Citizenship in Health

Self-Direction theory to practice

In Control Discussion Paper

DRAFT version-02

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An invitation to contribute…

In Control is a charity that believes in the innate dignity of all human beings and the vital importance of everyone being be able to play their full part in the community as active citizens. In order to achieve this mission, In Control believes that we will need to find ways of reforming the welfare state in order to make it easier for people to make the most of their lives.

In 2008, In Control began to extend its work into health, education and employment. In particular, In Control launched its *Staying In Control* membership programme for National Health Service (NHS) organisations. 37 organisations, mostly Primary Care Trusts (PCTs) joined the programme alongside their local authority partners in the spring of 2008.

This discussion paper provides an overview of the work of In Control and its members over the last 12 months. It is a work in progress and we invite contributions from everyone interested in these issues to comment and suggest ways of improving the discussion paper prior to its publication as a report in the autumn.

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Thanks

We would especially like to thank Professor Jon Glasby, Chair of our National Steering Group, for all his help, knowledgeable advice, encouragement and constructive input to the thinking in this document.

We would also like to place on record our thanks to the members of our National Steering group for *Staying in Control* whose members were: Alison Austin, Andrew Sanderson, Jeremy Porteus, Ailsa Claire, Jon Glasby, Jill Stannard.

Thanks also go to the members of the Operational Group: Carey Bamber, Jo Harvey, Tom Mc Lean, Wendy Lowder, Dr. Paul Hodgkin, Julia Thompson, Robin Lorimer, Edward Harding, Jo Fitzgerald, Stephen Lorrimer, Alison Austin and Rebecca Pyne.

Thanks to the Integrated Care Network of the Department of Health for their support from the outset to the Staying in Control programme.

And, importantly, thank you to each and every one of our *Staying in Control* members whose enthusiasm, energy, hard work and commitment to improving the lives of their local communities has shone though the last year.

Executive Summary

Below are the main points, chapter by chapter, which we make in this report.

Chapter 1: Overview of some critical issues

This chapter considers the context for the introduction of personalisation in Health. While drawing on the experience of work in social care, it is important to give due weight to important differences between health and social care services and their different professional, legislative and cultural contexts. The chapter states clearly that, in order to create a new approach that is relevant and fit for purpose, we are *not* assuming that a systemic model chosen for one environment could simply be naively imposed onto another.

Chapter 2: What is this all about?

When talking about personalisation in Health, each of us is likely to mean slightly different things. One person might think of person-centred planning, another might focus on hospital choices. For In Control, personalisation is one aspect of Self-Directed Support – referred to here as Self-Direction, which is a whole-system approach designed to fundamentally change the relationship between the NHS (as part of the welfare state) and the population or citizens. Moreover, Self-Direction has a **purpose:** to enable full citizenship for everyone and thereby contribute to the creation and sustaining of healthier, more cohesive communities.

Self-Direction not only has a clear purpose, it is also founded on an explicit set of **values**. These are the bedrock of In Control's developmental work with its members. By being able to refer to a guiding set of values, we are able to address the complexities and tensions inherent in finding new ways of working with individuals, families and professionals as part of whole communities.

Chapter 3: Why it matters – Mitchell's story

Self-Directed Support was developed by a grass-roots partnership of disabled people, families and local professionals which has eventually led to innovation across the whole system of social care support. But we know that people do not fit neatly into a box of health or social care. People have a mixture of needs: physical, mental and social which are intertwined and inter-related.

In this report we will hear the voices of some people who describe why change matters to them and why having control within Health as well as social care, makes such a useful difference in their lives. We will also consider in a later chapter, why having control in some contexts is likely to lead to better outcomes. And we are all aware that there are other demographic and economic pressures driving the need to find new ways of considering the public's relationship with Health and the NHS.

Chapter 4: What does citizenship mean in Health?

The idea of citizenship can be understood in many different ways. This paper suggests that citizenship is a way of describing what it takes for us to belong, be part of a community and to live with self-respect and the respect of people around us. Citizenship and health are seen to be symbiotic but very different kinds of goals.

Doctors who care about our health rightly remind us that good health is impacted on by many more things than good health care. Amongst other things, our health is influenced by our isolation or connectedness, our poverty or affluence, our poor or good housing, our work or unemployment. We can see then that a society which excludes people from citizenship guarantees poor health. This is why the concept of citizenship is important in considering new approaches in Health.

Chapter 5: Where might these ideas apply in the NHS?

It is useful to consider in what types of situations Self-Direction is likely to be most useful, and to focus our developmental work there. We are not trying to change an entire NHS system but to consider some aspects where doing things differently could be directly beneficial for individuals, families and professionals, and also for the tax- paying public in terms of making best use of public money. This report gives an analysis of how we might weigh up where it is useful to consider change and where it is useful to cherish what we have.

Chapter 6: What can we learn from elsewhere?

This paper cannot do justice to the range of relevant, related initiatives currently emerging within Health, and is not a research document. However, we do refer to some of these initiatives as vital indicators and valuable resources in an emerging consensus around Self-Direction.

We will draw here on our learning from within Self-Direction in social care whilst acknowledging that there are fundamental differences between health and social care which make this learning, whilst useful, insufficient without further exploration and debate specifically within the NHS. We will also outline an evaluative framework for measuring the outcomes of Self-Direction in Health.

Chapter 7: What might be the wider implications of Self-Direction in Health?

We will include a brief discussion of some of the possible wider implications or effects of moving towards Self-Direction in Health and specifically address some of the most commonly arising concerns and queries.

Chapter 8: How might it work?

This is perhaps the question that most people want to see answered. We believe that we can outline many of the essential ingredients necessary to make Self-Direction work effectively within Health. What we do not yet have is a complete set of instructions for how to use these ingredients. These instructions may be developed through testing out the ideas in practice with small numbers of people in carefully considered innovation, and sharing that learning. It may be that there always remains a need for some flexibility and local tuning to enable Self-Direction to flourish across widely diverse illnesses and different demographic communities.

It is certainly true that we cannot write 'instructions' for every eventuality. The multi-layering of illnesses and conditions in people makes this impossible. 'Looking down a daunting flow chart of treatment options, the GP concludes that "algorithms are one thing, patients are another."' (*The Talking Cure*, Demos 2008). Professional judgement, based on expert knowledge and wisdom gained from experience, will remain vital. With Self-Direction we can usefully combine professional judgement with the unique perspective of individuals themselves and potentially enhance health outcomes.

What next?

Our work with Health members is very new and we have much to learn before a robust model of Self-Direction in health emerges. Our work over the last year, however, has enabled us to draw together this summary report as the first iteration of what is intended to be a process of learning created and shared by our members. Over the summer, we welcome comments and suggestions from as many people as possible from both within and outside of our *Staying In Control* (In Control Health) learning community. An amended report will then be published in the autumn.

Over the next couple of years, the most important learning is still to be gathered from those members who work together to try out in practice the ideas contained in this report. Updates on that learning will be regularly shared with everyone interested in these issues, and specifically with the Department of Health Personal Health Budget Pilot Programme.

Chapter 1

Overview of some critical issues

An emerging consensus among people and professionals

Self-Direction was developed by a grass-roots partnership of disabled people, families and local professionals. This partnership has eventually led to innovation across the whole system of social care support including: the way information on funding is shared, the way decisions are made and support is planned and provided and lives improved. This in turn has led to significant changes in central government policy which endorses this innovative practice for everyone eligible for social care support.

The ideas underpinning Self-Direction are also increasingly originating within the NHS, perhaps using slightly different words but following the same themes of shifting power and control closer to people who are directly experiencing an ongoing illness. 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* and the latest Department of Health *Personal Health Budget Pilot Programme*. It seems there is an emerging consensus that it is possible to successfully apply the principles of Self-Direction to some parts of the current health care system. At the same time, everyone acknowledges that there is much further thinking and work to be done together to evaluate how this might work best in practice: for individuals, families, communities and professionals.

In order to consider how Self-Direction may work best within health care, it will be necessary to build on and adapt the critical innovations within Self-Direction to this different policy and practice environment. To do this we must aim to make best use of learning from several sources at once:

- learning from NHS initiatives such as those mentioned above, and other health service examples of new practice in this field including the use of new technology
- learning from people’s personal experiences
- learning from developments in social care.

Innovation not imposition

Crucially, in order to focus most usefully and not be hampered by misunderstandings or unnecessary anxieties, it will be necessary to clearly define what Self-Direction is, what situations or conditions might benefit from a new approach. We also need to specify what Self-Direction is not, and where it will not apply.

In Control and its members are interested in considering how it may be useful to apply the lessons from reform in social care (in which they have taken a significant role) to the health care system. We have been clear from the outset that it is important to give due weight to and respect the key differences between how health and social care services have developed historically and the different professional, legislative and cultural contexts within which each works. This is why we have described our approach as innovation not imposition. In order to create a new approach which is relevant and fit for purpose, it is necessary to state that we are *not* assuming that a systemic model chosen for one environment could simply be imposed onto another.

Giving more power and control to an individual can make a big difference to the quality of their life and perhaps to their health and wellbeing. We need to gather information to evaluate the impact of any changes in ways of offering health treatment and support. However, there are already clear indications that there is potential for health gain. Self-Direction has had a powerful impact on the current system of social care that is leading to major improvements and efficiencies. This learning, whilst useful, is insufficient without further exploration, testing and debate within the NHS.

It's not only about money, but …

Our experience suggests that while personal health budgets may be very useful, they will only work if there are also:

- opportunities to meaningfully plan and shape treatment and support flexibly
- 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 individuals and the NHS.

In Chapter 8, we will present the concept of 'real wealth' and stress its importance in considering what support someone may need to be able to make best use of Self-Direction. We know that simply offering someone control over money is rarely sufficient and may even be pointless without this deeper consideration of someone's whole individual context.

It is important to remember throughout this discussion, however, that within Self-Direction, personal budgets are only one part of a series of steps within a whole process of change.

Personal budgets, for In Control, have a specific definition: the person controlling the budget (or their representative) must:

- know how much money they can have for their support/treatment
- 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.

We can see immediately from this definition that, whilst money is important, it is neither sufficient on its own to enable useful change, nor is it essential to always have to have money directly in one's hand.

In Control have outlined at least six ways in which someone can get a better life through directing the way in which the money is spent. Only one of these involves the money being paid directly to the person him or herself.

Nevertheless, many people would acknowledge that money is a powerful tool, and can be an important lever for change in the ways people relate with providers of services and with professionals. It is currently creating significant problems for some individuals that health care money cannot be given directly to them. For example, there are a number of situations where people have been in control of the money they have had for support from social care. They then become more poorly and are assessed as being eligible (and therefore have to be funded) by health care money through continuing health care. They then lose the control. This can even include losing the paid support staff who have helped them to live their lives.

See, for example: http://www.yorkshireeveningpost.co.uk/news/Paralysed--Wakefield-exsoldier-takes.4975276.jp or see appendix 1.

In Control members must work within current legislation, and we must therefore be constrained by the fact that the legislation does not yet allow people to have money paid directly to them. We can and will work to have in place other ways for people to be in control of the money, but this legislative block remains. In the near future, some of the DH Personal Health Budget Pilots will be given permission to use new legislation that will allow money to be given directly to people rather than through a third-party provider, but this process will only be available in a very few places. It seems important to make this clear so that families and individuals do not have their expectations raised only to be disappointed, whilst at the same time working with partners to seek new legislation that will apply to everywhere and everyone.

The best of both: professional and citizen together

Self-Direction and Personalisation does not need to threaten professional practice. Instead, done well, it can enable professionals to further improve the effectiveness of their professional practice. Self-Direction and keeping people safe and well are integral, not competing, ideals. We need to establish clear examples of best practice and also to emphasise how we can avoid taking forward any new developments in a way that is not properly thought-through and is overly bureaucratic. We are not dealing in absolutes. Rather, we are dealing with the full complexity of human lives. Professional judgement, wisdom and

expertise remain as crucial as ever alongside the valid expertise of someone's lived experience and uniquely personal priorities.

Self-Direction and Personalisation can enhance, not threaten the NHS. However, it does demand that we rethink some of our current assumptions about how we achieve a fairer society, make best use of scarce clinical expertise and have the very best outcomes from public money. It also means addressing some of the most challenging issues surrounding our health care in the 21st century, and our communities within wider society.

In Control's approach

Some of our approach is to create a framework for innovative practice and a membership network for learning together. We will remain focussed on small steps with real people in real life as our way of finding creative solutions and testing and evaluating those, small scale, in practice. Our intention is to be optimistic and also pragmatic, enthusiastic and also grounded, and to invite input from everyone who is interested in this issue whether as a supporter or critic.

In Control will work to strengthen its membership network for innovation and to develop and test innovations with our members and partners in some key areas over the next three years. This report is, therefore, a first iteration of what we hope will become an evolving process of co-designing Self-Direction in Health.

Background information about In Control

In Control was established in 2003 in order to find a better way of organising support services for disabled people, people with mental health problems and older people.

In Control developed, with its members, the concepts of Self-Direction, Individual and Personal Budgets, Small Sparks, Support Planning and Resource Allocation Systems, and many other new ways of organising services. These ideas are increasingly being adopted by local and central government.

In 2007, In Control was established in England as an independent social enterprise with the purpose of promoting citizenship and community by developing a network for social innovation. In Control's mission is to help create a new welfare system in which everyone is in control of their lives as full citizens. In 2009, In Control was registered as a charity.

In Control works by supporting an active membership network. Its members include 120 adult social care departments, 24 children's departments, 37 NHS Primary Care Trusts and 80 provider members.

In Control's intellectual property is developed by its membership and is free for its members to use. This methodology for supporting innovation is efficient, sustainable and empowering. In Control's website, www.in-control.org.uk, is the leading source of expertise on Self-Direction.

In Control also supports In Control International to share learning between other countries, including Scotland, Wales, Northern Ireland and Australia.

Chapter two

What are we talking about?

Key Message: Self-Direction has developed through a grassroots partnership of disabled people, families and local professionals. This partnership is calling for improvements to systems of support to enable people with a range of illnesses or conditions to have the best possible lives and to contribute to society as full citizens. Self-Direction is part of a spectrum of control and clarifying its meaning will be vital to exploring its application in Health.

History

The changes that led to the development of Self-Direction stem from the growth of the Independent Living movement. This movement, which is represented by a number of different organisations and individuals, (in particular, RADAR – The disability network, the British Council of Disabled People and the National Centre for Independent Living), has pursued the goal of independent living for disabled people since the 1970's. In practice, their work led to a series of national and local policy changes, including:

- **Disability Discrimination Act** – banning forms of discrimination against disabled people
- **Direct Payments Legislation** – giving people the right to control their own funding for care and support, but constrained by the way social care and funding decisions were organised.
- **Centres for Independent Living** – local organisations, led by disabled people, offering support to disabled people.

Increasingly, disabled people organised themselves around an understanding which is called the 'social model of disability' and argued that the difficulties they faced were rooted not in their impairment but in the failure of society to adapt itself to the fact that some citizens have such impairments.

This movement is not restricted to people with physical and sensory disabilities. Other groups have emerged who have also demanded greater control and respect for their perspective, for example:

- **Inclusion Movement** – people with learning difficulties controlling their own lives
- **Expert Patient Programme –** people controlling the management of their illness
- **Recovery Movement –** people with mental health problems working for a focus on recovery and living with mental ill health in ways they prefer
- **Grey Power –** older people making sure they stay in control.

It is highly unlikely that there would be any demand for Self-Direction without the work of these movements which not only provide a collective voice but also offer a way in which individuals can rethink their own situation and begin to see themselves as part of a group which can, and arguably should, take on more control and responsibility for its own destiny.

Co-producing the new system

In Control was founded on an alliance of professionals, disabled people and families in order to co-produce a new set of solutions, initially for the re-organisation of social care. In fact, within the genesis of the current model of Self-Direction, there were at least three important threads. As we consider how Self-Direction may apply within the NHS we can see important parallels emerging:

- **Local people's willingness to share** – In Control's work is built on the work of all those individuals and families who had already been doing 'person-centred planning' or who had been managing a Direct Payment. These people shared their experiences, both good and bad, and helped to try out some new ways of working. All of the success of In Control's work depended on the willingness of local citizens to try these new approaches.

  In considering new developments in health care, it is important to remember that innovation will again rely on the courage of individuals and families, to trust in the possibility of improvement through innovation and to be willing to try new things. We are fortunate to already have direct contributions by some people who are in the middle of trying innovative approaches to their own or their family members' health care, and we have plans to extend and deepen this connection.

- **Statutory organisations being willing to change** – On an organisational level, the development of Self-Direction was reliant on a number of local authorities coming forward and expressing a strong willingness to experiment with their own systems, and on a recognition that the current system was falling far short in delivering what local leaders really wanted for their local communities. None of the critical innovations developed by In Control could have been implemented without the courageous leadership of local directors of social care.

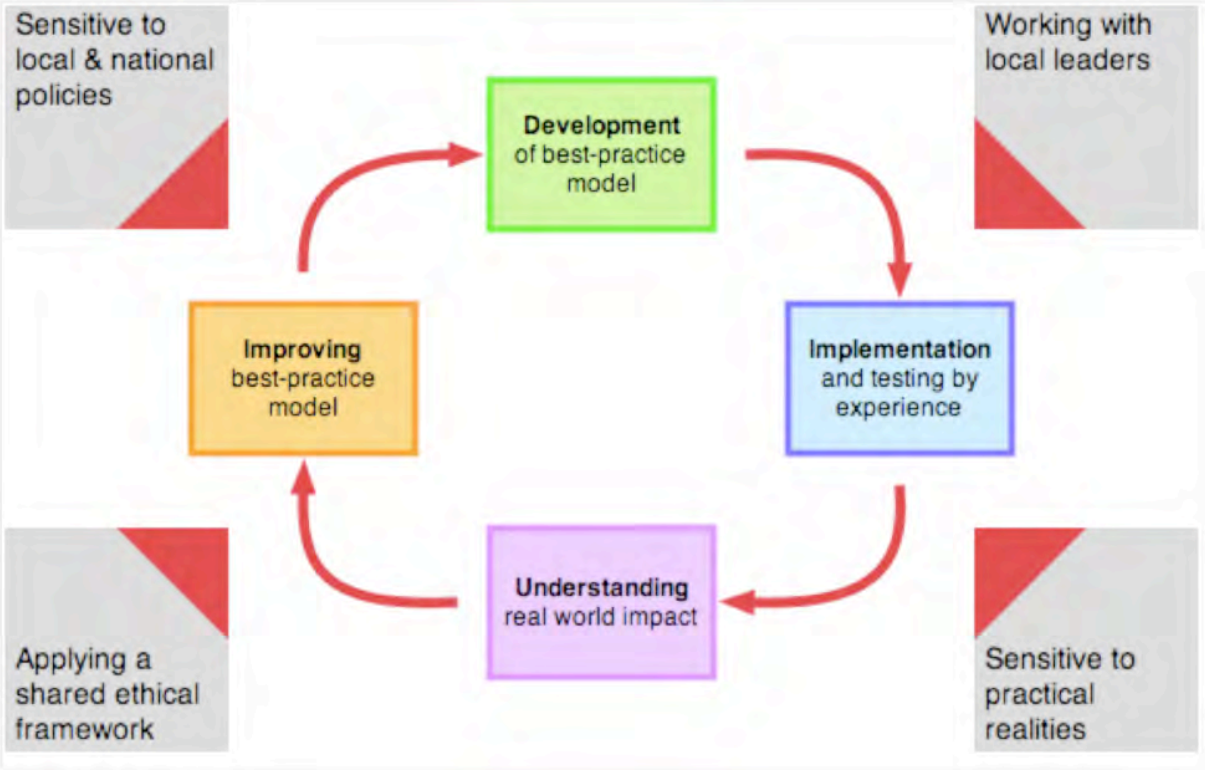
  The emergence of innovative leaders in health care has been similarly seen in the number of Health organisations which joined the *Staying In Control* (In Control Health) progamme, in the spring of last year before the Darzi report (DH, *High Quality Care for All*, published summer, 2008) made the idea of piloting personal health budgets the legitimate 'business' of the NHS. We are currently working with 37 PCTs in 35 Local Authority sites. There is a groundswell of support from professionals keen to make a difference in complex situations where they can see that the divisions and differences between health and social care are impacting negatively on the people they're trying to help.

- **A network for social innovation** – Innovations did not emerge from England alone. In Control's whole-system model of Self-Direction extended and integrated several innovations that had already been tested in the UK and internationally. Together, local people and professionals then took the models developed by In Control and its members, amended them to work locally, implemented them and shared their learning with the wider community.

In health care we see a similar network emerging. The work of Vidhya Alekeson (*Putting Patients In Control: The case for extending self direction into the NHS,* the Social Market Foundation, June 2007) and the work of Patrick Hendry (*The Florida Self Directed Care programme*, Patrick Hendry National empowerment Centre, February 2008) are two notable examples.

Best practice, in our experience, cannot be defined by statute or fixed in time. It takes a real community of people willing to learn and unlearn in order to progressively move things forward. We have been delighted to see the emergence of just such a community in our *Staying In Control* programme over the last twelve months.

Of course, developing a good model, even a model that has been tested and proved effective, is not itself a guarantee that change will take place. Within social care the process of bringing about change has involved building a progressively stronger alliance for change within both professional and citizen communities. Our understanding is that we are building a creative new alliance across the NHS.



Progress and change

Developing innovations in health care

The lesson that these experiences teach us is that developing similar innovations within the health care sector will not be easy and it will be necessary to develop a similar alliance of professionals and citizens if we want

to see a similar level of change. Amongst the many particular challenges we will face are the following factors:

- Health care is a more complex public service than social care and Self-Direction will be relevant to a smaller percentage of overall activity.
- The coordination role in the NHS is much more complex and multi-layered.
- The 'patient groups' within the NHS are more diverse and patient involvement can often be more episodic.

However, there are also, as mentioned above, some very promising signs that the NHS does present a good environment for the introduction of Self-Direction and similar innovations:

- Case law
- Independent Living Movement
- Recovery Movement
- Marie Curie – people with cancer getting help so they can stay at home
- Hospice Movement – the dying and their families preparing for death
- Diabetes UK and DH Year of Care – people supported in self-managing their Diabetes
- Health Foundation Co-creating Health programme
- Carers' Movement – people supporting their own family to manage some conditions
- Professional interest
- PCT In Control membership
- DH Personal Health Budget Pilots.

In following chapters we will sketch out how and when Self-Direction might be relevant to the reform of the current health system. We will subsequently identify some of the learning there may be from social care and elsewhere, and the adaptations or further practical developments that may also be necessary to make Self-Direction in the NHS useful and effective.

Before dong this, it is important to make clear In Control's support for the values and principles of the NHS as a public service.

The NHS is the primary organisational means by which high-quality health care is delivered in the UK. The creation of the NHS was one of the great achievements of the post-war development of the welfare state and in the UK we are rightly proud that the NHS provides:

- **highest quality care –** our doctors, nurses and other health professionals are amongst the best trained in the world
- **universal and equal access** – the same care is provided to the poorest and the wealthiest
- **free to those who need it** – the whole community pays for health care from general taxation and when we need health care we do not need to pay for it.

It is the view of In Control that these are important principles, highly consistent with In Control's values and the promotion of citizenship and community. (In Control's Ethical Framework is being revised to be appropriate across all ages and across health and social care. The current unrevised document is in Appendix 2)

Any reform of the NHS should seek to improve one or all of these NHS principles and must not undermine any of them. However, as we will go on to discuss, there are different ways of understanding some of these principles and in order to make progress we will need to at least clarify our understanding of them.

The space for reform

One of the reasons that positive reform is possible is that there are many different ways of achieving these key principles. The current system is not the only way of organising things. In fact we frequently see attempts by central policy-makers to change the macro-architecture of the NHS by organisational restructuring (splitting up or merging the different organisations within the NHS).

In Control is more interested in exploring how citizens and professionals can themselves change the micro-architecture, the spaces between themselves and the patterns of interaction. It is this 'Interactive Process' for health care that will be the main focus of In Control's work, for it is in this space that the real experience of health care can be improved. This process needs a clear methodology or 'Operating System' to best enable it to happen and to evaluate its effectiveness and impact. It is how the Operating System is *applied* as an Interactive Process between people and health professionals which shapes people's interactions with the NHS.

The best Operating Systems can be misapplied if attention is not given to the manner in which people relate and it is not founded on clear values and aims. It is useful to consider here learning from treatment for mental illness: *'The importance of a deep relationship between health professional and service users is often overlooked. Mutually beneficial interactions between service users and doctors depend on subtle interpersonal dynamics. Healthcare in general can learn from particular "talking therapies" in mental health. There are numerous schools of thought within talking therapy, each with its own approach. But the technicalities of the various methods are not the most important factor in achieving positive patient outcomes. Instead we know that most importantly across all methods are the personal qualities of the therapist and the quality and nature of the patient-therapist relationship.' (The Talking Cure – why conversation is the future of healthcare.* Demos May 2008)

Experience in Social Care suggests innovations in how systems and people work together lead to benefits for professionals, individuals and communities.

The space for reform – changing the Operating System

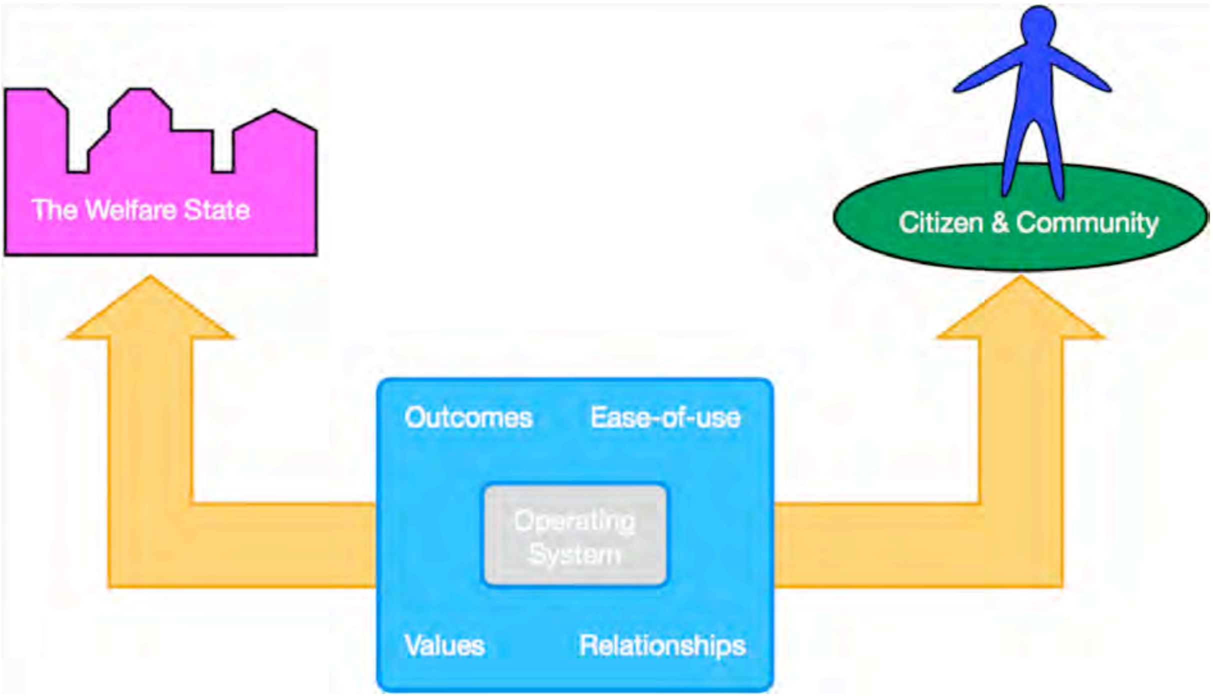
One way of thinking about these possible reforms is to think of them through the metaphor of the Operating System. An Operating System (or OS) is the interface between the system and the user. In computers, Operating Systems are the things that make computers useable by ordinary people and these include systems like Vista, Windows, Linux and the Apple OS.

The welfare state can also be thought of as a system. Like computer hardware, it has rules, resources and limits. It is there to provide us with a level of protection from poverty, homelessness, sickness, ignorance and abuse. Yet, like any system, we need to be able to interact with it, be able to use it to access our entitlements and use them effectively to live our lives as positively as possible. Our contention is that we need to give more attention to the OS that citizens need in order to make best use of the welfare state, including the NHS. We cannot simply think of systems as things that deliver benefits to people. Instead, we need to think of systems as things that people can use and which are more or less useful to the extent that their OS is effective.

We may even be able to identify, at least provisionally, some of the key elements of an effective Operating System:

- improved outcomes – systems that are more likely to give people what they want and value, will be more prized by citizens
- ease of use – systems that are easy to use and where the chances of success are greater and the risks of making a mistake are limited, will be more valuable
- better relationships – systems that build stronger relationships between different people, both professionals and citizens, will encourage greater solidarity
- coherent values – systems that express values that are coherent and positive will draw upon the commitment of professionals and citizens.

We could picture this relationship between the citizen and the welfare state through an Operating System as follows:



Applying the concept of an Operating System to the welfare state and the NHS also suggests that there is likely to be an interesting space for reform between the system itself and the users of that system. In other words 'reform' does not need to be something that can only happen in Parliament or at the top of the system. Instead, it is possible for citizens and professionals to renegotiate the means by which they work together and to work in the OS space.

The nature of reform – exploring different forms of control

Not only does the idea of an Interactive Process (and the Operating System to enact it) tell us more about the possible space for innovation, it also hints at some of the kinds of innovation one can expect. In particular, there are four key concepts which we need to define and which hint at what might be possible:

Personalisation – To personalise something is to make it more fitting, more appropriate. In fact, if we take the idea of public service seriously we are already committed to personalisation, for it is self-contradictory to serve someone in a way which is inappropriate or unfitting. **Personalisation promises better outcomes by attending to the details of the individual's situation.**

Co-Production – To co-produce is to produce together and almost everything that professionals attempt to do to help others can be better thought of as co-production. Whether it is improving health, education, society or income, the public servant can rarely act alone. There are some important exceptions – the life-saving surgeon or Accident and Emergency Nurse produces the most vital of all outcomes: survival. This exception applies to situations where we are unable to participate and are desperate for someone to act swiftly on our behalf and with their best medical judgement. In general, though, it is the citizen who must take exercise, learn, eat better, manage their health care, find a job, work or make friends. Citizens generally produce outcomes, not services. **Co-production promises better outcomes by attending to the partnership that is necessary between the citizen and the professional in order to achieve those outcomes.**

Self-Direction – Self-direction means giving people real power and control over their own lives. We take Self-direction for granted when we are not dependent on the welfare state for our life, health, income or well-being. But if we are dependent, we can find that we have lost control of vital aspects of our life for reasons which have nothing to do with the effective meeting of our needs and which may even frustrate our needs. Increasingly, it is clear that people flourish when they are in greater control of their lives, their homes, their work and their support. **Self-direction promises better outcomes by moving power and control closer to the citizen.**

Citizenship – Citizenship is being someone who has respect within the community and who, when able, acts to support and sustain that community. Our commitment to each other and to the public services which support us relies on the willingness of all citizens who are able, to contribute practically and financially to the strengthening of these services. If we erode citizenship, make participation and contribution harder, then we will eliminate the very fabric of the community itself. **Citizenship promises better outcomes by strengthening the commitment of each of us to each other and to the whole community.**

These are similar and related but not identical ideas. There can even be some tension between them. It may be helpful to think of the four concepts as forming part of a spectrum of control as follows:

- Personalisation is useful because it can make services more relevant to a particular person rather than a rigid block of care into which they must fit. When considering the differing needs and also the cultural preferences of our richly diverse society, personalisation can be a helpful concept. However, it is a concept which may not shift power and control closer to someone, and may do little to improve their ability to be full citizens. Professionals and service providers can legitimately claim that they offer personalised solutions without allowing an individual any real power. The personalised service in this concept is reliant on those in power benevolently sharing it through consultation.

  Involving people is not the same as sharing power. A hitchhiker is always grateful when someone kindly stops and gives them a lift. The person with the car retains all the power. Personalisation could potentially be like this, with some real benefits but perhaps not moving us all on as far as we would like. It could be subject to, at worst, the whim, or at best the chosen professional practice, of individual personalities, rather than being universally available.

- Co-production is useful because it supports the partnership that is necessary between people and public servants in order to achieve outcomes. It is about collaboration and encouraging people to take an active role. The following excerpt from a recent SCIE research briefing outlines co-production**:**

'*The term "co-production" is increasingly being applied to new types of public service delivery in the UK, including new approaches to adult social care. It refers to active input by the people who use services, as well as – or instead of – those who have traditionally provided them. So it contrasts with approaches that treat people as passive recipients of services designed and delivered by someone else. It emphasises that the people who use services have assets which can help to improve those services, rather than simply needs which must be met. These assets are not usually financial, but rather are the skills, expertise and mutual support that service users can contribute to effective public services. In the words of Cummins and Miller, co-production is about how services "work with rather than do unto users".*

Co-production is also being used as a way of talking about participation and community involvement in social care services in the context of personalisation. The Putting People First concordat asserts that the transformation of adult social care programmes "seeks to be the first public service reform programme which is co-produced, co-developed, co-evaluated and recognises that real change will only be achieved through the participation of users and carers at every stage". (*Briefing 31: Co-production: an emerging evidence base for adult social care transformation, Dr Catherine Needham, Queen Mary University of London and Sarah Carr, Social Care Institute for Excellence, March 2009):*

The idea of co-creating health is an exciting initiative which echoes some of these ideas: *"Providing education and information for patients is an important part of the support they need. But supporting self management also means fundamentally transforming the way that patients and clinicians interact with one another; working in partnership to achieve the best possible level of health and quality of life for patients." Importantly there is an acknowledgement that decisions are made in partnership not by the clinician alone "The patient is supported by the clinician in defining their own goals." "These goals do not need to be clinical in nature- but achieving them must be important to the patient.....achieving these goals builds confidence and momentum..." (Co Creating Health briefing, May 2008) The aim of this co creating health work is to "embed self management support within mainstream health services".*

Key messages

- *Co-production emphasises that people are not passive recipients of services and have assets and expertise which can help improve services.*
- *Co-production is a potentially transformative way of thinking about power, resources, partnerships, risks and outcomes, not an off-the-shelf model of service provision or a single magic solution.*
- *To act as partners, both users and providers must be empowered. Co-production means involving citizens in collaborative relationships with more empowered frontline staff who are able and confident to share power and accept user expertise.*
- *Staff should be trained in the benefits of co-production, supported in positive risk-taking and encouraged to identify new opportunities for collaboration with people who use services.' (Briefing 31: Co-production: an emerging evidence base for adult social care transformation, Dr Catherine Needham, Queen Mary University of London and Sarah Carr, Social Care Institute for Excellence, March 2009):*

Whilst wholeheartedly endorsing an approach which emphasises the skills and abilities of people who may seek support from public services, In Control seeks to push the boundary of participation and collaboration further, and to consider Self-Direction specifically as a way to enable citizenship, and to influence community cohesion and participation:

- **Self-Direction** is about achieving better outcomes by deliberately seeking to move power and control closer to the person who is seen as an active citizen with rights and responsibilities. The state support offered is part of a reciprocal contract with each person and part of a broader context of a just society.

  In our analogy of the hitchhiker, Self-Direction is more like someone choosing where they want to be, deciding what kind of transport suits them and when they want to get there. They may need to learn to drive, and have adaptations to the vehicle, but if they choose a car, it is they who will be in the driving seat and if they need advice or support either on directions or about the mechanics, it is they who will choose which professional they pick up to accompany them. One way (hitchhiker) relies on generosity, the other (driver) on giving people the means to choose how to both help themselves and also to have expert help, in ways that make sense to them.

Citizenship is the goal of Self-Direction and as such it is indivisible from it. The concern that Self-Direction leads to isolated individualism could not be further from either its intention or its impact. Professor Chris Hatton of Lancaster University has analysed data from 196 people who are directing their own support in 17 local authorities. 63% said they took part in and contributed to their communities more since directing their support: *'People who are no longer dependent on a day centre or residential home are able to venture out more, often with friends, to access education or training, go to the cinema or shopping, play a sport or undertake voluntary work.....Traditional public services support people but often at the cost of cutting them off from society, reinforcing their sense of dependency. Personal budgets make it much easier for people to get the kinds of services they want and to be more social. It is better for individuals and society.'* (*Making it personal*, Demos 2008).

Each of the concepts in the spectrum of control shares in common the view that we can no longer usefully think about the reform of welfare systems as if those systems were just a professional concern. Increasingly, we will have to re-examine the *public* dimension in public services. This is as true in health care as in social care, if not more so, since every one of us uses and appreciates health care, whereas only a minority access social care support.

Health care approaches the idea of community in terms of public health and health promotion, and considers contribution around someone's personal health through active engagement and self care. The words may differ but the goals are consistently compatible. In a subsequent chapter we will explore what citizenship may mean in Health.

Moving from definitions to real life, what does any of this mean to someone with health needs, and why does it matter?

Chapter 3

Why it matters: Mitchell's story

Key Message: Giving more power and control to an individual can make a big difference to the quality of their life.

Mitchell's mother writes:

> When my son, Mitchell, was born seventeen years ago, I joined a 'community' of people whose lives have been transformed by the birth of a child with complex needs. An MRI scan showed there had been no trauma, no accident, no-one to blame; his brain had simply grown in a unique and disorganised way which would shape and define both his life and mine. Whilst this is Mitchell's story, our situation is common to many families of technology-dependent children so you will also hear the voices of other mums, the staff who support Mitchell and medical professionals. It is just one example of how the work of In Control could change the lives of other families who are disempowered by packages of support that frustrate their needs.
>
> Life changes for all of us but for medically fragile children, change often comes swiftly, dramatically and with life and death consequences. Peaks and troughs are characteristic of this experience. In 2001, Mitchell suffered a medical crisis. As he lay in the Intensive Care

Unit with an unstable airway and fighting pneumonia, surgeons performed a tracheotomy. Although we were delighted to welcome him home a year later, we were also acutely aware that his life had changed considerably. A home care package had been agreed and whilst this ensured he stayed safe, it felt like living in a goldfish bowl.

Our experience of being supported by a homecare service

Feeling powerless and scrutinized in your own home is a familiar experience amongst individuals who rely heavily on the support of home care staff. The experience has been described as *'a double edged sword'*. Although support staff can enable someone to remain at home with their family, having little or no control over who fulfils that role, can be immensely challenging. One mum I spoke to said,

'There are times when your home isn't your home. It's not really. It's so invasive isn't it? ......You pretend to be someone you're not....'

Another mum resented the lack of privacy. She said:

'If I want to drink a bottle of wine on a Tuesday night, I don't want to think they are watching and judging me for it.'

Until Mitchell was nine, our family had rarely accessed support services so it was a huge adjustment when Mitchell received funding for a substantial home care package. One of the biggest challenges was adjusting to the involvement of a team who had the power to control so many aspects of our lives. The care coordinator chose the people who would provide the support to *our* son in *our* home. She dictated the shift times, what staff could and could not do, how they should and should not behave and also wrote the care plan.

I harboured intense feelings of frustration and hopelessness in those first couple of years. Things just weren't 'right'. The service took a 'one-size-fits-all' approach and since it was commissioned from the acute Trust, it also operated firmly within hospital policies and procedures. For instance, one risk assessment required his regular staff to sign a sheet on every shift confirming they had checked his identity. They did this by checking Mitchell's appearance against the photo in his care plan. Likewise, the team were prevented from using aromatherapy oils to massage Mitchell at home because of the risk to other 'patients'. The 'service' was central to decision-making rather than the needs of the children and families. It was overly clinical and bureaucratic and it felt like Mitchell was 'in hospital, at home'. Then a chance meeting with a sympathetic listener cemented my thoughts. If we could take control of Mitchell's package, we could write a person-centred plan, we could choose the people who supported him and we could manage the rota to fit around our lifestyle. It just seemed to make sense.

The turning point

Although it made sense, it seemed risky to 'rock the boat'. Drawing the commissioner's attention to our situation would expose us to scrutiny. We feared a reaction to the fact we were challenging the system. Another concern was the outcome of an independent review of Mitchell's needs commissioned by the Primary Care Trust to inform the process. Would the reviewers support our view? Contrary to our fears, the outcome was positive. A detailed picture of Mitchell's needs emerged and the insights gained had an unexpected outcome. One reviewer, Tom, became a trustee for the MG Trust which is a simple governance arrangement or 'circle of support'. The benefits are three-fold: not only do the trustees offer support and wisdom they also provide independent oversight in a way that feels safe to our family. The PCT can also be reassured that we are getting the support we need to make sound and sometimes difficult decisions.

Advocacy and enablement were also important even though there was no one 'appointed' to the role. It was the nature of two relationships that accomplished the brief. What 'qualified' our advocates to support us was their understanding of our situation and the fact they truly listened: the 'power dynamic' was right. 'Professional power' had often made us anxious; knowing an individual can influence the fabric of your life can very stressful. So, working with people we trusted and who sought to empower us was a tremendous help and is another manifestation of choice and control. They did not take responsibility for us but encouraged us to find and exercise our own power and resources.

It took four years to achieve our goal. Although the process was challenging, it was indicative of the outcome. It was collaborative and empowering. We took an active part in every discussion which shifted the balance of power; we became active agents in our own process. Of equal significance was the commissioner's approach. She understood our aims and took a pragmatic view. By agreeing to use a third party domiciliary care agency with Care Quality Commission registration to hold an indicative budget, we were complying with the law whilst gaining more choice and control. There was only one stipulation. The Primary Care Trust insisted we employed a Registered Nurse to facilitate the package. There was a degree of anxiety around clinical governance; this proviso helped alleviate some concerns. We also chose to retain some existing home care services.

Identifying the budget was fairly straightforward as Mitchell already had a care package. Once we knew the annual support cost, it empowered us to develop our own business plan. This was approved on the basis that it was commensurate with the existing budget. Personalisation was our main goal but there have been several important benefits. Knowing and working within the budget has encouraged resourcefulness. When three of Mitchell's carers expressed an interest in completing an NVQ 3, we 'shopped around'. The freedom to access training from any provider is important. Staff employed by the home care team had been constrained by the system and were reliant on hospital-based training. By choosing a provider with funding available, NVQ training is now underway at no cost to us.

Getting started

It was agreed that the new arrangement would take effect from 1st September, 2008.There were several important factors that readied us to manage Mitchell's package. Three experienced and knowledgeable carers chose to join Mitchell's team. A transition plan was developed. This meant that whilst we trained our new carers, the home care team would continue to staff uncovered shifts. We also used the experience of being supported by the home care team. We reflected on what had worked well and what we would do differently, particularly in relation to managing the team. Would we have been as ready to manage this package if Mitchell had just been discharged from Alder Hey? I doubt it. Although those first few years of home care had been difficult, they had given us confidence. It was a period of adjustment in which we had learnt to cope with the tasks, the machinery and the responsibility of caring for a technology-dependent young person. If our readiness to take control was a lot about timing, it is an issue worth considering as we figure out the complexities of personal health budgets.

Supporting Mitchell is highly technical and intensive. Nursing tasks performed safely and well are integral to the support he receives; he has a gastrostomy, tracheostomy and is on long-term ventilation. But of equal importance is the need to see Mitchell as a person first and foremost who has a wide range of needs. Our first task was to rewrite his support plan and develop a training programme that was personalised to him. We also worked on policies and procedures, recordkeeping, communication systems and much more. This work could have been a huge barrier to achieving our aims, if it were not for the guidance we received. The Registered Nurse and I co-produced a holistic training portfolio using resources from an NHS Long-term Ventilation website, the Royal Liverpool Children's Hospital and our own knowledge and experience. It was a lengthy task and chapters include: *'Supporting Mitchell and his Family', 'Communication', 'Tracheostomy Care' and 'Ventilation Principles and Practice'*. The work of In Control suggests that active citizenship amongst families with personal health budgets will encourage them to share their learning and their resources. Training 'templates' that include underpinning knowledge and good practice but are easily adapted and personalised to individual training needs could be helpful.

What has changed for Mitchell?

Ten months down the line, whilst much has changed, much has stayed the same. Mitchell still has weekly physiotherapy from the home care therapist who reviews his daily care records. Likewise, he still has the services of the home care paediatrician. Having an individual budget has not meant cutting all ties; rather we have taken a pragmatic approach to maintaining clinical involvement and oversight whilst exercising choice and control. Professional clinical input has not changed; Mitchell continues to be reviewed on a regular basis and accesses acute services when he is unwell. When I asked his physiotherapist to comment, she told me that despite once feeling sceptical she is now confident that *'the quality and safety of care hasn't changed.'*

She sees:

.'...a small team that knows very specifically what Mitchell's care needs are. Everything is geared to Mitchell's well-being, happiness and his ability to integrate in all circumstances.'

Her one reservation concerned training. Since the staff were no longer under her direction, she was concerned that this may affect her capacity to train them. We have resolved this by rotating staff onto the Friday physiotherapy session.

What *has* changed is the way Mitchell is supported. His team has been carefully chosen and personal qualities were valued over experience. We looked for intuition, commitment, enthusiasm and fun. What we found were people who also embraced our aim of providing continuous, person-centred and high quality care. Flexibility and adaptability are high on our agenda. One of our greatest developments, the introduction of a better system of communication, is a good example of how Self-Directed Support can encourage resourcefulness. We now use a free service called 'Google calendars' to manage the staff rota, holidays, and audit and review schedules. Being able to view the calendars from any computer is an invaluable resource and has been well received by staff.

I was keen to find out what Mitchell's team felt had changed. This is what they said. Nicola feels that *'The focus is on Mitchell now. He's what binds us all together.'*

Angela had similar thoughts. She told me that *'The team seems more settled, organised and the care we provide seems more family centred.'*

Lee's comments show that Mitchell's staff had once felt constrained by an inflexible service. He said *'Since we've changed over, the thing that stands out is that Mitchell has more freedom to do what he wants to do. We don't have to stick to hospital policies and we can make our own decisions about things.'*

He also felt that *'There is good support, encouragement and better communication within the team. We know where we are.'*

There are many situations where families' creative solutions mean spending the budget differently. Our aspiration was simply to recruit, train and manage our staff in the belief that, above all, good relationships are the key to a successful healthcare package. We trust our staff and feel comfortable around them, which had always been our goal.

This is a common goal amongst families who receive home care and it is easy to understand why. **Choosing staff you like and trust is infinitely preferable to having staff chosen for you. Less obvious is the link between being 'in control' and 'living with uncertainty'. Whilst none of us can guarantee what happens from one day to the next, for people with unpredictable medical conditions the lack of certainty can be extremely stressful. It is ever present and can change the way you live your life. For this reason, being in control of the things that can be planned for and controlled has become important to our family and seems likely to be important to many others.**

I cannot predict when Mitchell will suddenly become unwell but what I *can* be certain of now is that the 'right' people will be there in the event of a crisis. I'm confident that they *know* him and are fully equipped to meet his needs. Being able to choose who supports Mitchell helps us to cope; being able to influence important aspects of Mitchell's life also mitigates some of the anxiety we face with each new medical crisis.

Looking to the future, we plan to lobby for direct payments for health care. Our experience of using a third party agency to hold Mitchell's indicative budget has been problematic and raises a question in my mind. How can we ensure that third party agencies truly embrace the philosophy that underpins Self-Directed Support when putting families in control can feel risky? Unless there is a clear understanding of roles and responsibilities and a commitment to risk enablement, then a power struggle may ensue. We felt we'd swapped one bureaucratic, 'one-size-fits-all' agency for another, so we are moving to a small, not-for-profit local agency who support six adults in their own home. This arrangement was 'brokered' by a local community interest company which saw the potential for a symbiotic relationship. After a short 'courtship' we agreed terms. Since the agency is a Care Quality Commission-registered domiciliary care agency, it makes them a legitimate vehicle for our indicative budget. The fact that we will be paying them a fee for their financial and salary service makes this a win-win situation. It also gives me confidence that, until direct payments for healthcare are widely available, given the chance, individuals will find their own pragmatic solutions. Meanwhile, our plans include enjoying family life and a self-catering holiday in Keswick.

Summary of key issues

- Taking a 'one-size-fits-all' approach to home care services can cause individuals and families to feel frustrated and distressed.
- Overly bureaucratic and clinical home care services frustrate the needs of families.
- Families seeking to change their circumstances can be deterred by a fear of 'rocking the boat'. Even when people are dissatisfied with services, it can feel too risky to challenge the system.
- Being in control can help families live with the uncertainty that comes with ill-health.
- Supportive relationships that encourage families to use their innate resourcefulness could have a big influence on the success of personal health budget pilots.
- Using a third party domiciliary care agency with Care Quality Commission registration is a viable option for families wishing to control an indicative budget.
- Personal health budgets enable families to personalise training and encourage creativity and resourcefulness.
- Having an individual budget does not mean cutting all ties with existing services.
- Taking a pragmatic approach to the development of personal health budgets will encourage resourcefulness and will facilitate learning within the community of In Control.

Further illustrative stories of people directly affected by Self-Direction in Health, and real life examples of possible ways in which control of resources can be useful, are contained in Appendix 1.

Chapter 4

What does citizenship mean in Health?

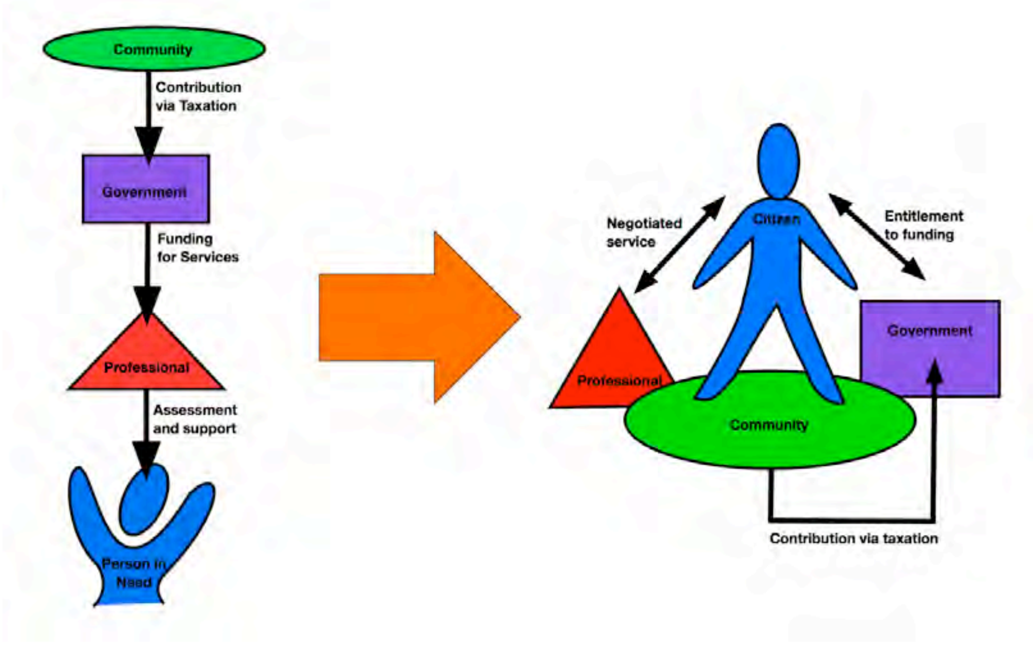
Key Message: Self-Direction is about much more than a 'new process' for health care. In fact, if this is how it is perceived then the roots of any innovation will be shallow. At the heart of the reform process is an attempt to re-think the contract that exists between citizens and the NHS. Citizenship matters because a society that excludes people from citizenship guarantees poor health.

The NHS is rightly highly valued – perhaps more valued than any other part of the welfare state. But we are all aware of the massive challenges facing the NHS in the twenty-first century. We need not repeat them here, except to point out that the solutions to rising public expectations without the possibility of ever-increasing resources, and growing chronic illness within a different demographic profile than ever before are:

'less about technology or treatment and more about people and behaviour. Health policy makers increasingly recognise that the shift to a preventative, early intervention model can't be imposed or delivered unilaterally. People need to participate in their own treatment, collaborate with professionals and change the way they live their lives. But this means that we have to put relationships at the heart of healthcare and move beyond a policy debate focused on structural fixes.' (The Talking Cure, Demos 2008).

Many believed that the injection of funding by the government would deal with these problems. The NHS was seen as 'under-funded' and the new spending widely welcomed. But today new funding will be harder to find and the returns on this injection of real income do not feel as significant as was hoped.

These problems do not arise from the NHS. They arise naturally from some of the unresolved tensions within the Beveridge model of welfare. The post-war welfare state was a great achievement, but it reflected its times. It was an industrial model of welfare, a fantastic step forward but a 'one-size-fits-all' approach with the potential for creating a passive, dependency culture and an over-medicalisation of people's symptoms, separate from their lives and social context. It was a 'professional gift model' rather than a 'citizenship model'.



The professional gift model (left) and the citizenship model

Today we are only at the beginning of understanding how we might build, together, as fellow citizens, a better way of meeting needs and guaranteeing each other's security. This is the wider context for these reforms – not a private and technocratic fix – but a social innovation to sustain and strengthen citizenship for all.

A citizen-based approach recognises the collectivist foundation of the NHS, which will be explored in more depth in chapter 7. Here it is just useful to note that, *'unlike a consumer, a citizen has responsibilities towards the provider of services. A citizen-based approach requires professionals to relinquish some power. But in return it asks patients to play a larger part in achieving their own health outcomes, where they are able.'* (*The Talking Cure,* Demos 2008). It is a reciprocal contract.

Understanding Citizenship

Although the idea of citizenship can be understood in many different ways, we intend to use it in a specific way that we have found useful in helping people to understand why these new ideas are important to all of us. When we talk about citizenship we don't mean whether you have a passport, nor do we mean something vague and philosophical.

For us, citizenship is a way of describing what it takes for us to belong as part of a community living with self-respect and the respect of those around you. The keys to this kind of practical citizenship include:

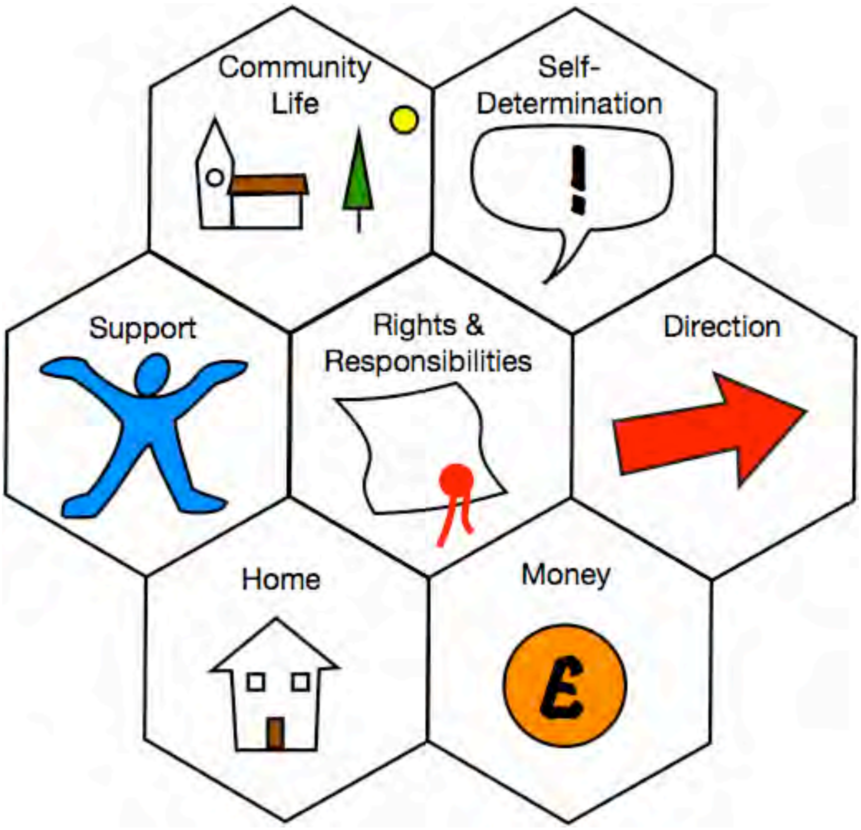
- **Self-determination** – having rights and being taken seriously
- **Direction** – being able to set your own course and live a life that suits you
- **Money** – controlling the resources necessary for living life on your own terms
- **Home** - having a place to call your own

- **Support** – needing other people and getting support in ways that make sense to your life
- **Community** – contributing to family, friends and wider communities
- **Rights and responsibilities –** having clear and public rights and duties.

This is not the place for a full explanation of all of these ideas. However, it is important to note two things:

1. This framework does not pretend to describe the real value of human life. We think all human beings have the same essential dignity and worth. Human beings are not better people because they find it easier or more difficult to be citizens. However, what we have come to understand is, unless we are very careful, we can quickly struggle to give proper respect to people whose status as a citizen appears weaker. We are not right to do so, but it is a psychological reality that we struggle to give proper respect to people who lack control, a sense of personal direction, money, home, support that they control, or who don't contribute to their community.
2. However, it is also very important to note that nobody needs to be excluded from citizenship. This also may be difficult to see, but in each and every aspect of citizenship it is possible for us all to be included. It is possible for us each to be valued. Even people who may be seen as lacking in some vital physical or mental capacity can, with the right support, be full and active citizens within the meaning given here. In fact, in the right environment, even our very need for help from others can be organised in such a way that it underlines our status as citizens – for communities rely as much on the existence of another person's needs as they do on their gifts – it is the need which gives value to the gift.

If we understand citizenship in this way, we can go on to see why it is such a powerful framework for understanding the purpose and organisation of the welfare state. For, if the welfare state is organised to enhance citizenship, it is also enhancing the means by which we gain in self-respect and strengthen community life and the very foundations of the welfare state itself. However, if the welfare state actual works to undermine citizenship it will not only damage the fabric of community life but, in the long-run, it is bound to undermine the support it needs to function, for example, the commitment to a collective taxation for collective good.



Keys to citizenship

Citizenship and health care

Thinking about these values in the field of health care is important but also challenging:

Self-determination: I may like being in control, but sometimes I need to trust others to take necessary control over me (e.g. I don't want to do my own surgery)

Direction: I may have aspirations for the future, but I also need to accept that ill health or death may make these dreams impossible

Money: I may want to control the services I need, but perhaps I shouldn't spend every last penny on trying to stay alive, at any cost

Home: I may want to be at home, but sometimes I can't be made safe or well at home

Support/treatment: I may want the right people to support or treat me, but I sometimes need to accept that those with me, right now, are doing the best they can

Community: I may want to contribute to community, but I just can't – for now

Rights and responsibilities: I want the best health care when I'm unwell. What responsibility do I have for maintaining my own health?

Death marks the end of citizenship and this fundamental point is worth acknowledging; but it still leaves a number of possible roads that might still be travelled:

Dying well – We will all die and, for many of us, how we die is important. This is particularly true for those who know that their life is coming to an end, who may even be able to accept that fact, but who want to live those last days, weeks, months or even years, with dignity. For these people, the themes of citizenship do become important: being at home, being with loved ones, spending time doing valued things, being in control where possible. These considerations become perhaps even more important than they are for those who are well.

The Department of Health's 2008 *End of Life Care Strategy* is seen by some as beginning to make a significant difference to the current situation where 60% of people die in hospital but most people when asked say that they would prefer to die at home. *'I have never known a better time for absolutely transforming care of people at the end of life.'* (Deborah Murphy lead nurse for Liverpool Care Pathway and Associate Director of the Marie Curie Palliative Care Institute – quoted in HSJ article, 18 June 2009).

Perhaps introducing Self-Direction can be a further useful catalyst in this transformation.

Recovering and managing our health – Some health conditions do not seem subject to a simple 'passive patient and active doctor' cure. If we suffer dementia, schizophrenia, depression, it matters what we think, how we live and what we do. It matters to our health and to our whole lives. If we suffer from obesity, a bad back, asthma, diabetes, we cannot just await a magical cure, we need to do something ourselves. If we have complex medical needs that may shorten, complicate or hold us back in our everyday lives, we still want a life. Nobody wants to be defined by their illness, disability or condition for ever.

Giving birth – Birth stands in a very interesting relationship to the rest of health care: for most people it is a natural process that needs some expert support. However, it is also a natural process that is full of risks and which can, very quickly, become dangerous for both baby and mother. A better understanding of our rights and our responsibilities for ourselves and our babies may help us understand some of the new ways we could forge partnerships between people and professionals.

Healthy communities – When we are poorly we seek health care. But doctors who care about health rightly remind us that good health is impacted by many more things than good health care. Amongst other things, our health is influenced by our isolation, poverty, poor housing, and unemployment. That is to say: a **society that excludes people from citizenship guarantees poor health.**

So citizenship and health are interestingly symbiotic, although very different, kinds of goals. Even if we care primarily about promoting health, it may turn out that we should also care about citizenship as a means to that end. And, if we believe that citizenship is important to health, then it is worth considering to what extent and in which particular circumstances shifting control towards the citizen can help improve health and improve the health of the whole community.

Chapter 5

Where might these ideas apply in the NHS?

Key message: It seems possible to apply Self-Direction successfully to some parts of the current health care system. To find a likely useful focus we can consider several factors including two key parameters: urgency and strength of evidence.

Self-Direction – general contexts

Before considering the particular context of the NHS, one way of approaching the question of when Self-Direction might most usefully apply is to examine when Self-Direction is likely to be an effective approach in general terms. This leads to the following potential areas:

- **When Self-Direction adds real value** – Whether something is genuinely in our control makes much more difference in some areas than in others. If I need heart surgery I want excellent and effective treatment and I am able to bear much inconvenience in order to receive the best possible treatment. But if I need regular nursing care I will find it deeply frustrating if that care is delivered in a way that means I can no longer work, live at home, travel, or see family and friends.
- **When there is the potential for alternatives of supply in community** – If what I need can genuinely only ever be provided by a very limited number of individuals, then we will quite properly adjust to that fact. If, however, there is a range of different ways of meeting that need, Self-Direction creates an opportunity to open up choice, control and contestability within a market and to develop a market. It will be important to always remember in this point, that people themselves often create alternative solutions for meeting needs which professionals may never have considered. People's creativity will be best engaged by enabling the most flexible approach to planning ideas to meet needs, not by offering a restricted menu of choices from what is available within current service provision.
- **When people need to be at home, not hospital** – In hospital we expect certain restrictions on choice and largely look forward to getting home as soon as possible. At home we expect support and care so that we can stay at home and be an active citizen within our community. Self-Direction creates an effective structure for support at home.
- **When people need help from family and friends** – Most care and support is provided by families or friends (support of more than 50 hours per week to over 6 million people). Self-Direction is an ideal framework for enabling the effective integration of paid support with the help of family and friends.

- **When people need control to be well** – Sometimes it is right and proper that we let others take control and have faith that they will do their very best (for example, during an operation). However ,often being in control is actually important to physical or mental health. Self-Direction not only provides the means to give people more control, but it also enables decision-making to be varied and personalised to meet the varying needs of the individual.

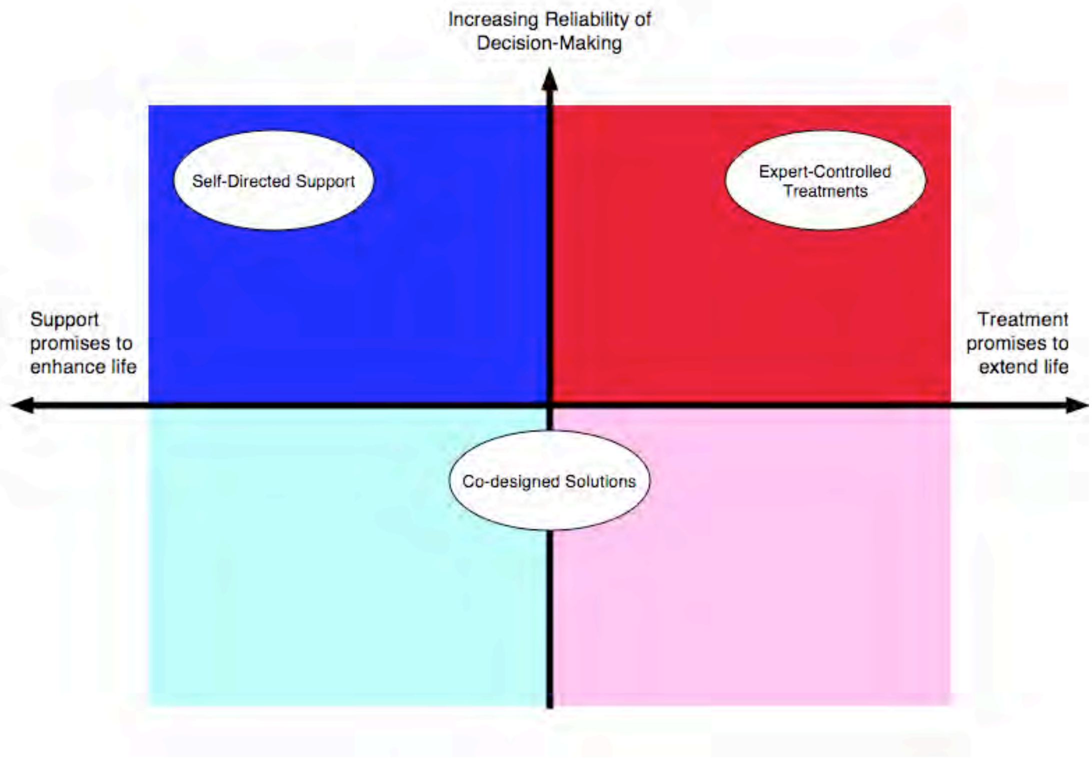
Self-Direction in health care

In Control's model of Self Directed Support in social care has been a powerful method of improving outcomes (including some health outcomes) because it improves the quality of decision-making. However, decision-making in health care is different for a number of reasons, for example: the fact that they may more frequently be 'life-or-death' decisions, the complexity of the evidence to be weighed up, the expert knowledge required and the number of professionals involved.

One of the biggest challenges for introducing the idea of Self-Direction into the field of health care is that we often think about health care in terms of the most extreme and urgent forms of medical treatment. For example, we may think about the kind of treatment carried out in Accident and Emergency, or life-saving drug treatments or surgery. In such cases it is understandable that our picture of good health care places all the emphasis on the active treatment of the citizen by the skilled health care practitioner. And, at critical moments, having trust in others and in their expertise, can be very helpful for our health and well-being.

However, this is only part of good health care and we need to have full understanding of how decision-making in health care works. Firstly, it is important to recognise that even when we allow a professional to treat us, it is almost always with our consent – health care is something we choose and which (in most circumstances) we quite properly control. Nobody has the right to give us drugs, to cut us open or to prod or poke us without our consent and health care professionals exist to provide us with services we want and choose.

Secondly, we will quite naturally give an enormous amount of trust to health care professionals if we believe two things: **(a) that their actions are likely to save us from death, and (b) if their expertise is well-grounded, that any treatment is likely to be successful. If we combine these two factors we can provide a framework for understanding how and why we will entrust our lives and bodies to health care professionals:**

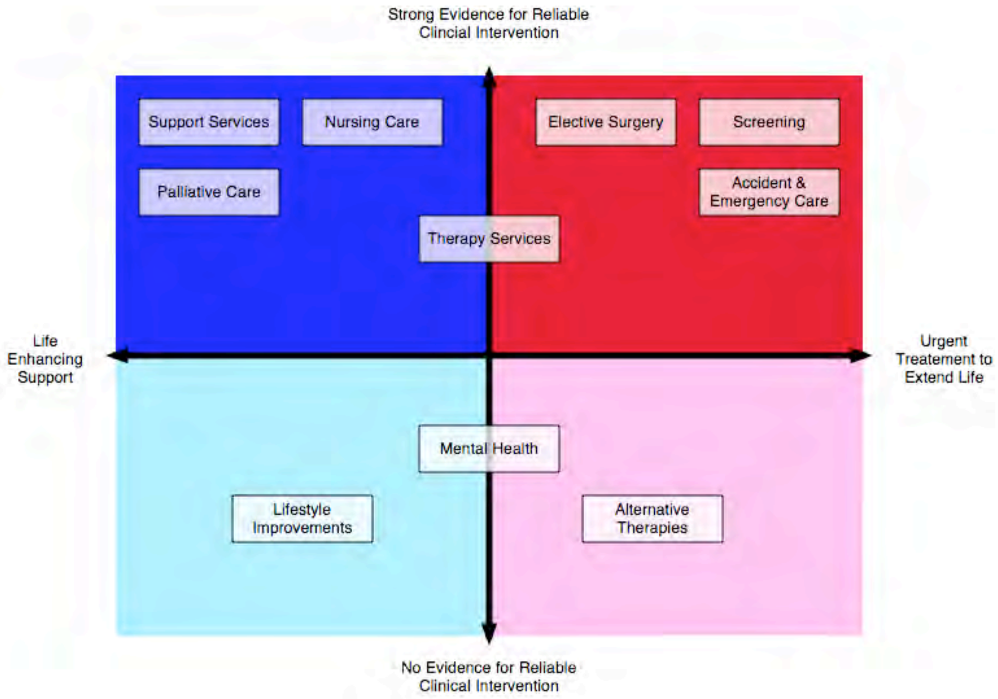


The red top right quadrant of the diagram represents those possible interventions that are both reliable and where a successful treatment will extend life. These interventions might be called ***Expert-Controlled Treatments***. These are the paradigmatic examples of health care which operate so powerfully in our imagination – for good reasons.

However, we can also see that in the blue, top-left quadrant are other interventions that are also well-grounded in expertise, which may not offer extended life, but which ***enhance life***. This is the natural territory for Self-Direction because it is the expertise of the individual and those around them that is essential to getting a better quality of life.

Thirdly, we can also identify in the green and pink, bottom quadrants the areas where life enhancements or extensions are possible but where knowledge is weak on both the side of the citizen and the professional. It seems natural to see this as the terrain on which ***Co-Designed Solutions*** would seem to be the most appropriate response.

If we apply to this framework some of the different interventions with which we are familiar, they could be distributed – tentatively – as follows:



In doing this, we do not imply that we already know when and how Self-Direction will apply to health care. However it does suggest areas where it is likely to be more relevant. The majority of crisis treatment, including for mental health problems, is likely to lie in the top right hand box. But even here, advance directives or contingency planning can bring in a person's voice to the crisis situation, and may usefully affect outcomes.

Of course, in reality, individual people and their health care won't fall neatly into one box. A person with diabetes who has recently been diagnosed with cancer may want little Self-Direction in relation to her cancer but much in terms of how to improve her diet or prevent depression. However that is not the issue. The issue is that there are, in principle, some aspects of health care where decision-making will improve where the individual has either greater involvement in decision-making or, in some circumstances, control.

This does not mean, at any point, that the views of either professionals or citizens can be ignored in the process of decision-making. The best arrangements are likely to come from the combination of their different forms of knowledge and perspective. But it does mean that we cannot treat all decisions as similar. In some situations, better decisions will arise if we have found the right way of supporting the authority of the individual, and Self-Direction is one powerful system for doing so. This analysis suggests then, that there are some areas where Self-Direction is likely to be a very helpful methodology.

Chapter 6

What can we learn from elsewhere?

Key Message: Self-Direction has had a powerful impact on the current system of social care which is leading to major improvements and efficiencies. We are at the beginning of gathering information about what effect Self-Direction may have in Health. It may be most useful to put together several strands of information as soon as it is available including: personal testimonies, Staying in Control members' evaluation data and DH research from the Personal Health Budget Pilots.

Policy Developments

Although In Control's work did not begin at the level of central government, there has been a growing interest at a national level in the ideas of Self-Direction and active citizenship. We can identify some of the key policy milestones including: *Improving the life Chances of Disabled People* (2005), *Our Health, Our Care, Our Say* (2006), *Aiming high for disabled children: better support for families* (May 2007) *Putting People First* (December 2007), *High Quality Care for All* (June 2008), *Healthy lives brighter futures - The strategy for children and young people's health (*Feb 2009).

Our Health, Our Care, Our Say set the strategic direction for community services as being: *'more services in local communities closer to people's homes, supporting independence and well-being, supporting choice and giving people a say, supporting people with highest levels of need, a sustained re-alignment of the health and social care system and support for the active engaged citizen.'*

Also of particular importance was the Department of Health's Individual Budget Pilot Programme which ran from 2005 until 2007 and provided resources to 13 local authorities and researchers to test the idea of Individual Budgets using randomised control trials. However the programme was complicated by the fact that the programme also took on some extra challenges:

- It attempted to integrate several extra funding streams into the local authority funding streams (Supporting People, Independent Living Fund, Access to Work, Disabled Facilities Grant and funding for the Integrated Community Equipment Services).
- The definition of an Individual Budget was made more open to local interpretation and no consistency was required between the different sites testing Individual Budgets (despite the fact that all the data was to be pooled).
- Some sites began work after being established members of In Control's network while others started outside that network.

Despite these complexities and the inevitable ambiguity of the final findings, the overall result of the research was to reinforce the value of all of the components of In Control's model of Self-Direction.

Self-Direction

As we have already discussed, there are probably many ways in which we can better engage people in the improvement of their own health outcomes. However, as Mitchell's story in Chapter 3 shows, one powerful approach is to shift power and control closer to the person. In Mitchell's case, this meant Jo, his mother. This approach is an example of what In Control terms Self-Direction.

Although we will go on to discuss other possible innovations, we will begin with Self-Direction, firstly because it is an innovation which has already been significantly tested and developed and, secondly, as we have outlined, it is highly likely that, in some specific areas of the current health care system, it is a model which is likely to bring clear benefits.

Self-Direction is one way of strengthening citizenship and enabling people to build stronger communities for themselves and others. The principles of Self-Direction are:

- **Independent living** – we should be entitled to get the support we need to be a citizen.
- **Individual budget** – we should know what we are entitled to receive.
- **Self-determination** – we should be able to make our own decisions, or have good representation.
- **Accessibility** – any rules and systems should be easy to understand and use.
- **Flexible funding** – we should be able to use our resources to best effect.
- **Accountability** – we should let people know how we are doing and what we are learning.
- **Capacity** – we should each get enough help, but not too much, and we each have something to contribute back.

In practice, the principles of Self-Direction have enabled the design of radical reforms to the old social care system. Self-Direction builds on previous innovations (for example, direct payments, care management, person-centred planning) but it takes these innovations deeper whilst building in a flexibility that ensures everyone – older people, disabled people and people with mental health problems – can use it.

In practice this means changing the current system of social services so that most people who need a lot of help are supported in the following way:

1. Everyone is told their level of entitlement (their Individual Budget) and they decide what level of control they wish to take over their budget.
2. People can plan how they will use their budget to get the help that's best for them. If they need help to plan then advocates or brokers can support them.
3. The local authority still helps people to create good support plans, checks they are safe and makes sure that people have any necessary representation.
4. People control their budget to the extent they choose. There are six distinct control options, ranging from a direct payment where money is paid directly to you, through to having a service commissioned by your local authority.

5. People can use their money flexibly. They can use statutory services (the cost of which can be taken out of the Individual Budget) and any other forms of support. If they change their minds they can quickly re-direct their budget.
6. People will use their money to achieve the outcomes that are important to them in the context of their whole life and to support their role and contribution within the wider community.
7. The authority continues to check people are okay, share what is being learned and can change things if people are not achieving the required outcomes.

In Control sometimes uses the following graphic to represent this seven-step process:

In Control's 7 Steps to Self-Directed Support

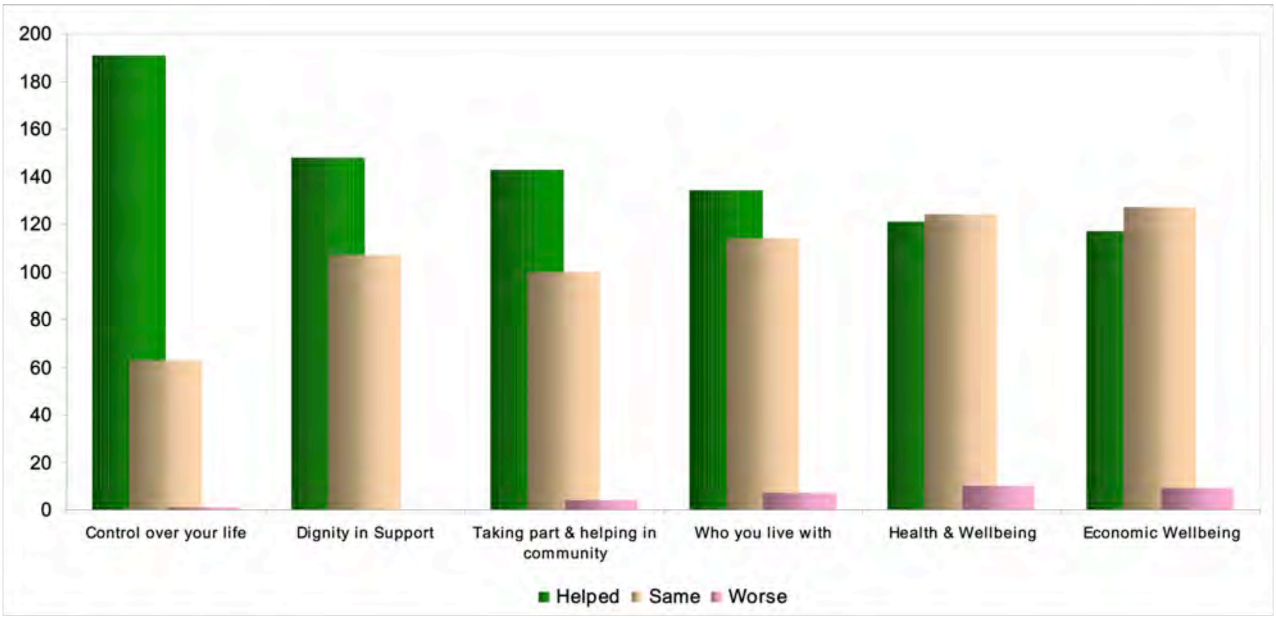
It is particularly important to note that, while money plays an important role in these reforms, it is absolutely not correct to say that this is simply a matter of giving people money. Instead, there are a series of checks and balances in this system:

- The local authority still has a duty of care, which it meets by agreeing with the person or their representative, how the money will be managed and by continuing to monitor progress.
- The arrangement is still fundamentally contractual. If the individual or their representative cannot manage the arrangement effectively the contract will be terminated and a new arrangement put in place. When deemed necessary, the State may also take back or take over control.
- The key to improved outcomes seems to lie in the increased ability people have to plan effectively in the light of their budget. It is the fact that people plan better when managing their budget, rather than the budget itself, which seems to improve outcomes. Planning better leads to committing to and engaging in or acting on the plan, because it has been self-directed.

Nevertheless, without financial transparency and a shift in financial control, many of the improvements in outcomes would not have been achieved.

Effectiveness improvements

The outcome improvements have been consistently positive since the first testing of Self-Direction in 2005. Since then, In Control, in partnership with the University of Lancaster, has gathered data from nearly 300 people using Individual Budgets. Aggregating the data from five independent reports we see the following pattern.

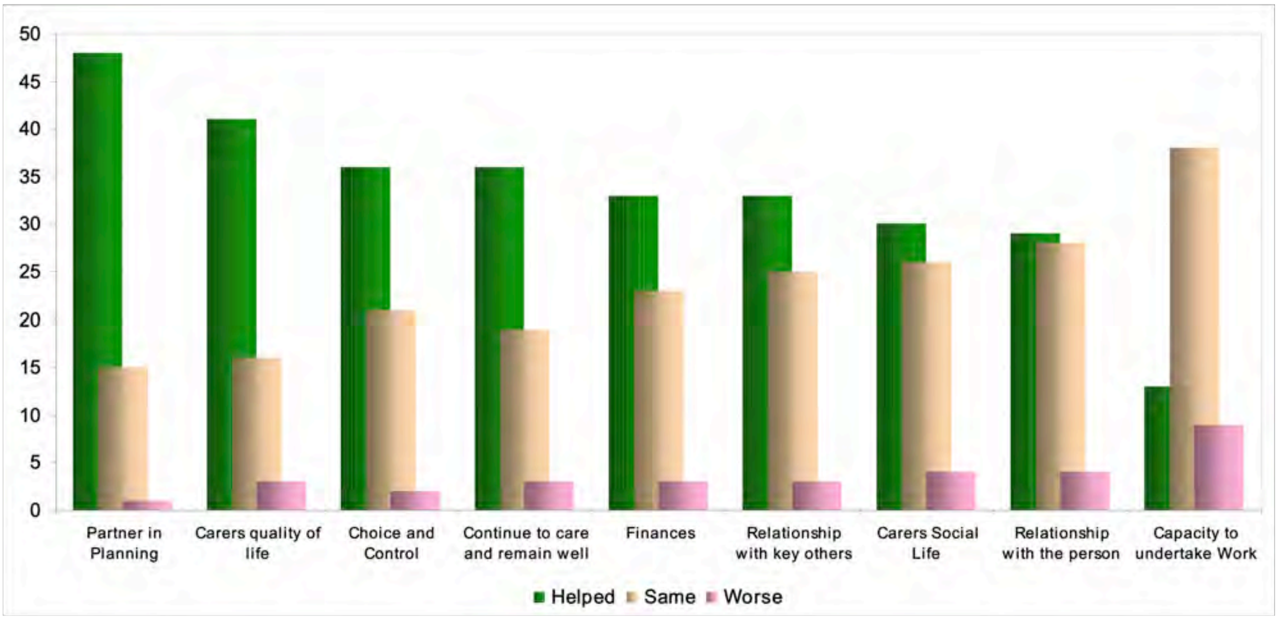


The views of people directing their own support

It is noticeable that these outcome improvements are not restricted to those areas that we might naturally associate with Self-Direction (choice, control and personal dignity). In addition we see significant benefits reported in terms of health, well-being, community life and social networks.

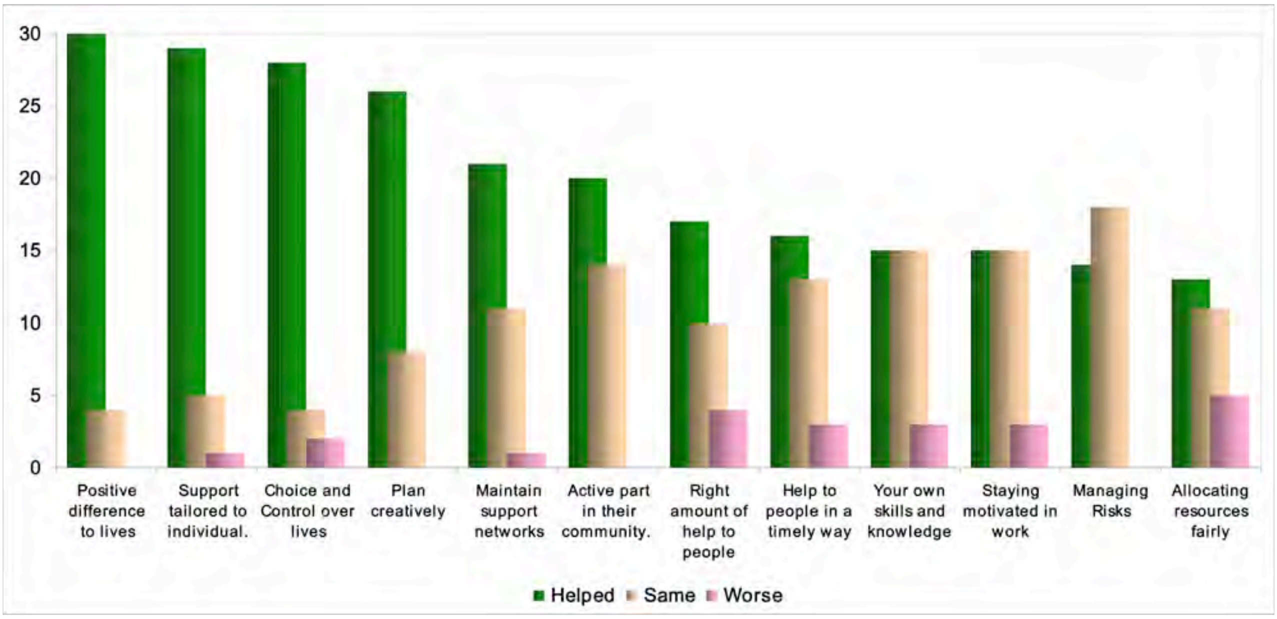
Neither are these improvements limited to older people or people with disabilities. The same positive findings have also emerged with Self-Direction by people with mental health problems and others. An example from Rotherham illustrating Self-Direction by people with mental health problems is in Appendix 3

In a more recent series of examinations, In Control asked friends and family members (people who are sometimes called carers) how they have experienced the change to Self-Direction. Again the positive improvements from their perspective are striking:



Carers' views of Self-Direction

Finally, In Control asked social workers, the key professionals whose role is most impacted by Self-Direction, how they perceive these changes.



Social workers' and care managers' views of Self-Direction

Overall, these results show a surprising win-win. Shifting power and control towards citizens leads to outcome improvements for the citizen and leaves social workers feeling that the impact of their work has become more effective either because (a) some people need them less and yet are achieving more while (b) some people actually need them more in order to make best use of the new system with its new flexibilities and benefits.

Efficiency improvements

Naturally, some people have assumed that this shift towards Self-Direction and more personalised solutions must cost more money. However the reality, to date, has been the opposite. While there is still much to learn, the data collected seems to show that these outcome improvements have been matched by reductions in per capita funding.[1]

Report title	**Number of local authorities**	**Sample**	**Change in per capita funding**
In Control Phase II Report	17	128	-9%
Report on Individual Budget Pilot Programme	13	203	-6%
My Budget, My Choice	1	17	-18.7%
Doing it Your Way	1	10	-30%
This Time Its Personal	1	73	-17%

Paradoxically, some observers have reacted to this data by arguing that personalisation is simply an excuse for making cuts. However, this seems both perverse and unlikely to be true. In Control has explored at length elsewhere the economics of Self-Direction, but in summary it seems to us:

- Self-Direction is more efficient because improved decision-making leads to resources being directed in a more focused, timely and appropriate manner.
- The details of how Self-Direction is implemented will make a significant difference to the final efficiency of the approach. That is, the efficiencies have to be earned by effective and thoughtful implementation.
- The overall economic impact of Self-Direction will also be influenced by both the new demand for this more attractive way to use resources and the reduced demand coming from initiatives including but not limited to Self-Direction itself, which focus on reducing need.

In other words, Self-Direction has the potential to be a significantly more effective system for using state funding, but it is too early to tell what the long-term financial impact of Self-Direction will be. It will be local and national leaders who will probably determine, by the quality of their policy-making and implementation, its full economic impact.

Transformation

Finally it is important to note the size and complexity of the task of introducing Self-Direction into the current social care system. There is hardly one part of the current system that is left untouched by Self-Direction and the process of transformation has had a dramatic impact on the work of leaders and citizens at every level.

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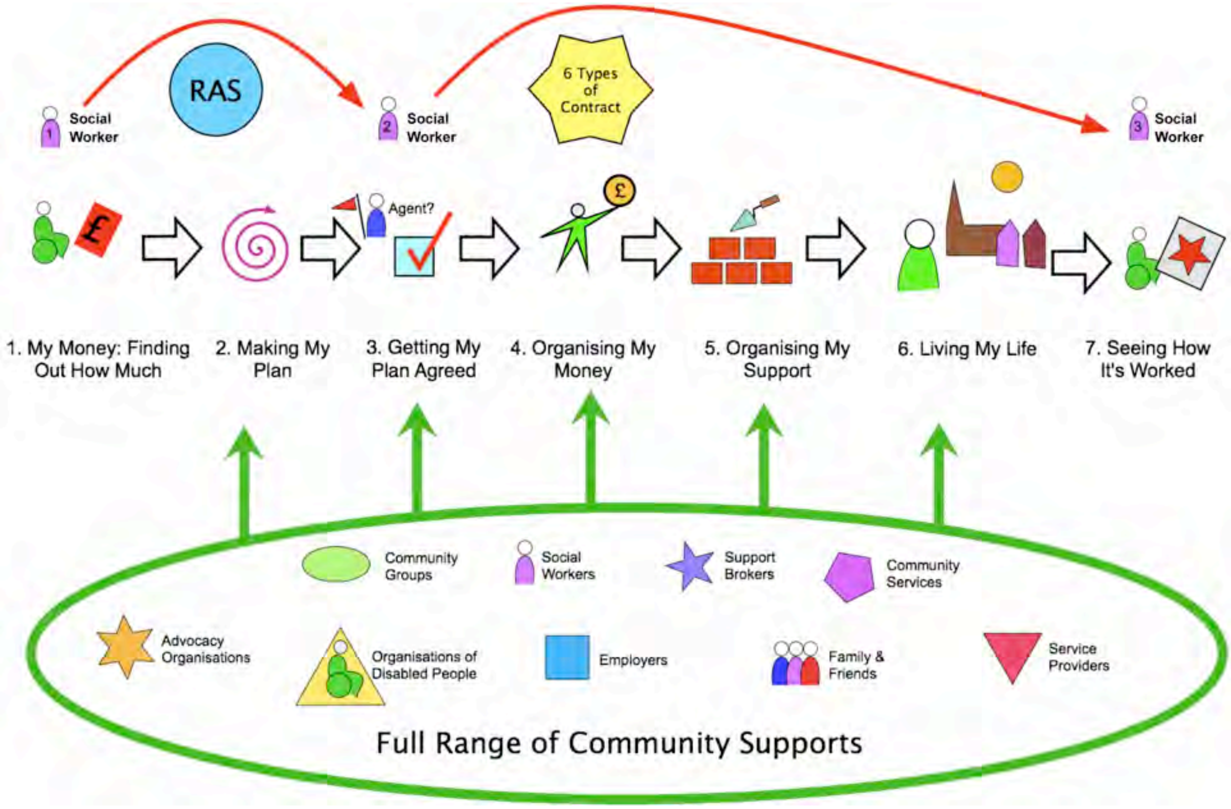
[1] It would not be appropriate to aggregate this data for a number of reasons. For example the IBSEN report on the Individual Budget Pilot Programme had a very large number of people in the sample who had been receiving Direct Payments, which is typically a very low cost service. On the other hand several of the other reports have a higher than average number of people with learning difficulties in the sample and the average package size tends to be higher. In Control will be publishing further data from our latest large scale sample in our forthcoming Phase III Report, this should provide a more reliable measure.

- **Systems and technologies** – Self-Direction relies on new rules for allocating budgets, making decisions and managing relationships. The system needs to be internally coherent and it tends to lead to radical change in old forms of practice.
- **Culture and learning** – Underpinning the new systems and technologies are new paradigms for professionals and citizens. People need to be able to see their jobs and their relationships in new ways and they need time to be able to adapt to a new environment.
- **Leadership and partnership** – Change at this level can only be achieved by leadership at senior and local levels and by a strong partnership with other stakeholders, in particular service providers and citizens themselves.

Just to take one area as an example, Self-Direction radically changes the role of the social worker. In the old model of social care, the dominant role they played was as a care manager engaged in assessing and developing care plans for people. The primary focus of the care management process was on ‘placing’ the individual within a service. Reviewing people’s packages was often either a minor role or delegated to non-social workers.

With Self-Direction, this whole way of working changes and the energy and skill of the social worker can be redirected towards enabling people to be in control of their own package of support. As decision-making lies primarily with the person and as they can change their minds over time, it is much more important that the social worker focuses on the review process, making sure people are successfully managing to be in control and are able to make the best use of their Personal Budget. The graphic below indicates both the changing nature of the social work input and the range of different organisations and interests that are involved in Self-Direction.



Social work role in relation to other organisations and interests in Self-Direction

The reality of bringing about complex change in public services is that there needs to be a real understanding of the professional roles and responsibilities of all those who will be affected by the changes. It is vital to the success of the implementation of Self-Direction in social care that the social work profession is leading the process of change and that the new model gives it a positive future role. Self-Direction in Health will need input and leadership from doctors, nurses, OTs, physiotherapists and all those professionals who can contribute.

Effective change in complex systems must come about through leadership from within those systems. It cannot be imposed externally without risking failure and misunderstanding. In Control's ability to help the successful re-design of social care is closely linked to the fact that In Control was and is an alliance between professionals and those citizens who use social care services.

Similarly, in Health, increasing evidence shows that engaged and informed patients achieve the best health and quality of life. There are currently only a very few examples of Self-Direction in Health (using our definition). But there is a growing wealth of evidence in the allied development of self-care. The Health Foundation's ambitious new initiative, *Co-creating Health,* is a three-year programme focussed on a whole-system approach to embed self-management support within health services. Interestingly, the programme states that, whilst providing education and information is part of this, supporting self-management also *'means transforming the way patients and clinicians interact with one another; working in partnership to achieve the best possible level of health and quality of life for patients'.*

One of the studies considers chronic obstructive pulmonary disease. Dr. Hans Hartung, clinical lead for NHS Ayrshire and Arran, describes seeing patients transformed as a result of gaining self-management skills: *'Before, many patients with COPD were feeling hopeless, depressed and frustrated. A few months later they return in control of their illness and empowered to manage their lives.'* (*The Health Foundation Briefing*, May 2008).

It is interesting to note that In Control's second phase report has shown that almost half of the people asked (196 people in 17 local authority areas) reported improvements in their perception of their general health and wellbeing since starting Self Directed Support (47%). This was using social care funding. The report represents a snapshot of some of In Control's work. It is not the result of a large-scale, formal research project and does not claim to be formal research. Rather, it is part of an ongoing collaboration that attempts to develop low-cost methods for routinely monitoring and evaluating Self-Direction as it develops.

Thinking about some potential outcomes of extending Self-Direction into Health has led to the following suggestions:

- strengthening citizenship and improving health
- building more productive roles for professionals
- increasing the focus on health outcomes
- extending control to more people ('nationalising choice')
- clarifying entitlements and improving equity
- increasing focus on healthy lifestyles and prevention
- tilting the balance – giving more power to citizens
- improving management through Self-Direction and self-care
- creating a healthier, adult-to-adult culture in health care
- integrating services effectively – around the individual
- increasing innovation and experimentation
- encouraging new services and forms of care
- investing more effectively to promote health.

We do not yet know which, if any of these, suggested outcomes may become reality. We do know that Self-Direction in Health will need to be tested over time by the extent to which it improves health outcomes, improves citizenship outcomes, improves equity and increases efficiency. The very best designed system reforms will improve all of these variables.

Given that we are at the beginning of working on these issues in Health, members of *Staying in Control* considered the 7 Outcomes referred to in *Our Health, Our Care, Our Say* and taken from *Independence Wellbeing and Choice*, as the start of thinking about how best to evaluate their work with local people. These outcomes are:

- improved health and well-being
- improved quality of life
- making a positive contribution
- choice and control

- freedom from discrimination
- economic well-being and
- personal dignity.

An intensive day's debate at one of our *Staying in Control* events and further reflection led us to agree a pragmatic approach to evaluating the first phase of our work with individuals. This will seek to capture feedback on:

- what, if anything, changes in people's lives which they attribute to having a personal budget, and
- what, if anything, changes in their experience of their relationship with health services and professionals, which they attribute to having a personal health budget.

Our *Staying in Control* community has therefore designed an evaluative framework focussed on two principal areas of direct personal experience:

1. Experience of everyday life and
2. Experience of health care.

Member sites have been keen to use the first questions to establish baseline information and have created a baseline questionnaire. We have also created different questionnaires for family members/carers, and for professional staff. We see gathering information and feedback from these three different perspectives as an important way to support our developmental work and thinking, and to engage actively with the key people involved in sustaining change and making Self-Direction successful.

The four questionnaires can be found in full on the In Control website.

A section from the individuals' questionnaire is included below as an example:

7.1. Experience of health care

In the following areas, how satisfied are you with the health care you have received over the last year?

	Very dissatisfied	Somewhat dissatisfied	Neither satisfied nor dissatisfied	Somewhat satisfied	Very satisfied
Control over the design of your care plan	☐	☐	☐	☐	☐
The level of choice in how your needs were met	☐	☐	☐	☐	☐
Control over the management and delivery of your health care	☐	☐	☐	☐	☐
The quality of relationship you have with health care professionals	☐	☐	☐	☐	☐

The degree to which you are treated with dignity and respect by those providing your health care	☐	☐	☐	☐	☐
The information available to you to make informed decisions	☐	☐	☐	☐	☐
Access to help at times that are right for you	☐	☐	☐	☐	☐
Access to and ownership of your care plan and records	☐	☐	☐	☐	☐

7.2. Impact of personal health budget

Using the following scale how would you say your personal budget has affected each area?

	Made things a lot worse	Made things worse	No Effect	Made things better	Made things a lot better
Control over the design of your health care plan	☐	☐	☐	☐	☐
The level of choice in how your needs were met	☐	☐	☐	☐	☐
Control over the management and delivery of your health care	☐	☐	☐	☐	☐
The quality of relationship you have with health care professionals	☐	☐	☐	☐	☐
The degree to which you are treated with dignity and respect by those providing your health care	☐	☐	☐	☐	☐
The information available to you to make informed decisions	☐	☐	☐		☐
Access to help at times that are right for you	☐	☐	☐	☐	☐
Access to and ownership of your care plan and records	☐	☐	☐	☐	☐

8.1. Experience of everyday life

Thinking about your life in general, over the last year how would you rate the following?

	Very poor	Poor	Satisfactory	Good	Very good
The symptoms of your condition	☐	☐	☐	☐	☐
The management of your condition	☐	☐	☐	☐	☐
Your general physical health and well being	☐	☐	☐	☐	☐
Your general emotional health and well being	☐	☐	☐	☐	☐

Capacity to make the changes you wanted in your life	☐	☐	☐	☐	☐
Opportunity to live with the people you want to	☐	☐	☐	☐	☐
Your ability to work	☐	☐	☐	☐	☐
Opportunities for personal or spiritual expression	☐	☐	☐	☐	☐
General quality of life	☐	☐	☐	☐	☐
Opportunities to take part in social activities	☐	☐	☐	☐	☐
Important family roles (parent, partner etc)	☐	☐	☐	☐	☐

8.2. Impact of personal health budget

Using the following scale how would you say having a personal budget has affected each area?

	Made things a lot worse	Made things worse	No Effect	Made things better	Made things a lot better
The symptoms of your condition	☐	☐	☐	☐	☐
The management of your condition	☐	☐	☐	☐	☐
Your general physical health and well being	☐	☐	☐	☐	☐
Your general emotional health and well being	☐	☐	☐	☐	☐
Capacity to make the changes you wanted in your life	☐	☐	☐	☐	☐
Opportunity to live with the people you want to	☐	☐	☐	☐	☐
Your ability to work [Leave blank if Retired]	☐	☐	☐	☐	☐
Opportunities for personal or spiritual expression	☐	☐	☐	☐	☐
General quality of life	☐	☐	☐	☐	☐
Opportunities to take part in social activities	☐	☐	☐	☐	☐
Important family roles (parent, partner etc)	☐	☐	☐	☐	☐

We are waiting with great interest to hear the first feedback from baseline questionnaires and from the evaluation of any changes over time. We can use this data alongside the personal testimony of peoples' 'stories'. We can also put our information together with the in-depth research being taken forward in the DH Personal Health Budget Pilot Programme, and with information from elsewhere.

A snapshot of information from the USA indicates the emerging discussion of the ideas. Evidence of their usefulness is not just within the UK:

'Self-direction is a concept in the recovery process which treats individuals as capable of determining their own purposes and achieving their own goals.' (*Florida SDC Operational Policies & Procedures,* 2007). *'The Florida SDC program hinges on the belief that individuals are capable of choosing services and making purchases that will help them begin or remain on the road to recovery and to develop or regain a life of meaningful, productive activity.'* (*Florida SDC Operational Policies & Procedures* 2007).

'A report on the effectiveness of the Self Directed Care community mental health programme revealed positive outcomes for participants in terms of community integration and residential stability, both strong indicators of recovery and community functioning. Compared with non participants, they used significantly less crisis unit and other crisis support services.' (The Florida Self Directed Care Program, Patrick Hendry 2008)

Vidhya Alekeson's report, *Putting Patients in Control* (The Social Market Foundation, 2007) based on research in the USA, identifies areas of health care where she says there is a strong case for introducing Self-Direction and which lead to clear benefits including: better coordination of care for people with complex health and social problems and better value for money through the development of personalised care that leads to health improvements without increasing costs.

Jon Glasby, Professor of Health and Social Care and Co-director of the Health Service Management Centre, University of Birmingham, has written that: *'Implementing Self Directed Support is complex. But direct payments and personal budgets have drawn on published research and also on the lived experience of people using services. While this can often be dismissed as anecdotal evidence, viewing it as human testimony changes the nature of the debate and starts to enable different interpretations about what constitutes valid evidence to come to the fore.' (A matter of perception,* Community Care 28 May 2009).

Chapter 7

What might be the wider implications?

Key Message: We will include a brief discussion of some of the possible implications of moving towards Self-Direction for the NHS and specifically address some of the most common concerns and queries.

Many of the fears and concerns that people have about applying Self-Direction to the field of health care are rooted in a right and proper concern that the values of the NHS must be protected. Moreover, anyone promoting change to an established system has to make a special effort to protect those elements of it which do work and need protecting during any process of change. So, in this chapter we will try to identify the main fears that people feel, explore how reasonable those fears are and identify strategies for minimising any real risks. We will end by reflecting on what these changes mean for the NHS as a whole in the broader context of the citizen's contract with the welfare state.

However, before beginning, it is important to reiterate the conclusions of our earlier argument, which is that it is not likely that ideas like personal health budgets or even wider concepts like Self-Direction will apply to all aspects of health care – quite the opposite. It is very likely that many forms of health care treatments will continue to be quite properly controlled by professionals. Moreover, in some areas of health care, for example transplant surgery, we have developed very specific rationing principles which are not being considered here at all. Here we are simply considering whether the application of Self-Direction in **some** parts of the NHS can be made compatible with the principles of the NHS.

Fear 1: Offering people money instead of services undermines the spirit of the NHS

One of the things we value about the NHS is that it is 'free at the point of delivery' and to introduce money, perhaps in the form of a personal budget, may seem hostile to this principle because it draws the individual into a commercial exchange, first with the NHS itself and then with whoever provides the relevant services.

However it is very important to distinguish two distinct values tucked inside the 'free-at-the-point-of-delivery' formula. The first is that we value the NHS because it provides the same level of care to everyone, without any regard to the 'means' of the citizen – in other words the NHS seems **fair**. However, the second value is that the NHS allows us to not have to worry about money at all: the NHS is **non-commercial** (at least at the interface with the citizen).

However, we should note that being fair and being non-commercial are not the same thing and we can see this if we look at other aspects of our own welfare state. For example, it is a positive feature of our income security system that we offer people money rather than food vouchers or food. We prefer a system which is both more dignified and which gives people the maximum degree of control and discretion over meeting their essential needs.

This is not an argument for making all of the welfare state commercial. Instead, it points us to the real issue which is that we need to understand when it is helpful to offer people money, which people can use flexibly to meet their needs, or to offer people support or care. We believe there is no simple answer to this question, but the experience of extending Self-Directed Support into adult social care has certainly seemed to show enormous benefits in giving people control where previously there was no mechanism that allowed control. Learning more about when and where the introduction of financial information into decision-making is useful is one of the areas that needs more research.

Fear 2: Personal health budgets make explicit the rationing carried out by the NHS

One of the most interesting fears that is commonly expressed is that being clear about what people will receive in a budget involves making explicit that health-care rationing is real. This fear is commonly expressed by policy-makers but rarely by citizens, for the simple reason that most citizens already understand that the NHS is a rationed system.

This fear is also of interest because policy-makers have actually been trying to be more explicit about rationing in the NHS for some years. In fact, one of the driving forces behind the development of the National Institute for Clinical Excellence (NICE) was to find a way of making much more objective decisions about what the NHS should fund and should not fund.

This is a fear that probably needs to be faced head on and resolved, not by ignoring it or by down-playing the reality of the rationing process, but by identifying the objective principles by which rationing decisions are made. This is the role of what we call the Resource Allocation System, the set of rules by which a fair allocation is agreed. In social care, the development of these systems has been seen by some as the key to increasing equity in what is otherwise a rather opaque system.

Fear 3: Personal health budgets increase the possibility of top-ups

A connected fear is that the existence of a clear personal health budget will make it all too easy for people to add to that budget from their personal resources. Again, it is important to understand that this fear is driven by an important principle: that the NHS will not give people more care than it deems is fair for all. It does not allow people to buy extra health care or 'top-up' from their personal resources. This is another aspect of how the NHS tries to be fair.

Of course, the NHS only takes this idea so far. We do not stop people purchasing private health care nor supplementing their care with private resources. Indeed, it is not uncommon for a GP to recommend private physiotherapists who may be able to treat problems more swiftly than state physiotherapists. In other words, even when we cannot top up our care we can supplement it.

In practice, there are at least two different approaches that can be taken to manage the risk that Personal health budgets do not open up the risk of greater inequity through the use of top-ups:

- **Ensure personal health budgets are sufficient to meet needs** – The best way of guaranteeing equity is to ensure that the budgets meet the necessary minimum level that people can get the support they need. If people are guaranteed all they need then the fact that some people spend more than they need to on health care does not undermine equity. This again reinforces the importance of the Resource Allocation System in establishing the level of care that is fair.
- **Ban the topping-up of personal health budgets** - As a Conditional Resource Entitlement it is not unreasonable that some restrictions are placed on how money is used. However, it should be noted that this approach will add cost and complexity and suffers from the same ambiguity as current policy which bans 'top-ups' but cannot bring itself to ban 'supplements'.

Fear 4: Smarter people will get better outcomes if Self-Direction is possible

A similar fear is that any system which allows Self-Direction to some degree or other will open up the possibility of a new kind of inequity – that those who are smarter at using the system will get significantly better outcomes than those who are less smart. Of course, it is always possible to claim that this is a flaw in the current system (the more able are already better at getting what they need from the NHS) but that current inequity does not excuse the inevitably greater inequity that must arise when Self-Direction gives people more power, control and, so experience teaches us, better outcomes.

This is one of the most important risks for us to consider. However it is possible to address this risk, particularly if the system is prepared to actually address the root cause of the inequity more directly.

One way to think about this is to distinguish two needs: (a) the need for health care and (b) the ability to manage the meeting of that need effectively. If two people have the same need for health care but a different ability to manage how they meet that need then those two people actually need different responses, and these might include:

- **Giving people a budget so that they can purchase help to manage better** – This might even mean building the 'ability to manage' into the Resource Allocation System. However, although possible, this does risk creating a market in support services that may simply add to the infrastructure costs of the current system.
- **Giving people direct support and guidance to manage better** – This might mean ensuring that professionals are commissioned to provide this support. This may make appropriate use of the skills of many professionals, although clarifying who is offering this extra support and when will also be important.
- **Indirectly helping people to strengthen their capacity to manage better** – This might mean providing people with training, peer support, information or other

approaches for strengthening their ability to manage. This approach is probably ideal, but may not always be practical in the short-run.

The research in adult social care does not give us enough empirical data to suggest that any one of these approaches is obviously correct. In fact, it may be better to see this as an area that will need on-going attention, innovation and research. This means that a permissive approach to meeting this challenge will provide the best opportunity for on-going learning and improvement. Indeed, it could be argued that increasing the level of Self-Direction in the NHS may also be the means by which the NHS could begin to see equity as an important and dynamic goal rather than as something that can be guaranteed merely as a side-effect of the administrative process by which it is funded and structured.

Fear 5: Self-Direction weakens the ability of the state to achieve social justice

Underlying all of these other fears is perhaps one larger but subtler one. As a community, we welcomed the creation of the NHS as part of the state’s commitment to achieve a fairer society. The NHS has freed us from a situation in which the poor lacked access to basic medical care, people could be bankrupted by illness or lived with the gnawing fear that they might not be able to afford treatment for themselves or those they love.

The NHS stands as a powerful symbol of this promise from the state to the citizen, the ‘welfare promise’: we will take care of you. This means that we will tend to see anything that threatens to weaken the control that state has over society as also a threat to the ability of the state to live up to its promise. We want a powerful state to give us the security we need.

Yet there is a problem here, for we know very well that much of what we need can only be met, or can be best met, when we ourselves take responsibility for achieving it. We cannot be ‘given’ a good life, we must live it ourselves. This then creates what we might call the welfare paradox: if we seek to meet our needs by giving up control to others we can find that we are no longer able to meet our needs effectively. Our needs may still be met, but those will be defined by those who have to meet them, and this may not be good or right.

The opportunity to rethink the welfare promise

But there is a much more positive way of responding to this fear (that Self-Direction weakens the ability of the state to achieve social justice) instead of regretting the inherent limitations of the state’s welfare promise, we could try and identify how the relationship between the citizen and the state might be put on a better footing. One helpful model might be to think about the welfare state not as a benign and paternalistic state-run service but as the constitutional foundation by which we live together.

If we think of ourselves as citizens, each with our own life to live, and each subject to all the needs that human beings face, then would we not want to ensure that each of us could be confident that we will always be guaranteed a basic level of security:

- enough money to live on
- decent health care if needed
- a home to live in
- the means to learn and develop
- extra help to overcome any disability.

In effect, these are the elements, not of a promise, but of a contract we could make with each other (for the state is in effect simply the guarantor of our own promises to each other). We might even go further and try to give these rights a constitutional status. And if we were able to do this, to rethink the welfare promise as a constitutional framework, then the possibility of Self-Direction would not be a threat to our welfare but a gift. Seeing ourselves as citizens who produce welfare, not just for ourselves but for others, too, could be the means for resolving the welfare paradox.

These, of course, are much bigger ideas than can be fully tested out in our early experiments with Self-Direction in health care. However, it will be important to ensure that, as we find ways to help people achieve greater control over some parts of their health care, we do not slip into seeing the state or the NHS as part of the problem. Instead, we need to be able to see how the NHS can regard these changes as a positive evolution in how it works and how it lives up to the fundamental principles upon which it is based.

Chapter 8

How might it work?

Key Message: The existing model for Self-Direction can be applied to health care, although some important adaptations and changes will be necessary. The most important next step is to put these ideas into practice.

Evolution and progression

Self-Direction is not a simple innovation. It is a complex and holistic system change which contains within it several other innovations. Some of these innovations will have to be adapted to fit the specific context of health care.

However, there is also a danger of over-complicating what has proven to be a very useful model. Having spent a year considering how Self-Direction could work in health care within our *Staying in Control* community, there still seems no immediate reason to move away from the application of the essential 7 steps of Self-Direction. Instead, we need to explore each of those steps in practice to establish the best ways of making them practical, meaningful and effective in Health.

We have already briefly outlined the 7 steps of Self-Direction above. These steps can be visualised by means of the following graphic:

In Control's 7 Steps to Self-Direction

In this chapter we will explore some of the practical work that will be necessary to put the 7-step model into practice. However before beginning, one subject needs to be discussed first. One element of good quality health care that is absent from the 7-step model and will need much more attention in future is the element of **assessment**. This is a matter which needs even more attention in health care than in other parts of the welfare state. So we begin this chapter by outlining In Control's approach to assessment and the underlying change in thinking that this will require.

Assessment and citizenship

Any professional who comes into contact with someone entitled to their help must use professional skill and expertise to discover what is the right kind of response to the need presented. Of course, each professional will explore different issues in more or less detail depending on their own expertise and role and on the information that others have already gathered. However, we can identify four distinct and general options for responding to any person in need.

Route 1 – Direct treatment

A GP may treat an infection with drugs, a dentist may fill a dental cavity or a surgeon may remove a tumour by surgery in hospital. The apparent need in these kinds of cases is very clearly the relevant treatment, although the underlying need is likely to be the reduction of pain or impairment or the extension of life. We tend, quite naturally, to take these underlying needs for granted.

Route 2 – Referral

Sometimes people need attention, but not from the particular professional that they are in contact with. In this case, the professional will make a referral. We are very familiar with the idea that it is part of the role of a GP to make referrals to hospital consultants, but of course people might also be referred to other kinds of professionals or to people who would not qualify as professionals at all. (Bill Schwab, Professor of General Practice at the University of Wisconsin, for example, taught his medical students that it would be malpractice not to refer a family who had a child with a disablity to another family with a child with a disability.) The skills necessary to make the right referral should never be undervalued. Being able to identify the right person, with the right skills to understand your needs is vital.

Route 3 – Self-Direction

Sometimes people need care and support which is co-designed: the citizen plays a fundamental and on-going role in shaping and re-shaping that support. In these circumstances the professional may find that they are effectively a partner with the citizen, offering guidance and support and where necessary authorising the use of resources, such as personal health budgets.

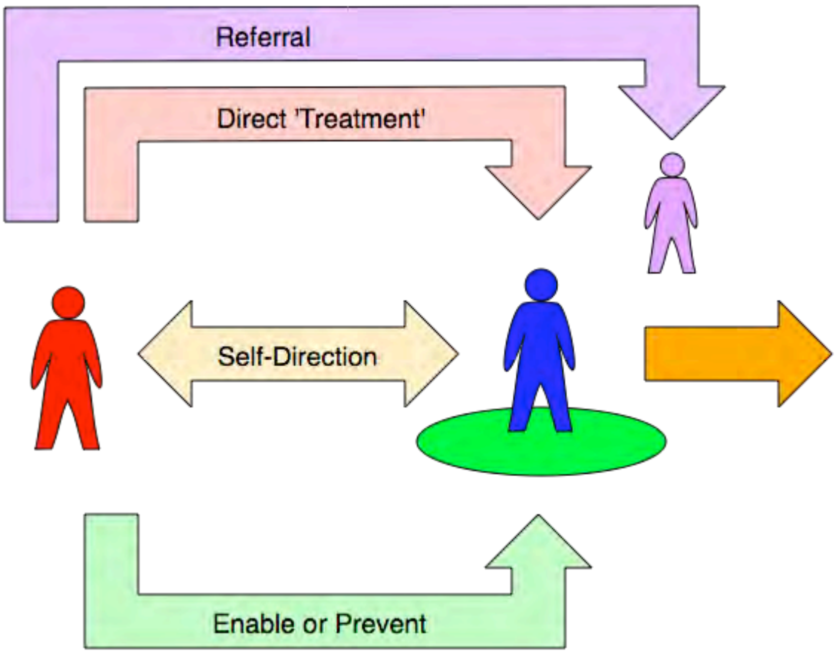
Route 4 – Enablement and prevention

Sometimes the professional must work to enable the citizen to manage their own health or to prevent their health deteriorating. There are many ways in which this kind of indirect or facilitative support can be powerful:

- helping someone make physical adaptations or get equipment
- linking someone to a self-help group
- aiding someone in finding work
- providing information or practical advice.

This kind of enablement, although it may seem the most distant from ordinary professional practice, is arguably often the most important, for it enables the individual to take more control over their own life and support without any undue sense of interference or obligation.

The graphic below provides a way of visualising the four assessment routes:



Four assessment routes

It is particularly important to note that there is no conflict between the four assessment routes – all may be combined. For example, the relationship between someone with a complex long-term condition and their GP could often involve all four elements:

- Treatment of pain by medication will be directly managed by the GP.
- Expert advice could be provided by the relevant consultant.
- A budget could be used to pay for support and care at home.
- The citizen could be encouraged to join an expert patient learning network.

However, although all of these options are currently used by the best professionals, it is not the case that we always think about health care in this way. Instead, it is common for citizens to think of health care only in terms of the first two pathways: treatment or referral. Yet this limitation in thinking is problematic for all concerned.

Understanding Need

We may limit our understanding of the full range of professional practice options because we have not really considered how needs are either generated or met. Properly understood, a need exists not because of an illness, condition or impairment. Real needs only exist when people are obstructed from achieving the outcomes they want. For example, if we need treatment x in order to avoid death then it is the presumed outcome of not wanting to die which gives rise to the need for treatment x. Take away the valued outcome and the need no longer exists.

Instead of treating needs as objects, things which can just exist or not exist, we need to apply a more dynamic and holistic model of human life which recognises the fact that:

- people seek to achieve **outcomes** that they value
- people have **capacities** which they can use to achieve their outcomes
- people live in **communities** which enable those outcomes to be achieved.

Now, in reality, people cannot achieve all the outcomes that they may wish to achieve – life is full of both challenges and constraints. This will give rise to needs in the ordinary and everyday sense: I need x in order to achieve y. But the existence of these ordinary needs is not a matter for moral or social concern because nobody is obliged to help me achieve all my desires. However, some needs are special.

Social justice demands that we have consideration, not just for ourselves, but for others as well. And social justice tells us that the failure of some of us to achieve some critical outcomes is a failure for all of us:

- Everyone should have shelter.
- Everyone should have enough to eat.
- Everyone should have a decent education.
- Everyone should be able to get medical care.

In fact, for us, the framework of citizenship that we have already set out above is precisely a specification of the outcomes everyone in a just society should be able to achieve.

If this analysis is correct then we must avoid the trap of defining needs in terms of the treatments or interventions that we are perhaps most familiar with. Instead, we must be prepared to ask whether, at root, the need is not created by the combination of:

- the desired outcomes of the individual - whether these be valid or not
- their own capacity to achieve those outcomes
- the community’s capacity to enable those outcomes to me achieved.

We have recently developed a model for capacity which is useful for reflecting on achieving valued outcomes and the different ways in which we can help each other. This model is called the Real Wealth Model (originally created by Nic Crosby and Pippa Murray).

Understanding capacity

It is useful to explore why some people cannot achieve all the things we hope they would. However, there is always a tendency to simplify the underlying explanation. Doctors may focus on physical impairments and health conditions, teachers may see a failure of education, economists or political theorists may focus on the lack of money. The reality is that we use a number of distinct capacities to achieve the outcome we value. The Real Wealth Model offers a framework for thinking about our capacities and it has five elements:

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.

2. Connections

Who we know – our family, our friends, our colleagues, our 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

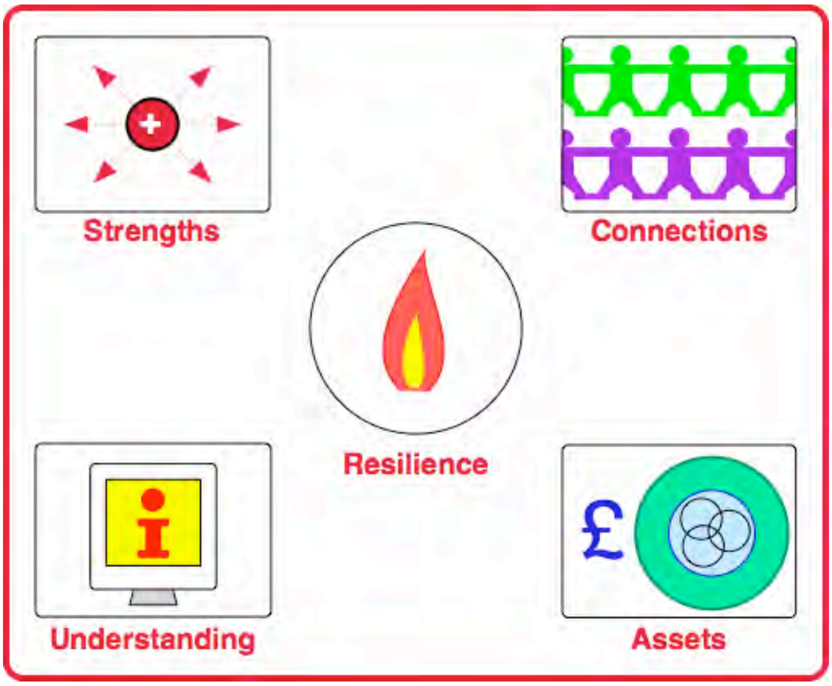
Money, capital, property and other financial assets are also vitally important in the modern world, both to our sense of identity and our ability to be independent. If we are rich in assets we can pay for things, employ people or commission support. However, if we are poor we become utterly reliant on 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 wide or limited they may be) that we construct our lives. However, if we are lacking in ability or our gifts go unrecognised by others, we will feel trapped and incapable.

5. Resilience

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 – all make up our personal resilience. Resilience is likely to vary over time and will be impacted by recent or current stressors. This is one reason why the timing of engaging in Self Direction is 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. There is growing evidence however, of the importance of not under-estimating people's ability to take control, given the appropriate support, and the transformative effect of this on their lives. It is this flame of inner resilience that is the most important dimension of real wealth.



Real wealth

Real Wealth and assessment

The Real Wealth Model is useful because it allows us to put in place the appropriate types and levels of support. Using this model, we can break away from simplistic notions of need and can begin to understand all the different things that people need.

Much of what normally passes as good health care will be concerned with overcoming illness or disability, which is largely about improving physical capacities. However, there are other things which people and health care professionals can usefully consider in order that their assessment is rooted in a fuller understanding of human need. This means we attend to:

- the need to connect people to others
- the need to provide information and opportunities for learning
- the need to grow people’s financial assets
- the need to strengthen people’s abilities and skills
- the need to foster resilience and the will to survive.

If we pay close attention to each person’s unique ‘wealth’ and address those places where there are blocks or gaps, we will be better able to help people to really meet their needs and to achieve positive outcomes. For example, many people who have mental health problems lose so much more than their ‘health’ wealth. They frequently lose their job, family, friends, home, status and perhaps most significantly they suffer what David Brandon (a leading author and academic who was directly affected by mental health problems) once described as a ‘cataclysmic lack of confidence’. This is one reason why treatments which focus too narrowly on treatment compliance may be less successful than those which see and connect with someone as a whole person.

All people have a mixture of needs and strengths and we know from research evidence how important it is that people's diagnostic label does not then bar them from being seen as whole people with a range of needs and abilities: physical, mental and social, for example:

'International evidence shows that people with long term mental health problems on average die 10 to 15 years younger than other citizens, often from preventable illnesses. They also live with poorer physical health which means people who are already exceptionally socially excluded – on every measure from education and employment to housing and social networks – often face the additional challenge of diabetes, heart disease or other long term physical illness. This makes it harder to participate socially and economically as well as harder to play an active, valued role within the family and community.' (Disability Rights Commission. Equal treatment: Closing the Gap Interim Report into a Formal Investigation into Health Inequalities, 2005).

Example from the management of long-term conditions

Interestingly, this shift in thinking by our community is mirrored by the work of other groups. For example, a recent paper, *Re-thinking Long Term Conditions* (Degeling et al, Durham University, 2006), helpfully outlines many of the key developments necessary to more effectively support people who have *'health problems that require ongoing management over a period of years or decades.'* This report has some striking parallels with our work to develop Self-Direction and contains a useful resonance of some shared ideas, a few of which we will touch on here.

The report's analysis of the care customarily provided was that it *was 'characterized by the absence of both the patient's voice and integrated working.'* It emphasises that clinically dominated pictures of people as dependent patients buries individuality under the deficits and needs ascribed to them by clinicians. *'We argue that the inherent link between the body and the self calls for a model where people are recognized as sentient beings who retain ultimate responsibility for their health as well as the right to exercise their voice and volition in constructing and determining their lives. These rights and responsibilities are inscribed in their relationship with carers with whom they co-produce their health.'*

The report includes a call for a move from needs assessment to a joint assessment of risks. This they say *'signals that the issues involved in this stage are more to do with process than technical criteria. …..consistent with the principles of co-production, we believe that assessment should be structured so that the person's view of what is at risk is heard and heeded.'*

Furthermore, they argue that '*the pervasive absence of personal preferences and/or of social, psychological and economic determinants (in assessing needs) flies in the face of a growing body of evidence about how an individual's desire and/or ability to be directly involved in either managing their condition and/or changing their behaviour to the benefit of secondary prevention, is influenced by, for example, their socio-economic status, their health literacy, their gender and health status, their personal response to having a long term condition and the meanings that they attribute to their condition and* *the coping mechanisms that they have developed to "get through" day by day….In summary, assessment requires far more than needs assessment – it also requires assessments of a range of personal, social, psychological and economic factors that are impacting on individuals at specific points in time, and that limit' (or enhance) 'their ability to optimize their role as co-producers of their health ….'*

The phrase "at specific points in time" is highly relevant to our consideration of how Self Direction may work best, as mentioned above. Timing is a crucial factor for consideration. As Jo pointed out in Mitchell's story: "our readiness to take control was a lot about timing". We must be alert to the critical importance of considering when people may be ready to take more control, not assume everyone will be ready at the same point, allow people time for the impact of a crisis to pass, enable them to pick up more control when their confidence grows, allow them to change their mind, and offer examples of what others have done and connection with peers to encourage and sustain people's courage to take a more active role.

Ingredients not instructions

All of this analysis only shows that we have much further to go in understanding the full impact of Self-Direction in health care. However what we can see is that ideas like assessment, which seems so neutral and uncontroversial, are in fact fundamentally important and complex ideas. We cannot afford to treat the assessment process as a simple technical process – it is part of a much more complex human process which raises questions of knowledge, psychology and ethics. However, hopefully we can now find ways of exploring how we could use these new models for assessment and real wealth to test out some practical innovations which may take us further forward.

In the same spirit, in the last part of this chapter on how Self-Direction may work in health care, we will highlight key essential components. We will not, at this stage, aim to write detailed descriptions of every element which has yet to be tried in practice. Our belief is that it is by collaborative testing in practice, with due thought and reflection, that real learning will happen. This learning can then be shared and lead us to a more detailed description of best practice at a later stage.

Personal health budget – assessment and resource allocation

In Control created the concept of an Individual Budget in 2003. The idea of an Individual Budget – now more often referred to as a personal budget, is fundamentally quite simple, although it is also subject to being thoroughly misunderstood. A personal budget is the budget that is *indicatively allocated* to an individual and they are told the amount. It is not the same as giving people cash. Some people would choose to *manage* their Individual Budget in that way, by having it paid directly to them (if it were to become legally possible to have Health money given directly to people) but many people would not. We will explore the management options for Personal Budgets.

The primary benefit of this indicative allocation of a budget is that it enables the individual to plan in a way which both realistic and creative:

- People are more realistic because they know the budget in advance and so have an incentive to work within that budget.
- People are more creative because they know that the budget won't be taken away if they come up with a more innovative and personal solution to meeting their needs.

In particular, this approach to telling people their budget up-front helps them to integrate any paid support they need into their daily life and into the fabric of their community life. This overcomes one of the enduring problems of the current system. A professional, on their own, neither knows nor can plan for the kinds of personal or community support that an individual may well be able to take for granted. This builds in an inherent tendency of the current system to over-professionalise its input into the lives of citizens.

This may have different dimensions when considering health care and treatment but the issue of no-one being able to know what is most important to any individual and their whole context, is, we suggest, valid. Thus for example, two people may have the same diagnosis, be the same age, gender, live in the same street and have the same type of family – but where one person wants to have no pain and does not mind the impact on their life of the medication needed to achieve this, the other might far rather bear the pain and live their life differently.

In order to be able to tell people their personal budget it is necessary to develop a set of rules that determine a fair allocation of funding for an individual. In Control called this set of rules a Resource Allocation System (RAS). Developing such a RAS will be one of the early necessary innovations for leaders within the NHS to tackle, and there is a careful balance to be struck between seeking and perfecting technical solutions and actually developing real systems and learning through real experience.

In fact, the pattern in social care has been to move to increasingly sophisticated and generic approaches as the RAS is used in practice and as data on outcomes validates the success (or otherwise) of the methodology. Put simply, we may see a pattern like this:

1. primitive RAS based on current spend for a package of care
2. developed RAS based on a more generic set of assessment questions
3. outcomes-focused RAS based on feedback from the actual experience of those using their personal budgets.

We are already beginning to see the development of work to progress these early Resource Allocation Systems, especially in considering continuing health care money, and it will be particularly important to share early learning on this subject and to use, where appropriate, the existing expertise within social care.

Information (and decisions)

Many people in the medical profession have worked hard to move beyond paternalism to a model of partnership and there is good practice where doctors routinely discuss and inform patients in decisions about their care. But patient advocates and others remind us that there is still some way to go:

'The standard conversation between expert and layperson is hard to re-write. One study of over 1,500 consultations found that patients routinely possessed some relevant knowledge about their condition, but that doctors found it difficult, if not impossible, to fit untidy patient experiences into their professional frames of reference. Worryingly the harder the patients tried to express their expertise the more evasive doctors became. The paternalistic reflex is to see informed patients as an annoyance rather than a resource. But as paternalism starts to fade new possibilities emerge. There is no great competition for information. An informed patient does not mean a less well informed doctor.'

'According to one study, 71% of doctors said that the internet had changed the way they relate to patients. But there was little consensus on whether this change was positive or negative.....Expert professionals often worry about whether the information to which lay people now have access is correct or not....but patients don't see the need to separate the science from the broader narrative of illness. On myriads of blogs, people with illnesses are reading and writing about what illnesses mean, both scientifically and personally..they are not just looking for facts. They are looking to make sense of health and illness and they are looking for like-minded others.....the new challenge is to add the internet to the conversations at the heart of healthcare, to take advantage of all this feedback.' (*The Talking Cure*, Demos 2008.) We would suggest that we could also take advantage of the interchange of ideas, the creativity and peer support.

One area where there is no clear parallel in social care is the increasing use of Care Pathways in health care. This idea has become important as a way of conceptualising the decision-making path around particular health conditions. As we have discussed, Care Pathways may not always hold true for individuals: conditions, lives and treatments can always become more complex, more particular. However, as tools for exploring and defining best practice, Care Pathways are likely to continue to be important in the process of making decisions.

One interesting possibility is to explore to what extent particular Care Pathways might offer a useful framework for identifying how and when different Choice Points might be developed. Each condition will be different and so, too, the extent to which it is appropriate to build in Choice Points.

However, if we take one relatively generic map of a Care Pathway we could build in different kinds of Choice Points, depending both on condition and whether Self-Direction is useful and meaningful.

Care Pathways are just one way in which evidence and information, both general and personal, is likely to become increasingly powerful in the way decisions will be made. We could expect a number of different information layers to develop in the coming years.

The increased use of **Web 2.0 technologies** and the likelihood that these technologies will become even more sophisticated means that all innovations in this field need to avoid undue complexity or cost. It will make more sense to try and build on the pattern of emerging international technologies than to invest in expensive local solutions.

The Information on Prescription policy shows that the government is aware of the importance of information in Health. But general information leaflets alone may be of little use. *'Professionals need to perhaps be involved in the conversation to shape and make sense of information and to talk about what they don't know and to signpost* *people to other relevant sources. If health services want to benefit from Web 2.0....they must resist the temptation to centralise and control. Their role instead needs to be linking and guiding people, helping them on their own journeys.'* (*The Talking Cure,* Demos 2008.)

Brokerage or support to enable Self-Direction

As we have outlined above, some people need help to be in control. For example, people might need:

- help to manage funding and staff
- help to identify what is most important to them in their life and what to plan for
- help to find the treatment, equipment and/or support they want.

Some people will need no help with any of these tasks. The way help it given is also important. For example, we need help that is competent and genuinely helps us achieve our goals. The range of types of help has sometimes been bundled together and called 'brokerage'.

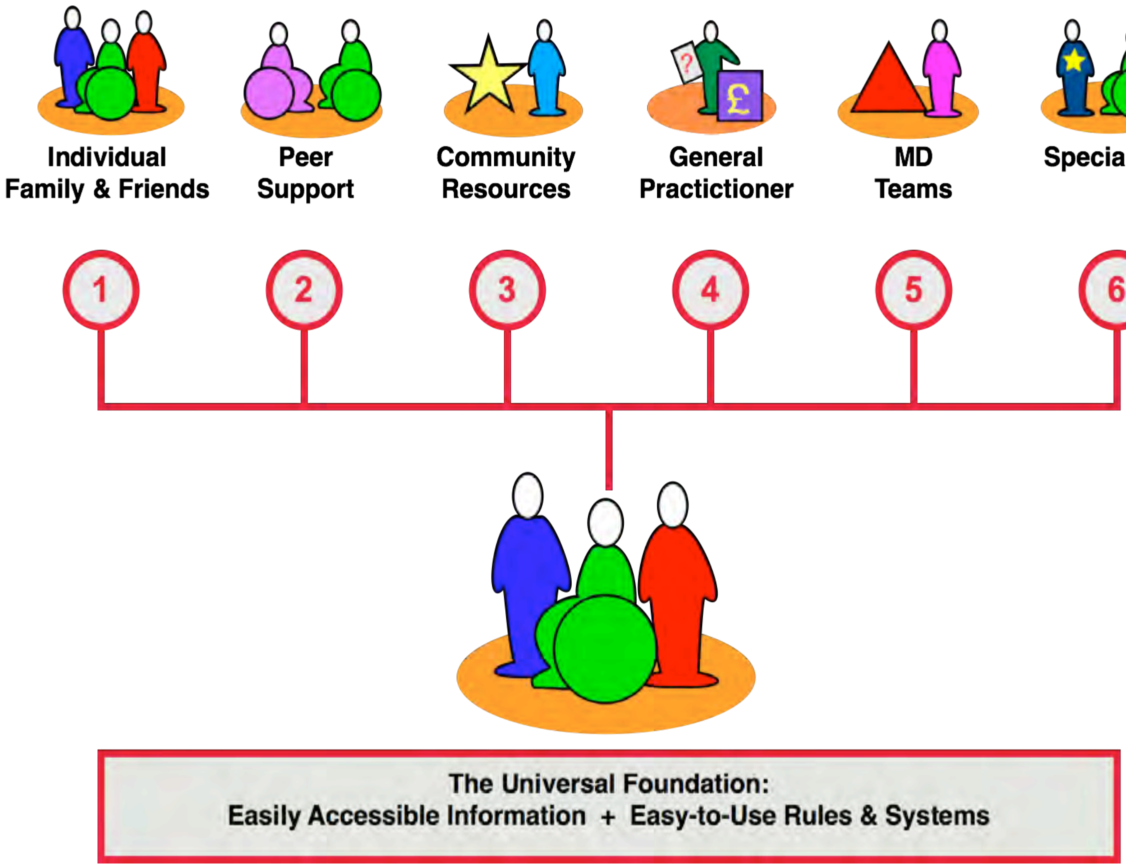
One of the more unusual innovations of In Control was, perhaps, to place less emphasis on professional brokerage in Self-Direction than is usual. Instead, in Control has developed a pluralistic and functional approach to brokerage. This means:

- not artificially ruling anyone out from playing a brokerage role, creating a wide market for brokerage
- not bundling together all the different parts of the brokerage function and allowing different people to do different jobs.

This approach was motivated by a range of factors:

- the danger of underestimating what people, families, peer supports can do
- the danger that new costs would be created at the expense of the people's personal budgets
- the danger of setting up a new professional group that would alienate other professionals and reduce their own receptiveness
- the danger of institutionalising a system solution rather than opening up opportunities for on-going innovation.

In Control has encouraged local authorities to use a six-stream model of brokerage which offers different choices for different people and respects the expertise of existing service providers and navigators.



Six-stream model of brokerage

A working paper has been developed which explores the brokerage or support functions in more depth and will soon be on the In Control website. Similar issues are likely to exist within health care and the functions or role are arguably highly contested by GPs, academics who write protocols, commissioners who buy care pathways, hospital consultants and others. In fact, the possibility of creating pure brokers or care navigators may be even more challenging:

- The rationing/gate-keeping role of many professionals will continue to persist where no Resource Allocation System is possible.
- There will be no single distinct professional accountability for navigators – instead activity will be framed by existing professional bodies.
- Funding for many professional groups is closely linked to case-load and this may pervert incentives.

One interesting approach is offered by considering the *'inverted pyramid of post-industrial health care'*. This approach distinguishes the following structure:

- individual self-care
- friends and family
- self-help networks
- professionals as facilitators
- professionals as partners
- professionals as authorities.

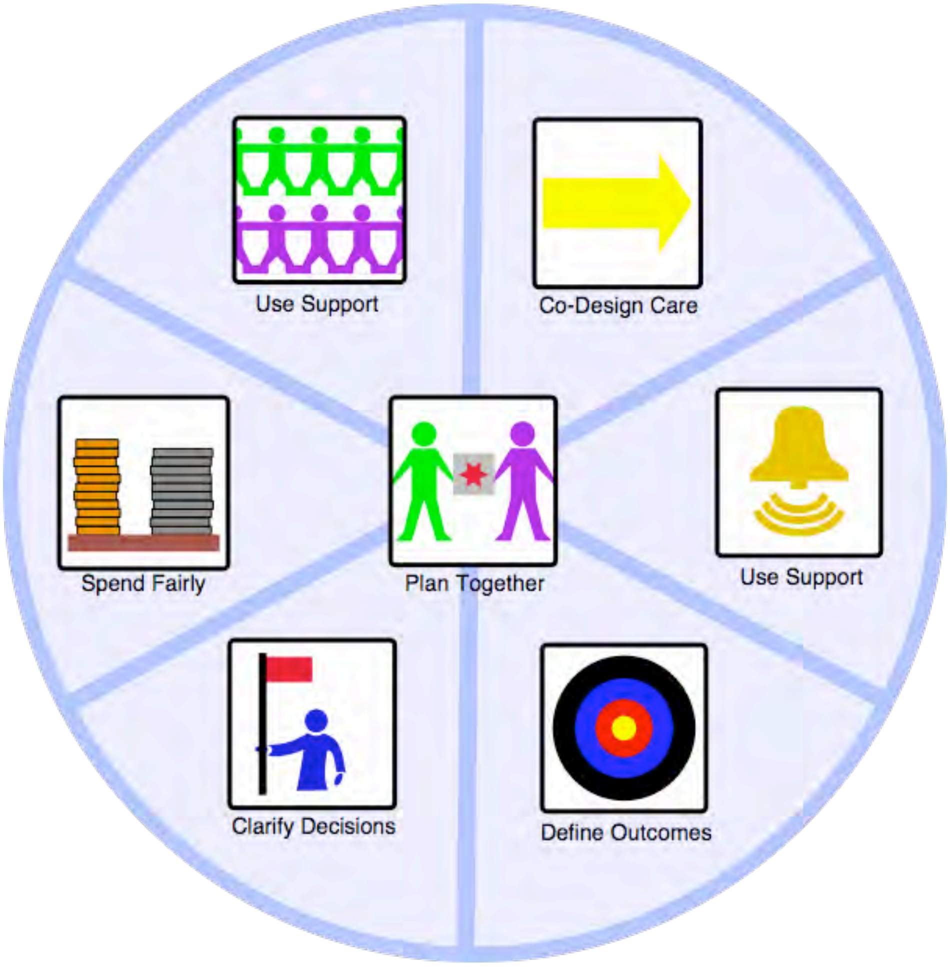
(Jennings, Miller, Materna. *Changing Health Care*. Santa Monica: Knowledge Exchange, 1997). These kinds of consideration demonstrate why it will be critical to focus efforts for innovation on those professional groups that have the capacity and the will to engage with people in a somewhat different way.

Planning for health

Often described as the *heart* of Self-Direction, support/treatment planning is the essential centre of Self-Direction in Health. It is through the process of creating, and having authorised, a personal plan, that Self-Direction in Health can come alive.

At its simplest, the personal plan allows someone to identify what matters most to them in terms of the health outcomes they are seeking to meet and authorises the choices they make about how to meet those outcomes using public money. A professional authorising the choices will ensure that, as well as there being a clear agreement about outcomes, issues of risk and capacity are also thought through.

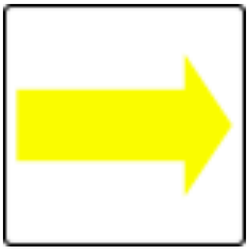
Any publicly accountable system must also ensure that appropriate monitoring is in place to check on how things are going, and will want to have measures of evaluation to determine whether the outcomes are being achieved. It is both as simple and as complex as this since any one of these elements may, or may not, be contentious within Health. The image we have used to illustrate these elements is:



This following table gives a summary explanation for each of these essential elements:

Plan Together - Improve decision-making by using medical & social information more effectively to make high quality decisions that respect individual needs and preferences

Define Outcomes - Set achievable & appropriate outcomes that make sense to the individual and to society and which are measured and recorded



Co-Design Care - Define the most appropriate and effective treatment, therapy or support to achieve the agreed outcomes

Use Support - Make use of the best possible support from both community networks & professional services

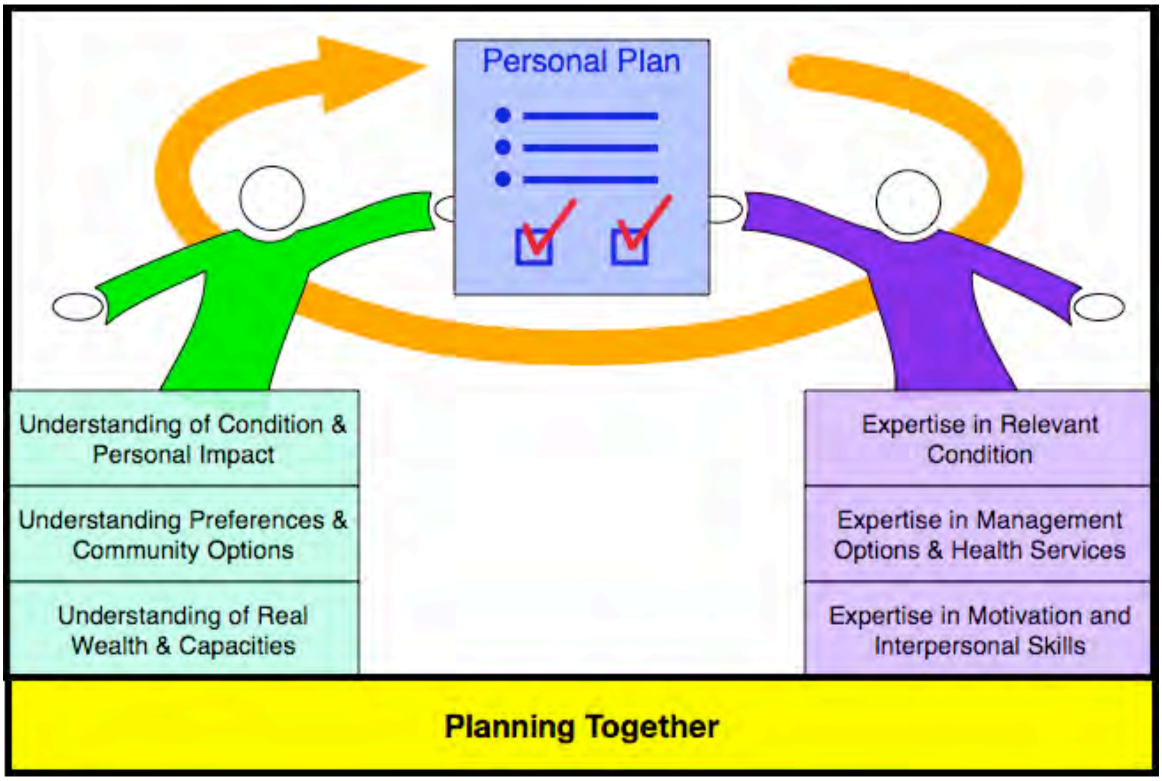
Stay Safe - Set policies & alert systems to keep people safe and ensure professional best practice

Clarify Decisions - Put in place an effective management system to ensure the quality and timeliness of decisions

Spend Fairly - Make best use of available of health funding & other possible resources.

The central focus is **improving the dialogue** between the citizen and the professional to create:

- greater mutual respect and understanding
- better quality decision-making
- better outcomes.



This should produce a **Personal Plan** which is co-signed by the citizen and professional.

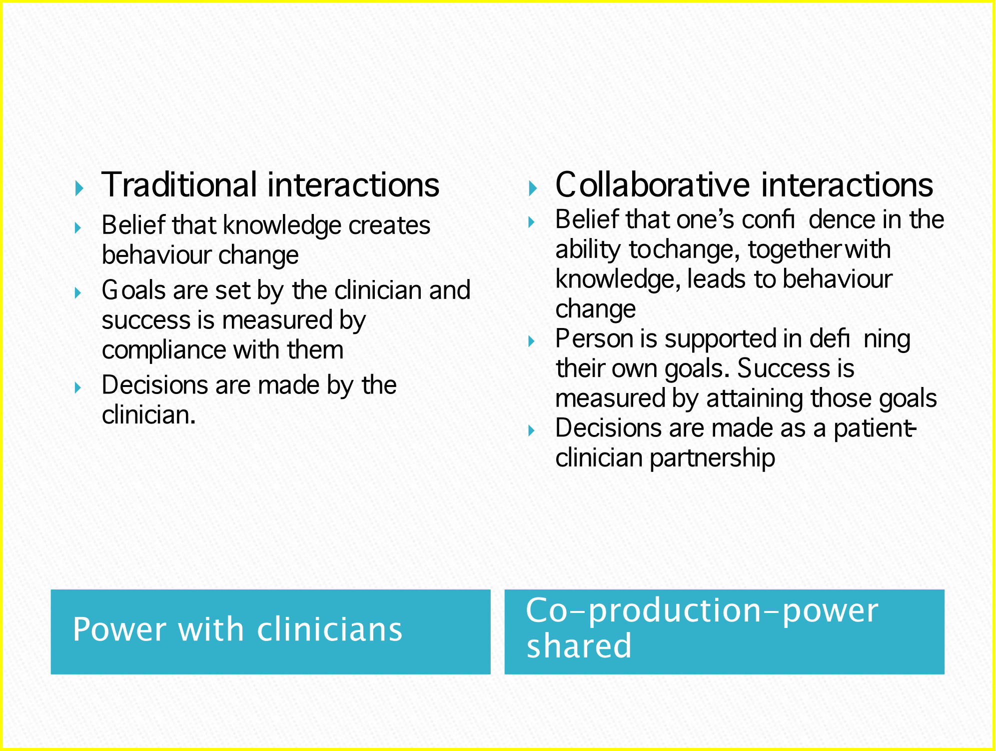
'Partnership demands personalised healthcare with a strong relationship at its heart.... Truly personalised healthcare allows patients to articulate their experiences, express their values, set their priorities, be aware of their options, exercise their preferences and be educated in managing their health... Professional cultures, communication skills and conversational styles will need to adapt and evolve. Personalisation also requires a change in the way success is judged, widening beyond biomedical indicators to look at the degree to which patients are able to lead the life they wish.' (The Talking Cure, Demos 2008.)

There is still some distance to travel to move towards personal plans being available to people. For example, in the 2006 Mental Health National Patient Survey, only 58% of people using services reported definitely understanding their care plans, only 53% had been offered a copy and just 40% reported being involved in deciding what was in their care plan.

A Self-Directed Support plan can be seen to 'start from a different place' – from hopes and dreams rather than illness and problems. It is unique to the person and takes an 'active citizen' approach. People are seen as citizens with skills to offer as well as support needs to be met. People interviewed for the *Voice and a Choice* In Control discussion paper spoke clearly of the value of being able to contribute as well as receive, to be seen as active participants, not passive recipients.

'A personalised NHS that engenders loyalty, self management, contribution and co-operation needs space for conversation, and it needs to ensure the system values it. An instinctive response might be that all of this demands more of what might be the NHS's scarcest resource-time. But healthy conversation does not necessarily mean that the doctors at the centre of health need to spend more time listening to patients. ...Valuable conversations are often diverse, decentralised and take place far beyond a doctor's gaze. The challenge is to take advantage of these rather than to control them. Healthy conversation asks professionals to talk differently, not talk more...In certain areas these conversations are moving in the right direction. We need to ensure that in the future they are supported by the system rather than happening in spite of it.' (The Talking Cure, Demos 2008.)

It is becoming increasingly clearer that the consensus around these issues, mentioned at the start of this paper, is growing. Some of the changes summarised in this chart below, indicate this. (Excerpts taken from the *Co-producing Health* briefing paper, Health 2008).



- Traditional interactions
  - Belief that knowledge creates behaviour change
  - Goals are set by the clinician and success is measured by compliance with them
  - Decisions are made by the clinician.
- Collaborative interactions
  - Belief that one's confidence in the ability to change, together with knowledge, leads to behaviour change
  - Person is supported in defining their own goals. Success is measured by attaining those goals
  - Decisions are made as a patient-clinician partnership

Power with clinicians

Co-production-power shared

Similarly, it is encouraging to note that the core aims of the Department of Health's self-care programme *Your Health, Your Way* are to empower people to take more control over decisions about their health and care, increase understanding and awareness of support for self-care and promote shared decision making between individuals and the professionals involved in their care. There are five elements that form the basis of self-care support: information, healthy lifestyle choices, support networks, skills and confidence training and tools such as self-monitoring devices.

And for long term conditions care, Miles Ayling, Director of Service Design at the Department of Health, says that *'We know what best practice looks like for long term conditions; the trick now is to get that best practice systematically and universally embedded across the NHS, and this will require a culture change.'* He goes on to say that *'to do this, patients must also be more informed and empowered to push the agenda for themselves'.*

Alf Collins, a consultant in pain management at Taunton and Somerset Foundation Trust, warns that: *'Health seems to have been made into just a physical thing, and medicine has become about disease … we need to redress this; we need to start to look at long term conditions, and people with long term conditions. It is a fundamentally different paradigm.'* (Quotes taken from *In for the long haul,* Health Service Journal, 4 June 2009).

Conclusion

Whilst the personal plan is at the heart of the process, it is of the utmost importance to see that all the elements and steps are integral to a coherent model. Unfortunately, an undue focus on the Personal Budget element of Self-Direction can lead to confusion.

As these ideas are going to be tested and developed in the different environment of health care it is important to remember:

- The overall aim is to **enable citizenship**, and the process is founded on this aim and the clear **values framework**.
- The budget is to be made explicit, primarily, to help people **plan** more effectively: so that resources can be used more flexibly and personalised to fit people's circumstances and better meet need.
- People also need systems of **support**: professionals can have a vital role in supporting people to make decisions and navigating the complexities of the options available.
- The outcomes people achieve will depend upon the choices and **options** available.
- In social care the local authority care manager still remains **responsible for ensuring people are well and safe and there is a clear system for authorising a personal plan.** Monitoring ensures that control arrangements can be changed if they are not appropriate. In Health we will need to establish how these functions are carried out.

In the context of health care reform our experience already suggests that, while personal health budgets may be very useful, they are not a simple solution to every problem. In some areas they may not be appropriate. Where they are appropriate they will only work if there are also:

- opportunities to meaningfully plan and shape your care and support
- effective systems of support, advice and information
- a range of meaningful and effective options
- appropriate systems for professional coordination and monitoring
- a shift in power and control – tilting more towards an individual's lived experience.

It may be useful to consider that power is not a zero sum or a limited quantity. Patients having more control does not inevitably mean that professionals will have less.

Another important dimension to the promotion of Self-Direction is the opportunities it creates for developing innovations within communities and between citizens and health care professionals – both at the level of the individual and the group. There is a danger that this dimension is forgotten by theorists and policy-makers eager to emphasise choice or contestability.

However, this may not be the most helpful way of thinking about what is at stake in these changes. In social care we have stressed the accountability of the person managing their personal budget. This is not to encourage undue interference in the lives of disabled people and their families. Instead, it is because it seems to In Control to be a virtue of Self-Direction that people have the chance to use resources flexibly, but also, importantly, to share what they have learnt by doing so.

In the same way, in health care, we must be careful to encourage people to see their actions as not simply private. Citizenship involves a necessary responsibility to contribute, to collaborate and to share your experiences with others. Moreover, failing to build in this social dimension to Self-Direction puts at risk the necessary shared public concern for our universal welfare system which is essential for its support, funding and accountability.

What next?

Our work with Health members is very new and we have much to learn before a robust model of Self-Direction in health emerges. Our work over the last year, however, has enabled us to draw together this summary report as the first iteration in a process of learning which is created and shared by our members.

During the summer of 2009, we welcome comments and suggestions from as many people as possible from both within and outside of our *Staying in Control* learning community. An amended report will then be published in the autumn.

In Control has created a new Health-focussed programme aimed at supporting collaborative testing in practice of all ideas in this report. Summary information is on the In Control website and will be circulated to all organisations.

Over the next couple of years, the most important learning is still to be gathered from those members who work together to try out the ideas contained in this report. Updates of that learning will be regularly shared with everyone interested in these issues, and specifically with the Department of Health Personal Health Budget Pilot Programme.

Appendix 1

Why it matters and how it can work – people’s stories

Steven’s legal challenge

Steven Harrison was one of two disabled people who went to the High Court to challenge the bar on them receiving direct payments for NHS services.

Their lawyers argued that continuing care patients can lawfully be provided with direct payments to manage their own care. The two argued that the denial of direct payments breaches their human rights.

The case was contested by the Secretary of State for Health. The court heard that legislation was planned which would enable pilot schemes to be carried out to explore the possibility of making direct payments to NHS patients.

The full story was reported on 12 February, 2009 in the Yorkshire Evening Post: **http://www.yorkshireeveningpost.co.uk/wakefield-news/Paralysed--Wakefield-exsoldier-takes.4975276.jp**

Jonathon’s story

Jonathon is a 19 year-old, outgoing young man who loves being physically active and working with his computer. He has a learning disability and significant ongoing health needs. These include epilepsy, scoliosis of his spine and a tracheostomy which impacts on his physical ability. When we first started working out how to meet his needs a number of things were expected. The most crucial of these was his mum’s belief that he would have an Individual Budget from social care

Life before

Jonathon was growing up and due to leave school at the point adult social care started working with him. At this point his mum felt that she would need to provide him with 24-hour support as previous attempts to find appropriate support had always failed. Places that could manage his behaviour couldn’t manage his tracheostomy or his epilepsy. Those that could manage these could not manage his behaviour. His life had therefore been shared between home and school.

During the planning process it was made clear to the family that Jonathon may be eligible for Health funding. At this point mum saw this as an opportunity to appropriately meet her sons needs. This was still her view at the point that she was told he was to be fully health-funded. Only when she realised this meant no direct payment and the risk of her son being placed in a residential or nursing home did she become concerned.

Having thought through the implications of the health funding decision mum decided that a nursing or residential home was not the option for her son. Her son was going to have an individual budget and this was the challenge she laid down to both health and social care.

What happened

It was at this point that the two organisations started discussing how they could meet this challenge. What would they need to do? Working closely with each other they started inching their way forward. At this time no clear action plan existed, we just knew our goal: to provide individualised support to Jonathon funded by Health – in a way that was legal, met his assessed level of need in a clinically appropriate way and paralleled the work in social care.

As no structure existed for identifying the allocation of money to meet need it was agreed the only way forward would be to plan to meet Jonathon's needs and then benchmark against clinical effectiveness and alternate approaches to meeting his needs. This process was done in a collaborative way with his mother and Jonathon central to the process and their lives. When the meeting took place to discuss the plan and whether Health would be able to fund it and to what level mum was the person who chaired the meeting. This is because it was seen as her meeting. The broad essence of the plan was agreed at this meeting and a number of jobs identified that needed further work, for example, sorting out contingency plans and transitional amounts of money to help set up the plan.

Jonathon's plan was not just Health-funded it also had Learning and Skills Council money for his educational needs. It was therefore important that his plan had both his support needs and his educational needs within it. From the family perspective, it was important that this was one plan and not two. As a consequence of a high level of collaboration Jonathon has one plan that was signed off by both funding agencies at one meeting and will be reviewed in one process.

Living life

Because Jonathon's plan includes both support and educational needs within it, it is highly complex in parts but it includes things that are important to Jonathon such as going to day activity that allows him to experience work-type skills and to contribute to the development and creation of products that can be sold and have value. His favourite pastime is drilling. He also has a very personalised approach to spending time with others, built around his interest in computers and strong relationships he has within his life. These give his mum her first break out of school hours in many years.

Jonathon did decide initially he wanted to continue with an activity he had enjoyed whilst at school. Within three weeks of leaving school he made a very clear statement he did not wish to continue with this activity by refusing to get out of the car on arrival at this destination. He now spends every week day at the place he sees himself working.

Outcomes

The outcomes for Jonathon are very significant. Anecdotally we know his quality of life has improved, we know he is learning new skills, we know he is making decisions for himself, something his mum did not always believe would happen. We also know from a Health perspective that whilst his health needs that triggered continuing health care funding have remained the same, his physical health needs have improved. His hospital admissions over the winter period have decreased, his nights are less disrupted, his need for incontinence aids has reduced.

Lessons learned

The biggest lesson is the importance of joining up aspects of people's lives so the difficulties and disparateness is restricted to organisations and not imposed on families.

The importance of working together across organisational boundaries towards jointly agreed objectives cannot be underestimated. In doing this a can-do approach is essential, trust in one another is paramount as is flexibility, openness and honesty and a determination to understand each other's problems and solve them in a positive and supportive manner. Competition and mistrust are certain to destroy the good that can come through developing this approach to meet people's needs. Finally, problems will always come from this way of working, it is important to solve these and to build on them for the next person. Learning by doing is crucial.

Hamish's story

Hamish is a young man in his 20's who has dark hair and is very handsome. He is particularly skilled with computers and he enjoys snowboarding. One day he hopes to be an instructor. He has a family but does not live with them as this is too difficult for him. This is because he has particular needs. He has both autism and sensory difficulties and he cannot tolerate many of the every day sounds and sensations that you and I do not even notice.

Life before

As Hamish was growing up, his family tried extremely hard to support him In a way that made sense to him. They were hugely successful at this up until a point where his needs clashed with those of his brothers and sisters, particularly his younger brother who also has autism, but of a very different nature. Because of this, his mother and had to look for somewhere else for Hamish to live. Because his needs were so specific they searched all over the world to find something that would meet his very individual needs. A place was found in Scotland which offered a very creative, innovative and individualised environment that for three years met his needs well.

Two years ago this organisation was sold. The people it supported transferred with the business. As the new owners implemented their regime, the environment became less and less appropriate for Hamish. Actions such as the handyman entering his flat to put up a shelf whilst he was home and drilling holes in the wall was intolerable – Hamish cannot be at home when the washing machine is on: such is his inability to handle noise.

His mother and father decided with Hamish that, because of the restrictions and the fact that Hamish had matured, he was ready to move on from his residential setting. The big decision Hamish needed to make was whether he wanted to live in Scotland or Sheffield.

What happened

At the point he decided he wanted to come home to Sheffield, Adult Social Care became involved in planning with his family. Hamish was given his indicative budget and the planning process started. It was a three-way process, working with Hamish's mother and father and then checking information out with Hamish as he was still in Scotland. Because of his very specific needs, the only viable option for somewhere to live was to purchase a property using shared ownership. In addition, his plan identified how he wanted to spend his days, evenings and weekends as well as the kind of support he needs and ways in which to develop his love of computers and snowboarding.

His plan was signed off by social care and the money confirmed. Steps were taken to identify a property. Two properties were found and lost and during this time Hamish was assessed and determined to be fully Health-funded.

This created a major hurdle to be overcome from the family's point of view. They asked for help and negotiations started with continuing health care to work through this process. The key part of the request was to look at accepting the support plan that had been written for social care, agreeing to the same amount of money and exploring the possibility of an Independent User-controlled Trust as a way of managing the money.

Health took the plan through its processes and agreed in principle that the plan could stand and the amount would be agreed. This has been communicated to the family. However, due to particular issues relating to clinical governance and the newness of this way of working, this young man's package is currently under additional scrutiny. This is particularly because of the very different nature of some aspects of his package.

Currently the family are trying to progress the shared ownership element of his package and to establish the transitional arrangements for his move back from Scotland.

As the package is not in place yet it is impossible to say how this has changed things for this young man. However, his mother and father are convinced that the move will be the key to a successful and happy future for Hamish.

Lessons learned

The key lesson in this journey was that that people who have autism experience overriding difficulty in making major changes in their life and how incompatible the speed at which organisations tend to operate is when applied to their situations. Also significant are: the importance of openness and honesty and a willingness to solve the problems that individualised and personalised services present to us. In this instance, key issues have included how to fund different approaches like supporting shared ownership and how to pay such monies to the solicitors. For health there have been further challenges in funding a package which varies so significantly from traditional care and in demonstrating how this will ensure needs can be more successfully met. Clear approaches to care management also need to be reached with the agreement of all parties.

Malcolm's story: Wanting a personal health budget

On the 27th August 2008, my father Malcolm was released from hospital. He had stayed there for nearly seven months whilst the doctors concluded what it was that he was suffering with. It transpired that he was suffering from Frontal-lobe dementia, a rare form of this disease.

During Malcolm's stay on the mental health ward, his well-being had deteriorated dramatically. By the time that he left hospital he was no longer capable of understanding everything that he was told, he was no longer capable of washing himself, of feeding himself, of toileting himself, and ultimately, of looking after himself. During those seven months, he had virtually lost all hope. He needed to get out that day before we lost him completely, as he was now a mere shell of the person that he once was. He was to rejoin an environment that allowed him to feel safe, secure and loved. Only one place can exist that would allow somebody to feel like this; that place was home!

A care package had been put in place for Malcolm's release designed to meet his needs. He would attend a daycentre for four days a week (Monday – Thursday) between the hours of 8am and 5pm so as to provide some respite for myself, who was to become Malcolm's full-time carer. Initially, Malcolm prospered in his new routine. He was thrilled to be home and his whole demeanour suggested that he was benefiting from being so. Suddenly, after barely speaking during his final two months in hospital, Malcolm was telling jokes again; bad jokes always considered a trademark of any dealings one may have had with my father. He even laughed from time to time.

Malcolm's family were delighted to have him home again. We each believed that we had been blessed with the gift of time, as we had been informed by professionals trusted with my dad's care that it would be necessary for him to live the remainder of his life in a care home. After seeing what Malcolm had endured during his seven month stay in hospital however, we believed differently. Thankfully, he was proving us right.

Entrusted with my dad's care, it was my responsibility to look after his personal needs. Each day I would shower and dress him before we tackled whatever obstacles that the day presented. I thrived in my role and responsibility. It was fantastic to see my dad have some joy in his life again, something that was so glaringly missing from his life over the preceding months. We did various things together, such as go to football matches, the cinema, on walks and sometimes out on drives as a family.

My dad was responding reasonably well to his time spent in daycare and he was being well looked after. However, each morning that I went to get him out of bed, I knew that I was sending him to a place that he did not wish to be. He vocalised such thoughts from time to time and even sometimes insisted that he did not wish to go. It hurt to know that after everything that he had been through during the previous two years, knowing everything that he had lost, that I would still persist with forcing him to go somewhere that he did not wish to be. However I knew the importance of continuing to maintain professional support within my father's life; I just wished for a different way to provide it.

During the spring time of 2009, some eight months after my father had first come home, my mum and I were approached about the prospect of altering my father's care. I had contacted my dad's social worker about the possibility of setting up some overnight care within our home for Malcolm, as I had been unable to have a single evening off since my dad's return from hospital due to my involvement in his care. We had discussed the possibility of Malcolm staying overnight at the 'home' which provided his daycare, but concluded that this would only unsettle him. This in turn, raised further discussion surrounding his care package as a whole.

Ian, the social worker, introduced us to a man named Bernie. Bernie discussed the prospect of taking more control over my father's care through the use of what he described as a 'personal health budget'. What he had to say sounded extremely appealing to us. The purpose behind this was for my father to gain more control over his life. My mum and I raised several concerns regarding Malcolm's current care package such as the lack of flexibility in his care; the hours that it was provided and lack of activities in which he wished to engage. My father had also vocalised his desire to spend more time within his own home.

We were offered the opportunity to join a scheme whereby a thorough care package and person centred plan would be created, highlighting my dad's needs and desires. Through this, we would identify what it was that was important to Malcolm, and how we may best meet his needs. Without much hesitation, both my mum and I confirmed our interest and signed up to join the scheme.

My mum and I attended four one-day courses. In each of these we discussed in depth what it was that Malcolm wanted in his life; what tended to ease his anxieties, which people were important to him, how he liked to spend his time, and ultimately what it was that he needed to feel safe and secure. We were introduced to a lady who had been through something similar in fighting for support for her son. She offered us several bouts of wisdom and much support and between us, we conjured up a package that would be far more suitable to my father's needs than the current set-up.

Now with only the finishing touches to his support plan required to be put in place, we look forward to having my father spending more time at home. Malcolm can look forward to spending more time with the people that love him – his family. He can look forward to spending more time doing the things that he enjoys, such as going for drives, listening to music, watching football, and going to the cinema. He can look forward to living his life in the way that he chooses to. For the first time in years, my father will be taking control again!

Peter's story

Prior to his brain injury, Peter was a fit 47 year-old man, a non-smoker, who enjoyed playing five-a-side football, snooker and walking. His main passion was supporting Sheffield United and he followed them around the country for years. He was a very placid man but, following his brain injury, he can now become agitated and angry on occasions. We have two daughters aged 22 and 19. We try and do as many 'normal' things as possible – like family barbecues, days out to the coast and parties. Peter is still a season ticket holder at Bramall Lane and occasionally travels to away games. He attends a Social Services day centre once a week and also attends a weekly group run by a local charity, Trinity Day Care Trust.

What was happening before

My husband had received support from an agency for four years following his discharge from Osborn 4 at the Northern General Hospital in Sheffield, where he had been a patient for twelve months following a severe brain injury.

I decided to apply for Self-Directed Support after some of Peter's regular carers decided to leave the agency and I was unsure of who would be replace them. I wanted to have the final decision on who looked after my husband because I know the sort of person he responds well to and who I felt comfortable having unsupervised in my home for long periods of time. Occasionally, the agency sent staff along who were not suitable and sometimes this caused a lot of stress to Peter, since the staff were not used to Peter's moods and occasional bouts of challenging behaviour.

What we did

I made an initial approach to our Social Worker in August 2008. Peter's package had three sources of funding: Social Services, Health and ILF. The Social Services part was straightforward and could have started within weeks, but the first hurdle we encountered was funding from Health, who would not make payments direct to me due to legal restrictions. One suggestion was that I received Direct Payments from Social Services, but Health would continue paying the agency to supply staff. This was not practical.

We had several meetings with Social Services over the following months, before eventually having a meeting with a representative of the PCT. Several options were put forward, including employing a third party to handle the funds or the possibility of setting up a Trust fund for Peter. It was eventually decided that a third-party option would be the best way forward and Health approached Home Farm Trust (HFT) which agreed to handle the finances and to provide support to me on contracts, staff training and legislation on a regular basis over the year. In order to set this up, a number of meetings were held with HFT to sort out some of the issues we needed to work through. The first meeting covered

Staffing Matters (for example, contracts, references, CRB checks, health and safety). The second meeting will cover welfare.

What life is like now

The package began on 18 May 2009. I have employed four regular carers (all from the original agency) and four relief carers who will step in to cover holidays and sickness. We were tested almost immediately because one of the daytime carers was admitted to hospital and has been given a doctor's note for two months. All care has been provided as normal by reworking the rota and everyone helping out where they can. Illness is obviously something that can't be planned for and definitely needs some thought putting to it before a package starts. One of Peter's registered carers is a family member who can step in and be even more flexible at short notice.

We are now four weeks into the package and all seems to be working well. Staff fill in hours sheets daily, and will be paid every four weeks. I have decided to prepare wage slips myself rather than use the local direct payment support provider because their annual charge would have been in the region of £300 because of the number of staff involved in our package. I inform HFT how much to pay each individual staff member, and the amount to be paid over to Her Majesty's Revenue and Customs each month.

There has been a lot of paperwork involved in setting up the package. I have had to create a staff handbook, risk assessment sheet, various daily record charts, obtain references, CRBs, Employer Liability Insurance, as well as finding out what sort of training the Personal Assistants had already received. Once this is collated, it will just need checking regularly and updating as necessary. I chose to do this paperwork, but it could have been handled by the third party. It was decided at a pre-meeting with HFT how much work I was willing to take on myself before their negotiations with the PCT over the fees they would charge.

I am not aware of how much HFT will be paid for being the third party. I do feel that it is going to be useful having someone to keep me up to date with legislation and they can also arrange free training for staff, such as moving and handling and medication. I can't understand, however, how Social Services can pay monies direct to service users but Health are not allowed to do this. Although being paid money directly is appropriate in Peter's case it would not be right for everyone.

I received a letter from the PCT detailing my weekly budget and the things that it covers. The budget also makes a weekly allowance which will accrue to cover staff holidays and for extra cover during my respite breaks over a twelve month period. The budget will be reviewed annually.

George's story

George is a young man with autism who had been living in the family home and was due to leave school. Choices for George beyond school appeared to be limited as he did not fit into any conventional provision. His new plan needed to be a holistic approach in order to meet his complex needs. Because of how George learns, he needed to learn independent living skills in his own environment.

The option of an Individual Budget was offered to George and provided him with the opportunity to create a full package of support around both his care and learning needs. George's budget was made up of a number of funding streams, including social services, ILF, Health and LSC. Once an overall figure had been identified, the family was able to plan and cost out the necessary support and desired outcomes in a way that enabled George to move in to his own house and put in place a team of workers that would support him both at home and in the community.

An independent learning plan was created that would allow his support workers to implement George's learning as part of everyday life, whether that be at home or accessing services across the city. As there are a number of health issues which impact on George's ability to complete the activities in his support plan, continuing healthcare funding played an important role in ensuring that George's health issues did not prevent him from maintaining his outcomes. As the majority of the budget was committed towards meeting staffing costs in supporting George, both health and LSC allowed flexibility in how their specific needs could be met. This allowed the family to be creative in working out a plan tailored to George's needs whilst still meeting the targets required to satisfy outcomes.

Examples of how Self Direction in Health can work by Julia Winter

(In Control team member)

Heather

Heather has a complex lung condition and was provided with a CPAP machine to help her breathe at night. But each time she needed the setting changed she had to travel up to a London hospital to get this done.

Using a personal health budget Heather, bought a variable rate CPAP which automatically adjusted to her breathing and a local supplier was provided with funding to pay for servicing of this device. This meant that Heather was able to spend her ‘well’ hours shopping – not at hospital.

Kate

Kate had COPD and was provided with an oxygen concentrator at home but was unable to stay away overnight with her friends as she could not take the concentrator with her. It was too heavy to move and a portable oxygen cylinder was not sufficient to last overnight.

Using a personal health budget, Kate was supplied with a portable oxygen concentrator which she was able to take with her overnight. It also had a battery back up which meant that she could still have oxygen during a power cut without the need to use cylinders.

Mary

Mary has complex health needs and is ventilator-dependent. She has personal assistants funded by continuing care through a nursing agency. This arrangement does not work very well as Mary is unable to travel to visit her family because her PAs are not allowed to work outside the county.

Under a personal health budget Mary uses a third party to employ her PAs which means that she is able to travel to see her family and stay overnight if she wants to. She is also able to use her PAs in a much more flexible way and choose who comes to support her and when.

Jane

Jane has cancer and is currently in hospital. She now 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 but will need considerable support to achieve this. The nurses feel she will be safer in a nursing home.

Under a personal health budget Jane is supported to plan for her future and discuss all the risks around her return home. As a result, an OT goes to her house to assess what work will be needed to accommodate the necessary hoist and electric wheelchair. As Jane will need her bathroom enlarged to accommodate the hoist, she is asked to consider going into a home while the work is done. She does not want to do this so a compromise is reached where she will use a commode in the bedroom until the work has been carried out. This approach allows Jane full choice and control and satisfies the necessary safeguarding issues for all concerned.

Sally

Sally has MS and is no longer able to speak. She has a team of PAs to support her at home. She is unexpectedly admitted to hospital and wants her PAs to help her with communication and personal care while she is there. The PCT is not able to allow help with personal care as the PAs would not be insured to use the hospital equipment and Sally is not allowed to bring in her own equipment. They also do not have any room for the PAs to stay during the night.

Under a personal health budget Sally is helped to write a support plan outlining the support she needs each day and the PCT work with the PAs in advance of Sally being in hospital to carry out an assessment of the PAs' handling of the necessary equipment to ensure all safeguarding issues are 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 which will get around the problem of accommodation for her PAs.

Appendix 2

In Control’s ethical framework

A document outlining In Control’s ethical framework can be downloaded from the In Control website.

Document title: Ethical Values

Sub title: The beliefs and values that underpin In Control’s work.

Download address:

https://www.in-control.org.uk/site/INCO/Templates/Library.aspx?pageid=242&cc=GB

Appendix 3

Rotherham mental health case study

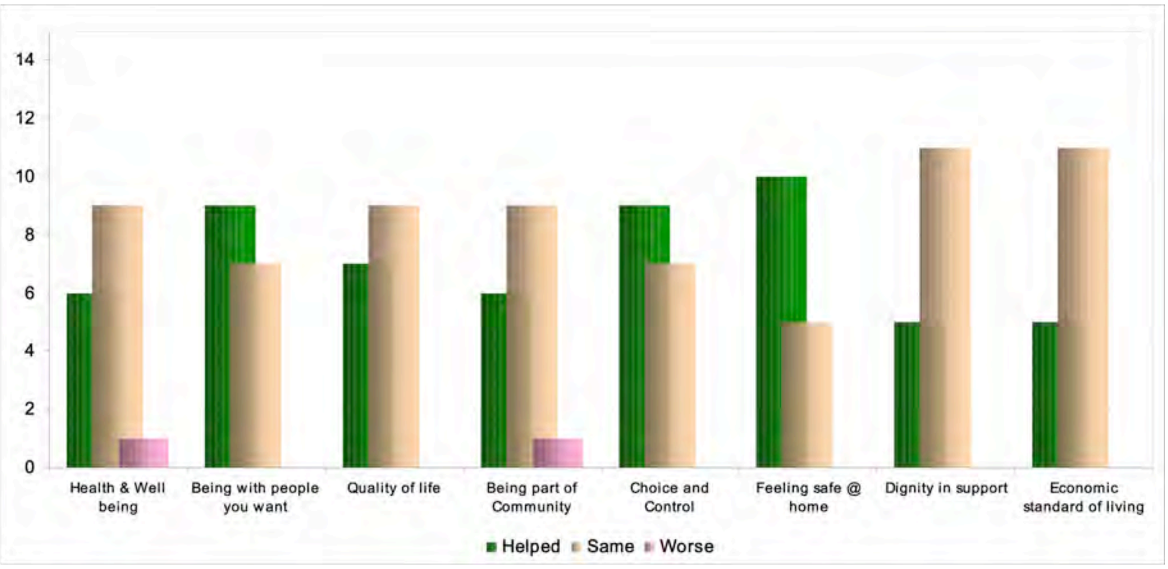
As has been discussed elsewhere in this paper, Self-Directed Support offers a framework within which individual citizens can exercise much greater choice and control over their support leading to improved outcomes for them and their family members. The introduction of direct payments legislation in 1996 was motivated by just this goal. However, the aspiration was often frustrated as restrictive policies were implemented at a local level. Many local authorities placed severe restrictions on how money made available through direct payment legislation could be used.

Work done in 2007 in Rotherham demonstrated the beneficial impact of offering greater flexibilities associated with Self-Directed Support. The Local Authority undertook an initiative with a group of existing direct payment recipients all of whom had been allocated direct payments due to their having experienced serious mental health problems.

1. The work involved re-categorising existing direct payments to become personal budgets. In practise this involved three simple but important steps:

2. The Local Authority reviewed its direct payment policy and removed any unnecessary or inappropriate restrictions on how money could be used.
3. The existing direct payments recipients were reminded of their allocation and informed of the new flexibilities, effectively becoming personal budget recipients.
4. Personal budget recipients were encouraged to review how they spent their allocation.

To judge the effect of the initiative, the local authority undertook a simple review with each personal budget recipient after a period of time using a simple standard questionnaire looking at the impact of the change on key areas of their life.



Responses of Rotherham personal budget holders

It is important to note that these reported improvements were seen within a service area, mental health, where direct payment uptake has been traditionally very low. This is also a service area where aspirations to increase choice and control have been particularly frustrated as service providers struggled to balance the aspiration of choice and control for citizens with complexity of risk management, and compliance with treatment and a duty care.

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A full bibliography will be included in the second draft of this report to be published in autumn 2009.

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