no* or *not sure*.

Participants were asked if it was easy to:

- find out about Self-Directed Support
- do the self-assessment
- get control over the money
- plan the support they wanted
- get the support they wanted.

Nobody found the whole process difficult. Seven people (37%) found at least one part of the process difficult. Nearly half the group (47%) found all parts of the process easy. Finding out about Self-Directed Support was reported as the most difficult part of the process: just over a quarter of the group (26%) said this was not easy. Getting the money was reported as the easiest part by more than three quarters of the group (79%). The self-assessment, getting the money, making a plan and getting support were all reported as easy by more than two thirds of the group.

How people used their Personal Budget



EVAL Fig. 13: What people in Richmond spent their Personal Budgets on

People were asked to identify how they had used the money in their Personal Budget. Nearly three quarters of the group (74%) used some of their Personal Budget to pay an individual to help them. Just over a quarter (26%) used some of their Personal Budget for traditional social care services (day care or registered home). Over a third (37%) used money to get help from people close to them, family or friends. Over half (58%) used some of their Personal Budget to get out and about, using a car or transport.

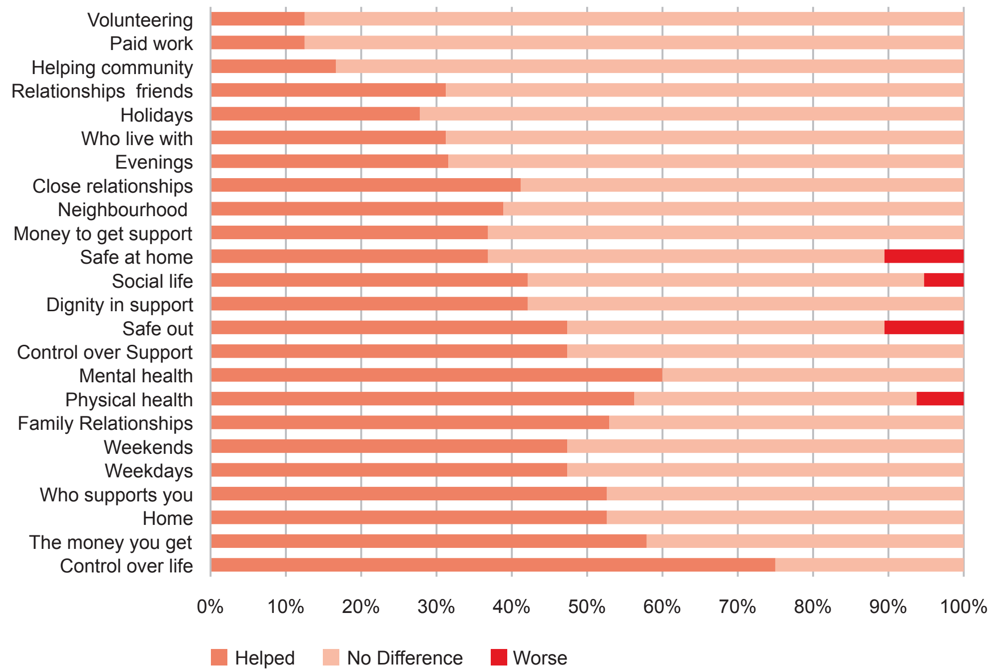
Outcomes

The questionnaire asked people about different aspects of their life and the support they had. People were asked to identify for each area whether having a Personal Budget had made things better, made no difference or made things worse.

The questionnaire included domains added since Phase Two and asked about:

Feeling safe when you go out	Feeling safe at home	The home you live in
Control over the support you get	Dignity in support	Who supports you to do things
Who you live with	The neighborhood you live in	The control you have over your life
Paid work	Volunteering	Social life
What you do in the evenings	What you do during the weekdays	What you do at weekends
Close relationships	Relationships with your family	Relationships with friends
Holidays	The money you get For support	Helping your local community
Your physical health	Your mental health	Health

EVAL Fig. 14: Additional domains used in the Richmond evaluation



EVAL Fig. 16: Outcomes for people with a Personal Budget in Richmond

Areas of the questionnaire associated with choice and control all scored relatively highly, such as control over your life (75%); who supports you (53%); control over support (47%); and what you do at weekends and on weekdays (47%).

A notable positive impact was reported on relationships with family (53%) close relationships (41%) and friends (31%).

Those areas concerned with making a contribution scored relatively low, such as volunteering (13%), paid work (13%) and helping the local community (17%).

Four areas were reported by at least one person (6%) as being worse. Feeling safe was reported as worse both in and out of the home by 2 people (11%).

Local evaluation – **Barnsley**

This short case study shows the results of work undertaken in the Metropolitan Borough of Barnsley to evaluate the impact of Self-Directed Support.

The evaluation considered the effect of Personal Budgets on three key stakeholders:

- disabled and older people controlling Personal Budgets (100)
- family carers providing support to those who had control over a Personal Budget (10)
- staff working directly with people taking control of Personal Budgets (35).

For all groups, the evaluation took the form of a short multiple-choice questionnaire. Questions were tailored to each group. The evaluation took place over the summer of 2009. Some data (for 16 Personal Budget recipients) were drawn from earlier work.

How people were selected

Samples of Personal Budget recipients and family carers were randomly sampled from Barnsley Council's database of people using Personal Budgets in the Borough until the desired number of responses had been achieved (100 people using Personal Budgets; 10 family carers). The staff survey was sent to all 50 staff who had been involved in Self-Directed Support (via their team manager), and 35 staff returned the questionnaire.

Personal Budget holders

There are currently 755 people in Barnsley who have been allocated a Personal Budget to meet their social care needs. The evaluation aimed to elicit the views and experiences of 100 of these. About half of the group (56%) had previously had social care support from the Local Authority. The remainder were receiving social care support for the first time. The vast majority (98%) had help to plan how to spend their Personal Budget.

The questionnaire asked people to identify how their life had changed in a number of domains since having a Personal Budget, using a simple three-point scale:

- got worse
- stayed the same
- got better.

Age

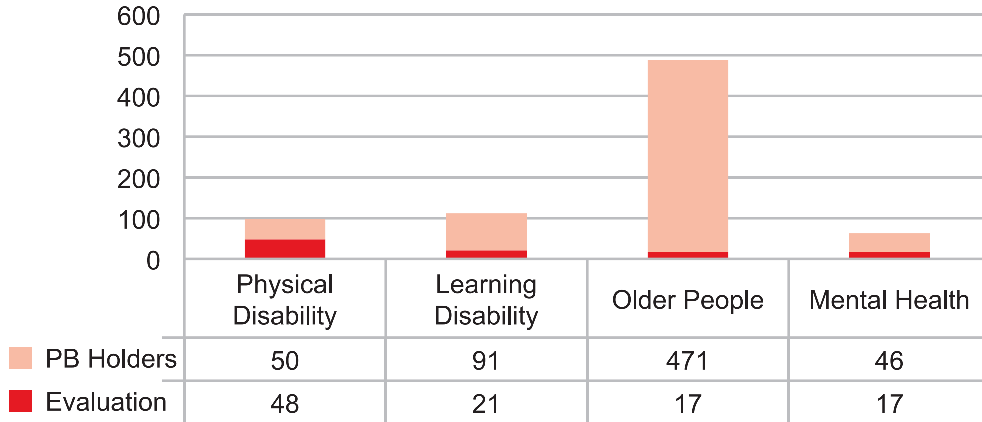
Of the 100 people in the survey, date of birth was available for 78 people. This showed an even distribution across the adult age range. The youngest respondent was 18 and the oldest was 97. The average (mean) age was 55.

Gender

There were slightly more women (53) than men (47) in the group.

Social care group

People from all social care groups have Personal Budgets in Barnsley. The biggest single group is older people (64%). However, this group was relatively underrepresented in the evaluation group.

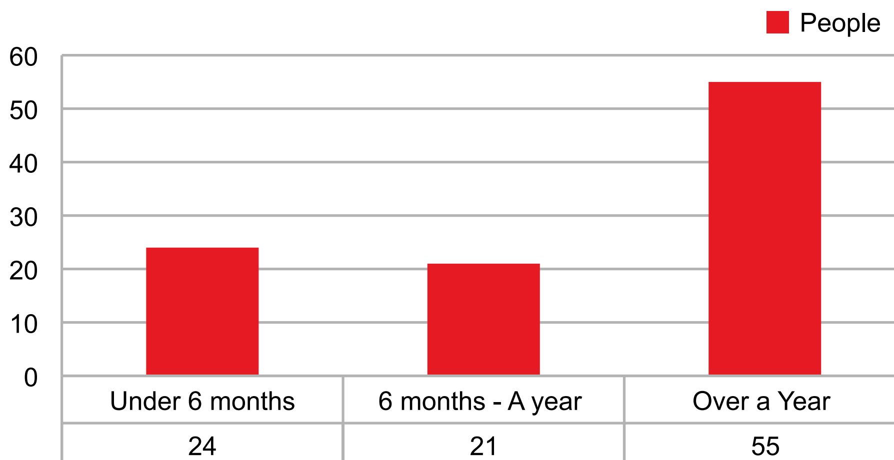


	Physical Disability	Learning Disability	Older People	Mental Health
PB Holders	50	91	471	46
Evaluation	48	21	17	17

EVAL Fig. 17: Participants in the Barnsley evalution by social care group

Length of time a Personal Budget had been held

Personal Budgets are a relatively new approach and most research and evaluation of their effectiveness has involved groups of people who have held their Personal Budgets for very short periods of time. This evaluation is notable because many of the respondents had held their Personal Budget for a relatively long period of time.



Under 6 months	6 months - A year	Over a Year
24	21	55

EVAL Fig. 18: How long participants in Barnsley had held their Personal Budget

Help to plan

All but two of the group said they had help to make their support plan.

Control over the Personal Budget

89 people – the vast majority of the group – said they could control how their Personal Budget was spent.

Knowing the outcomes

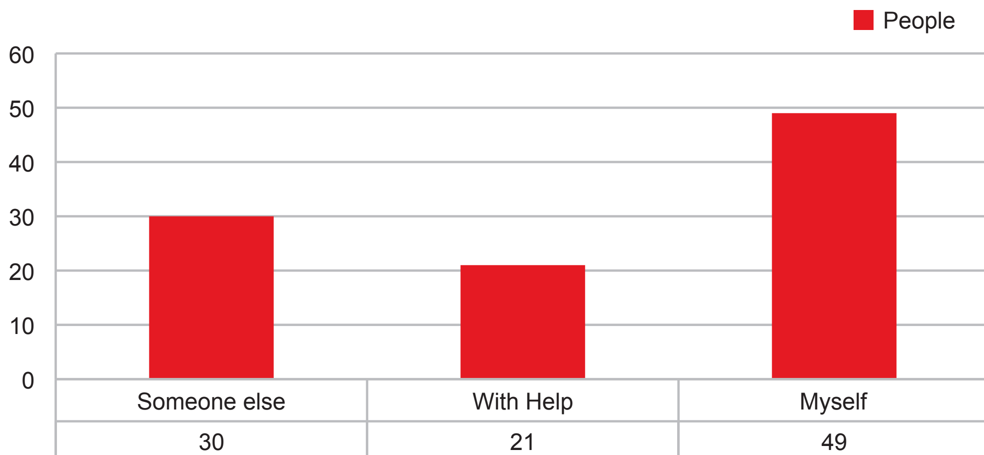
Nearly all (92) people said they knew the things the Council expected them to achieve with their Personal Budget.

Making changes

Just over half of the group (56) said they had had social care support prior to having a Personal Budget. Of this group, most people (65%) made changes to their support.

Completing the evaluation questionnaire

Almost half of people said they had completed the questionnaire themselves. A further 21 people completed the questionnaires with some help. 30 people reported that the questionnaire had been completed by someone else.



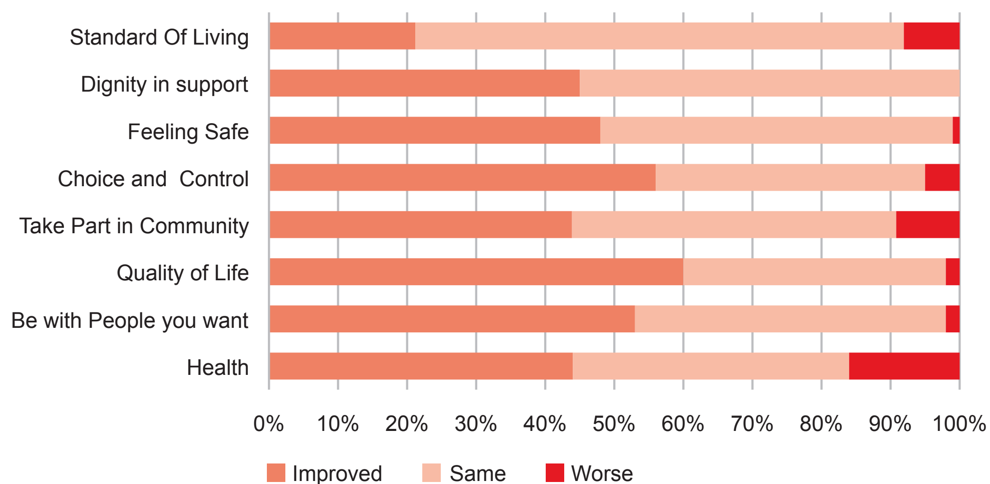
EVAL Fig. 19: Who completed the questionnaire

Outcomes for Personal Budget holders

The evaluation questionnaire asked people to say how their life had changed since having a Personal Budget.

Large numbers reported improvements across all areas:

- Your health
- Being with people you want
- Quality of life
- Taking part in your local community
- Choice and control over important things
- Feeling safe
- Dignity from those who support you
- Standard of living.



EVAL Fig. 20: Outcomes for people participating in the Barnsley evaluation

Although the number of people in some groups is quite small for statistical analysis, we explored whether there were any obvious statistical differences in outcomes ($p<0.05$) for Personal Budget holders according to people's age or gender, whether or not they had been using social care support before using Personal Budgets, their social care group, the length of time they had been using Personal Budgets, and who completed the questionnaire.

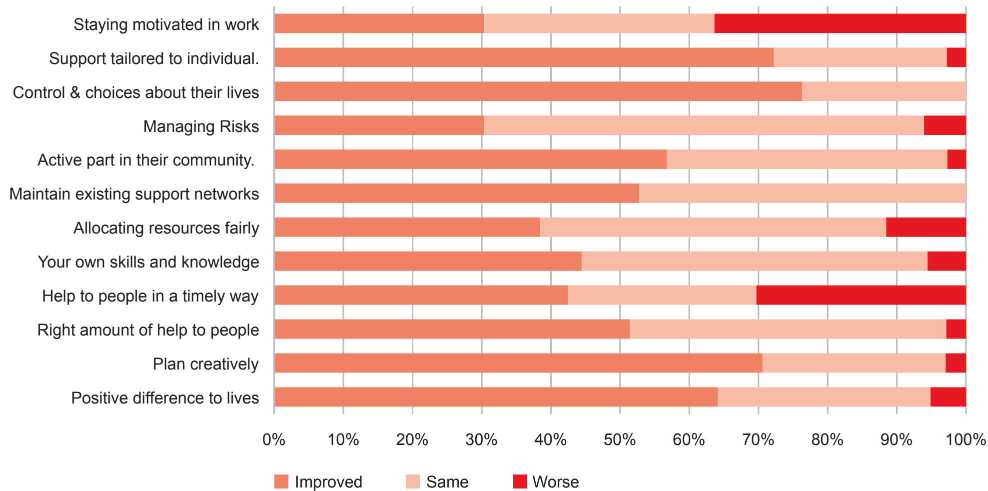
No differences in outcomes were found according to these factors.

Men were more likely than women to report improvements in their quality of life and their standard of living.

People with learning disabilities and people with mental health problems were more likely than older people and people with physical disabilities to report improvements in their health and taking an active part in the community.

The views and experiences of social work staff

The evaluation also gathered views from staff who had helped people take control of a Personal Budget. Staff were asked to complete a questionnaire covering aspects of their working life. 35 staff took part in the survey. Significant numbers of social workers reported improvements across all areas of the survey.



EVAL Fig. 21: Barnsley professionals' views on changes after Personal Budgets

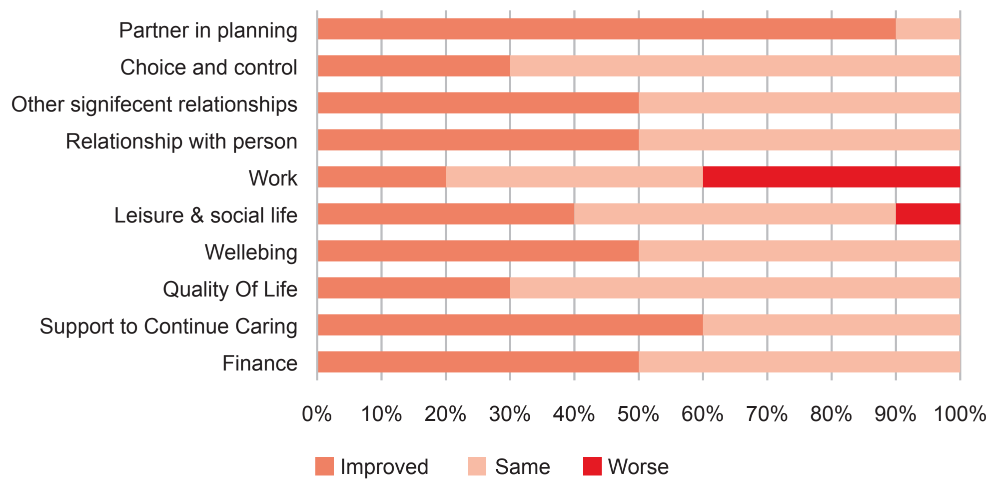
The views of family carers

A small number of family carers (10) also responded to a survey asking how they had experienced the Personal Budget process and how having a Personal Budget had affected their life.

The areas of enquiry in the questionnaire were drawn from the carers national strategy:

- Support to continue caring
- Your quality of life
- Your general health and well being
- Your leisure opportunities
- Your capacity to work
- Relationship with person you care for
- Your relationship with significant others
- Choice and control over your life
- Being an equal partner in planning.

See chart on following page.



EVAL Fig. 22: Barnsley family carers' views about Personal Budgets

NOTES

1 To qualify a Direct Payment as a Personal Budget (by In Control's definition), local authorities have been advised to take three simple steps: 1. The local authority should review its local Direct Payments policy and then remove any unnecessary or inappropriate restrictions on how money could be used. 2. The existing Direct Payments recipients should be reminded of their allocation and informed of the new flexibility. 3. Personal Budget recipients should be encouraged to review how they spent their allocation.

Appendices

Appendix 1
Risk Enablement Panel
– Terms of Reference

Appendix 2
What the words mean

Appendix 3
In Control Membership

Appendix 1

Risk Enablement Panel

Template terms of reference and procedure for use by local authorities implementing Self-Directed Support.

September 2009

This is a template document designed to be adapted for local use by local authorities, provider agencies and any other organisation which works to support individuals who use care and support services.

> *The governing principle behind good approaches to risk is that people have the right to live their lives to the full as long as that does not stop others from doing the same.*

Independence, choice and risk: a guide to best practice in supported decision making, Department of Health, May 2007.

Context

The responsibility for arranging a Risk Enablement Panel will be encompassed within the remit of the Safeguarding Adults Team.

It will convene only when there are complex risks identified during the normal process of signing off an individual's Support Plan which cannot be resolved through the usual channels of decision-making within the relevant team, and where there is a clear difference in opinion relating to the proposed Support Plan.

Aims

The aim of the Risk Enablement Panel will be to provide a forum for full and frank discussion and resolution of serious concerns relating to the positive management of identified risks highlighted in an individual's Support Plan.

When there is a significant or perceived substantial risk, it will provide a forum for a shared decision-making process leading to the Support Plan being agreed which ensures that the individual will be enabled by the support described to remain healthy, safe and well, and where the local authority will be seen to have discharged its legal duty of care.

Objectives

- To ensure a consistent approach is taken to considering complex decision-making, where the risk to independence or safety is balanced with the risk of not supporting an individual's choices.
- To come to a shared responsibility when dealing with complex risks between the local authority, its clients, their carers, providers and staff.
- To ensure there is a written record of discussions and decisions.

Nature of responsibilities

The Panel will not act in cases where Adult Protection / Safeguarding Procedures or Multi-Agency Protection Panel Arrangements (MAPPA) take precedence.

The Panel will support individuals to consider the potential consequences of any decisions that are deemed to carry a significant element of risk, and to offer advice, guidance and support in weighing up these consequences to arrive at an informed decision. The Mental Capacity Act provides essential guidance as to how to facilitate and support informed decision-making for individuals who have difficulty communicating, or for whom there are issues around capacity to make decisions. If an agreement is made, the Panel will then sign off the individual's Support Plan.

All discussions and any agreed actions arising from the meeting must be documented in the individual Support Plan and in the Panel records.

Any person presenting a Support Plan to the Risk Enablement Panel must ensure that all relevant parties are informed of the impending Panel discussion, in agreement with the individual. The outcome should be communicated to all parties within three working days of the Panel.

Membership

The Risk Enablement Panel should consist of:

- the individual and / or their advocate
- any carers requested by the individual to represent them, or who the Panel consider to be affected directly by the decision being considered
- an independent Chairperson, ideally drawn form the local Safeguarding Adults Board
- the local authority Safeguarding Adults lead
- the social worker / care manager responsible for the case and / or their team manager

- any relevant multi-disciplinary staff, such as Social Worker / Care Manager or Health professional
- any relevant specialists involved such as Consultant Psychiatrist or Criminal Justice Advisor
- note taker
- a contingency list of staff that can deputise for primary Panel members.

Frequency and location of meetings

The Risk Enablement Panel is a mechanism of last resort in individual cases, and as such it will not meet unless required.

The meetings will take place at a time and in a venue which is acceptable and accessible to enable the individual and / or their carers to fully and meaningfully participate.

How a Panel is requested

A referral to the Risk Enablement Panel can be made by anyone involved in the decision-making process in relation to Support Plan sign off, and can be made at any stage in this process. However, the Panel will only be convened where all other attempts to fully discuss the issues of concern and reach a mutually acceptable agreement with the individual and / or their representative have been exhausted.

The referral to the Panel can be made by any concerned party involved in the Support Planning process. It is important that individuals and their representatives are made aware of the Panel's existence and role when being given information about the Support Planning process.

The Panel will convene within seven days of the referral being submitted to the SafeguardingAdults team.

At the meeting

The Chairperson will explain to all present the nature of the disagreement and summarise all steps taken to far to resolve the issue. They will then invite each relevant party, starting with the individual or their representative, to present their view of the situation along with their suggested resolution.

An open discussion will then be facilitated by the Chairperson to enable members of the Panel to fully explore and understand the issues and for potential consequences of any decision to be identified and explained.

The Chair will then invite the individual and / or their representative to describe their preferred outcome, followed by the representative of the local authority social services team.

The Chair will then broker an agreement and describe any decision taken, taking care to substantiate any such decisions in terms of the requirements of the Mental Capacity Act and Human Rights Act, as well as the local authority's duty of care. Any consequences of the individual choosing not to abide by the decision taken must be clearly communicated at the meeting, recorded fully and communicated after the meeting to the individual and / or their representative as appropriate (see next page).

After the Panel has met

The decision of the Panel will be communicated to all parties within three working days of the meeting, in writing, or using an appropriate communication method for the individual service user.

NOTE that this may mean someone is required to visit to explain the Panel's decision in person if this is the only way to ensure the decision is adequately communicated.

The individual and / or their representative must be made aware at this stage of the consequences of not complying with any decision which the Panel has made.

The individual and / or their representative must also be made aware of their right to complain if they are dissatisfied with the decision.

Appendix 2

What some of the technical words mean

Direct Payment

Money that is paid to you so you can arrange your own support.

Direct Payments have been around since 1996. In many places, Direct Payments came with restrictions. In Self-Directed Support, you can still take the money as a Direct Payment and have more flexibility about how you spend it. Direct Payments are not the only way you can have control over your money. Someone else can hold the money for you – a family member or other representative, a trust, an organisation, or a care manager.

Personal Budget

A Personal Budget is money that is available to someone who needs support. The money comes from their local authority social services.

The person controlling the budget (or their representative) must:

- know how much money they have for their support
- be able to spend the money in ways and at times that make sense to them
- know what outcomes must be achieved with the money.

Individual Budget

An Individual Budget is money for support that could come from several places – including social services, the Independent Living Fund and Supporting People.

Personalisation

The Government's word for the new way of organising public services. Everyone who uses support should have choice and control over that support. The Government says this is the new system – it's here to stay.

Resource Allocation System

The system a local authority uses to decide how much money you get for your Personal Budget. The system has clear, public rules so everyone can see that money is given out fairly.

Self-Directed Support

Support that you decide and control. You control the money for support – your Budget. You choose what support you want and how to spend your Budget. You can get help to do this if you want.

Self-Directed Support is the new way of organising social care. In Control first figured out how Self-Directed Support could work. In 2007, the Government decided it would be the new social care system.

For a full glossary go to the In Control website:
www.in-control.org.uk/glossary

Appendix 3

In Control Membership

In Control believes everyone has something to contribute. So everyone can be a Member. There are three types of Membership.

Statutory Members

This Membership is available to statutory agencies like Adult Social Care Services, Care Trusts, Primary Care Trusts, Children's Services and Job Centres that are committed to learning ways of developing self-direction.

There are currently three programmes for Statutory Members:

- Adult Social Care Programme
- Health Programme (*Staying In Control*)
- Children's Programme (*Taking Control*).

At any point in your Membership you can supplement your support from In Control and its Organisational Members. In this way you can create a bespoke package of support suited to your area, the challenges you face and your plan of work. There is more detail about supplementary programmes below.

We offer special discounts for local authorities interested in whole-life Membership – for adult and children's services joining as one entity.

Similarly, for PCTs and local authorities that want to develop integrated approaches, we offer a special discount that allows Health and local authority partners to take up one joint membership.

Organisational Members

This Membership is for organisations that provide support, information, help, advice, training or services. It is for people who employ their own staff, voluntary organisations, charities, community organisations, social enterprises, not-for-profit organisations or commercial businesses.

The market in the new world of personalisation will undergo rapid change. Increasingly, individuals will be the new commissioners of their support, a change that will have a dramatic impact on organisations of all sizes.

This Membership enables organisations to join the personalisation knowledge network and find the best way to make changes based on evidence of what works.

Public Members

Until now, In Control's Members have been organisations. Now, In Control wants to make sure people who need support have real choice and feel In Control.

So, we are creating a Membership for the public and communities. Membership is for people who need support, family members or those who work in the sector – in fact, anyone who really and truly believes in all people having the right to live a good life. It is for people who want to make a real commitment to social change and who are prepared to stand up for what is right.

There are a number of programmes and products available to members:

Whole-life Membership

In Control believes that personalisation will work best if we take a whole-life, integrated approach.

Personalisation is not just an issue for social care – it will be implemented right across public services.

This Membership is for those statutory agencies which have already decided to form a cross-service personalisation alliance in their geographical area.

Adult Social Care Programme

This is the programme for all Adult Service Statutory Members. This Membership supports organisations to create a focused approach to change in adult social care departments and really give a strong message of commitment to personalisation.

Health Programme

This Programme is open to all heath service statutory Members. It provides a network of Primary Care Trusts working with local organisations and people. Members use In Control's initial framework in practice, evaluate, learn and refine. In this way, the Programme will develop a national best practice model.

Children and Young People's Programme

This Programme is available to all Children's Services that are statutory Members. It is a national network of Children's Services developing personalisation for children, young people and families.

Supplementary Programmes

shop4support

shop4support is a unique web-based technology platform. It supplies individual consumers, service providers, local authorities and brokers with the means to efficiently match needs and services locally, regionally and nationally. It provides a unique shopping experience for people who are disabled, are getting older and / or need support to live their life.

Making the change

Developing the market is a commonly used phrase. This programme will help you to turn the words into reality.

The programme supports commissioners and providers to work together to meet the challenges of change in the personalisation agenda.

Citizen Leadership

We have clear evidence that, when an investment is made in citizen leadership, Self-Directed Support happens much more quickly.

Below is a range of courses designed to meet local need.

The list isn't exhaustive but gives an idea of citizen leadership courses we have delivered on a local, regional and national basis:

- *Partners in Policymaking*
- *Sharing Knowledge*
- *Plan or be planned for*
- *All Together Better*
- *Partners in Personalisation*
- Bespoke courses.

Our Futures (formerly PLAN UK)

Our Futures is based on PLAN Canada. It was set up to address two major concerns: *What happens when I am gone?* and *How can I support my relative to have a really good life?*

Bespoke support planning

Because the situation of each Statutory and Organisational Member is unique, In Control has responded to requests for more individual, flexible support by designing a programme that can meet the specific needs of each organisation. This programme can be as little or as large as you want it to be and can be based on your budget and on the particular support you need.

Stronger Communities Programme

This programme is open to all Social Care and Health Service Members. It will focus attention on the original aspirations of Self-Directed Support: to develop stronger, more inclusive communities that welcome the presence and contribution of people who need support.

Real Jobs Programme

The *Real Jobs* Programme is a new product that will be delivered jointly by In Control and the Foundation for People with Learning Disabilities / The Mental Health Foundation.

The programme will work with local authorities to enable Personal Budget holders to get and keep a real job. It will enable local authorities to build capacity to commission new services that are person-centred and based on international evidence of best practice.

Commissioning for Personalisation

The Commissioning for Personalisation programme is a product developed and delivered jointly by In Control and the Office for Public Management (OPM).

The programme will work with local authorities and their partners to enable them to deliver against key policy imperatives in: *Putting People First* and the *Transforming Adult Social Care Local Authority Circulars*; the seven outcomes in the *Social Care White Paper*; *Opportunity Age*; the *Independent Living Strategy*; and *World Class Commissioning*.

In particular, the programme will enhance councils' capacity to evidence progress against the Government's five implementation milestones for progress in personalisation recently announced.

Market Intelligence Project

Demos (the leading think tank), In Control and the University of Lancaster are collaborating on a major piece of market intelligence work that will generate in-depth data on how demand for social care services will change with the implementation of Personal Budgets, and explore how social care providers and local authorities must respond. The project uses methodology from a recent, successfully completed project with five local authorities.

Paradigm Programmes

Paradigm, the leading consultancy organisation, has been a supporter and partner of In Control since it began in 2003.

Paradigm offers the following programmes:

- *Support Planning*
- *Developing Support Brokerage*
- *Planning for Change*
- *Getting Personal with Care Managers*
- *Housing and Support Options*
- *Person-centred Approaches in Schools.*

Pass It On Support Planning

This is a two-day course aimed at individuals, families and people supporting families at a local level. The *kick-start* course works with up to 25 families and mobilises local people to use their Personal Budget to create the life they want.

The course has a proven track record in Worcestershire, Newcastle, Cheshire and Australia.

Developing User-led Organisations

This course is aimed at individuals and families who want to develop their own user-led organisation in their community.

The course helps a local group to develop an organisation that works from the perspective of a social model of disability; promotes independent living; promotes human and other legal rights; is shaped and driven by local people and is based on peer support; includes all local disabled people, carers and others who use support (either directly or from organisations); is non-discriminatory; and recognises that carers have their own needs and requirements.

An electronic version of this document is available at:
www.in-control.org.uk/phase3

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