Citizenship in Health

Self-Direction: theory to practice

In Control Discussion Paper

By Rita Brewis and Jo Fitzgerald
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In Control
In Control is a national charity and a social enterprise. It is working to create a fairer society where people who need additional support due to age, ill-health, disability or other circumstance have the right and freedom to control their support and lead a fulfilling life.

In Control works closely with and supports a network of organisations including: the Department of Health; ADASS; NHS primary care trusts; adult and children's social services departments; as well as provider organisations and members of the public. It develops, tests and shares ideas with its members to reform the welfare state and promote citizenship and community.
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About the Integrated Care Network

The Integrated Care Network, part of DH Care Networks at the Department of Health, has over 7,000 registered members and provides information and resources on recent policy and practice in relation to integration. For further information, visit www.integratedcarenetwork.gov.uk
Executive Summary

Staying In Control is a membership community committed to a set of core values which underpin all its work. **We aim to create a more socially just society in which everyone is valued and can be an included citizen.** The purpose of our work on Self-Direction in Health is to enable citizenship and to support people to have the best possible quality of life. Citizenship and health are symbiotic. A society that excludes people from citizenship guarantees poor health. Meanwhile, good health depends on much more than just access to even the very best health care. It depends on active citizenship – a home, a job or opportunity to contribute, an income and friendships.

Our work on Self-Direction in Health complements the Department of Health’s Personal Health Budget pilot research and is distinctive through its emphasis on five critical issues:

- **Our aim** through our work on Self-Direction in Health is to improve the quality of:
  - the conversation between people and health professionals
  - decision-making and support/treatment planning
  - health outcomes – by shifting power and decision-making closer to the person directly affected.

- **Our focus** is on the **whole person in their whole social context** and aims to enhance **real wealth** – working with people’s strengths and skills as well as the needs they see as most important **to** them and which are most important **for** them.

- **Our programme** works with **individuals and family members alongside commissioners, professionals and providers** to put in place sustainable ways of working together and growing peer support, locally, regionally and nationally. We will work to create tools to **support providers and commissioners to shift power and control closer to people.**
Our work aims to find ways to make the context within which people are seeking to establish Self-Direction conducive to the process, for example by working with a community focus as well as a creative service-delivery focus.

We will learn through doing on a small scale and will evaluate developments by gathering the views of individuals, family members and professionals.
CHAPTER ONE
Background to Self-Direction

From the 1970s onwards, the development of Self-Direction was led by individuals with disabilities who wanted to take greater control of their lives. Having left institutions, many of them found themselves living in the community but segregated from other citizens, unable to play a full part in family and community life. By taking control of their support, these individuals set out to create a more meaningful life for themselves as active participants in their communities. This call for independence and control emerged from different movements across the disability spectrum, for example: the independent living movement of people with physical disabilities; the inclusion movement of people with learning disabilities; and the recovery movement of individuals living with mental ill health.

It is unlikely that there would now be any demand for Self-Direction without this social movement which not only provides a collective voice but also offers a way in which individuals can rethink their own situation. People can begin to see themselves as part of a group that can, and arguably should, take on more control and responsibility for its own destiny. It is a testament to the commitment and enterprise of these individuals that Self-Directed Support and personalisation have become important planks of the Government’s approach to public services.

Self-Direction sits at the core of In Control’s purpose to support improved decision-making and a better relationship between individuals and the welfare state so that people get better lives. While Self-Direction developed initially in social care, we know that people’s lives are not naturally split between Health and social care. We have acknowledged from the outset some of the significant differences between health and social care services, including differences in legislation, history, numbers and range of professional expertise.
However, to be most effective, our experience suggests that support needs to focus on whole people in their whole context – people who have contributions to make as well as needs to be met. In developing new approaches to Self-Direction in Health and social care, we believe in fostering innovation with our members and partners. We learn from doing and innovate as we go, bringing in at each stage the perspectives of individuals and families, providers, professionals, local authority and NHS commissioners.

What we can learn from our experience to date

In Control's work in social care – alongside international evidence – gives us confidence that expanding Self-Direction into some parts of health care makes sense. The impact that we have seen on people's lives from our work in social care has been consistently positive since the first testing of Self-Direction between 2003-2005. The Report on In Control’s Third Phase brought together evidence of how Self-Directed Support has made a useful difference to the quality of life of around 400 people. We include here three summary tables to illustrate the findings. (For more evaluation detail, please see Tyson A et al, 2010.).

Individuals’ evaluation of the impact of Self-Directed Support.

More than two-thirds of people using Personal Budgets reported that their control over their support (66%) and their overall quality of life (68%) had improved since they took up a Personal Budget (see Figure 1). The majority of people reported spending more time with people they wanted to (58%), taking a more active role in their local community (58%) and feeling that they were supported with more dignity (55%). Interestingly, more than half of all Personal Budgets users reported feeling in better health since they took up a Personal Budget, even though their budget only included social care resources.
Family carers’ evaluation of the impact of Self-Directed Support

Family carers also reported significant improvements in their lives following the introduction of a Personal Budget (see Figure 2). More than three quarters reported that they had become more of an equal partner in planning (77%) since their relative had taken up a Personal Budget. The majority of family carers also reported improvements in their quality of life (63%), the support they got to carry on caring and remain well (62%), their choice and control over their lives (57%), *their health and wellbeing* (57%), their financial situation (55%) and their relationship with a significant other (54%).

Social workers’ evaluation of the impact of Self-Directed Support

FIGURE 2. SATISFACTION LEVELS: CARER RESPONSES

FIGURE 3. SATISFACTION LEVELS: SOCIAL WORKER RESPONSES
In Control asked social workers, the professionals whose role is most affected by Self-Direction, about their perceptions of the impact of Personal Budgets on individuals and on their own working lives (see Figure 3). Around three quarters reported that people with Personal Budgets had more control and choices about their lives (79%), supports were more tailored to individuals (77%), Personal Budgets had made a positive difference to the lives of people using them (75%) and that professionals could plan more creatively. More than half of respondents reported improvements in people maintaining their existing support networks (59%), taking a more active part in their local communities (58%) and getting the right amount of help (53%).

Around equal numbers of professionals reported either improvement or no change in getting help to people in a timely way (46% improved; 34% no change), their professional skills and knowledge (45% improved; 48% no change), allocating resources fairly (42% improved; 44% no change).

Most professionals reported no change in risk management with the onset of Personal Budgets (60%).

Less than 10% of professionals reported things getting worse in nine of the 12 domains. More substantial minorities of professionals reported things getting worse with regard to allocating resources fairly (15%), getting help to people in a timely way (20%) and staying motivated in their work (20%).

Overall, these findings show a considerable win-win. Shifting power and control towards citizens leads to outcome improvements for those people 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) other people actually need them more in order to make the best use of the new system with its new flexibilities and benefits.

What we can learn from elsewhere

Self-Direction is now an important part of the social care systems in many European countries and in the United States. Exciting developments are happening in other countries, for example, the use of peer recovery coaches in the Florida and Texas Self-Directed Care programmes for people with mental health conditions (www.flsdc.org and www.texassdc.org).

The positive findings from In Control’s work described above are echoed by other UK studies and by international evaluations. International evidence consistently reports improvements in satisfaction among individuals using Self-Directed Support. For example, an evaluation of the Personal Budgets programme in the Netherlands found that close to 80% of people with disabilities and older adults who opted for a Personal Budget had a positive assessment of the services they received compared to less than 40% among those receiving directly provided services. There is evidence that access to services improves when individuals have control over their support and that people are better able to match their support to their needs.

Several evaluations have shown improvements in quality of life and some have shown improvements in health using social care money. For example, the UK Government’s Individual Budget Pilot reported a tendency towards improvements in the psychological well-being of individuals with mental health problems who had an individual budget compared to those who did not. (For more international evidence, see Alakeson V, 2010.)
Self-Direction in Health

Increasingly, the ideas underpinning Self-Direction are starting to emerge within the National Health Service (NHS), perhaps using slightly different words but following the same themes of shifting power and control closer to people. Work on Re-Thinking 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 are all examples of a wider shift in thinking about the NHS.

An emerging consensus

Together these initiatives indicate an emerging consensus in health care about the importance of shifting power and control closer to people who are directly experiencing an ongoing illness. As the latest NHS policy document states, ‘By putting power in the hands of people we have created a powerful engine for reform. Where once we had to rely on national targets to drive improvements, we can now drive change through the influence of patients. This will be the basis on which we renew our vision for the future.’ (NHS 2010-2015 from Good to Great, DH 2009)

From policy to practice

The policy of personalisation, epitomised by the scope, underlying values and vision of Putting People First (DH 2007) encompasses NHS and local council commissioning and services alongside those of the voluntary and independent sector. It is about them all working together ‘to harness the capacity of the whole system to shift the focus of care and support, across the spectrum of need, away from intervention at the point of crisis to a more pro-active and preventative model centred on improved wellbeing, with greater choice and control for individuals’.
Furthermore, it gives us a firm basis for the development of what the 2006 White Paper, Our Health, Our Care, Our Say called the ‘new direction for community services’, one which reflects the approach taken by In Control: the ‘commitment to independent living for all adults’ (DH 2007) which is ‘fundamental to a socially just society’. (DH 2007)

The term Independent Living is used as defined in Improving the Life Chances of Disabled People (Prime Minister’s Strategy Unit, 2005), and, as the joint statement of In Control and the National Centre for Independent Living says, ‘the goal for disabled people, whatever their age or impairment, is Independent Living – to have choice and control in how support needs are met. Self-Directed Support is the route to achieving Independent Living’ (NCIL, In Control (2007) Our goal is independent living). Our work in Health explores how Self-Direction can work best for people with a range of different health conditions, who may or may not consider themselves as disabled.

The implementation of personalisation is presented as having four key elements: the building of social capital; access to effective universal services; early intervention and prevention; and choice and control. Each of these has been a key component in In Control’s continuing development of the processes and thinking that enable Self-Direction.

A spectrum of control

In terms of practical action, the personalising of support and services and co-production are concepts that contribute to a spectrum of control which makes Self-Direction and the achievement of citizenship and independent living possible. It is useful to consider these key concepts in turn as part of a spectrum of control:

The personalising of support and services

Personalising support and services is one part of the broader policy of personalisation described above. It involves making support and services more personal to each individual, more fitting and more appropriate. Public services should already, by their very nature, be committed to such an approach since it is contradictory to seek to serve someone in a way which is inappropriate or unfitting. Personalisation of support and services promises better outcomes by attending to the details of the individual’s situation.

Co-production

To co-produce is to produce together. 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 need 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. Services can play their part. 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 involves 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.

Each of the concepts in the spectrum of control shares a common view that it may be more useful to think about the reform of health and social care systems not as if they were solely a professional concern but as if they also have a public dimension. 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 accesses social care support.

Self-Direction then involves a transfer of power to the individual who is seen as an active citizen with rights and responsibilities. It does not rely solely on the benevolence of professionals to share power through consultation or partnership. Self-Direction is about much more than a ‘new process’ for health care. In fact, if this is how it were to be perceived, then the roots of any innovation would be shallow. At its heart is an attempt to re-think the contract or relationship that exists between citizens and the NHS. Self-Direction puts the wide-reaching policy of personalisation into practical action through attending not only to changing services, systems and processes, but also to shifting power and control and sharing rights and responsibilities.

Cherishing as well as changing

We need to hold on to and sustain those things within the NHS that we rightly cherish. At the same time we must try to develop and enhance the way it works with us. The NHS is the primary organisational means by which we in the UK seek to deliver high-quality health care.

The creation of the NHS was one of the great achievements in the post-war development of the welfare state and in the UK we are rightly proud that the NHS provides:

- high quality care – UK doctors, nurses and other health professionals are amongst the best trained in the world
universal and equal access – the same care should be provided to the poorest and the wealthiest

free care 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.

In Control believes in cherishing the values of the NHS and the expertise of its professionals at the same time as seeking to change some parts of it to give greater power and control to individuals, thereby improving it for all citizens.

Real wealth

The purpose of Self-Direction is to enable improved decision-making and a better relationship between people and the welfare state so that people have better lives as active and included citizens. It is clearly not a matter of just giving people money. People can be most impoverished when they have plenty of their own money but have no information, no confidence, no-one who cares about them and no-one to help them plan. Consider, for example, a frail older person who has sufficient money to choose where to live when they feel unable to live alone in their own home. They may have sufficient money but, if they have no connections or information about alternatives or available support, they may end up making choices that lead to unhappiness and worse health outcomes.

We need to see people as whole people in their whole context. It is important to recognise the strengths and assets that each individual and family bring to Self-Direction, not just their illness and finances. Equally, if we are to provide meaningful choices, we must take note of when people lack certain key elements of real wealth. For example, it is not useful to routinely offer the option of Self-Direction at a time when someone’s inner reserves are run down through dealing with crisis. Alternatively, if we are sensitive to someone’s whole situation, we can put in place support that enables choice and control being gradually taken up over a period that makes sense to that person.
We identify five sources of real wealth that individuals and families can draw on in addition to support received through public services. These are illustrated in Figure 4 (opposite). When we, as citizens of our community and the wider world, make decisions, choices and plans, we draw on this real wealth. The nature of our real wealth influences the choices and plans we make.

**Five sources of real wealth**

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.

Similarly, in terms of planning for our futures, if we can hear about what others in similar situations have done, new possibilities can be revealed to us. We can't assume that someone’s preference for services they know is genuine unless they are aware of alternative ideas. We need to reflect on the question *How can we choose red or green if the only colour we've ever known is blue?*

2. **Connections**

The people we know – our family, our friends, our colleagues, our neighbours – are 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 and 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 however limited they may be) that we construct our lives. If we are lacking in ability or our gifts go unrecognised by others, we will feel trapped and incapable.

5. **Resilience**

Our genetic make-up, our cultural background, our mental and emotional health, our physical health, 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 these elements make up our personal resilience.

Resilience is likely to vary over time and will be affected by the impact of life events, good and bad. This is one reason why the timing of our engagement with the Self-Direction process is so important and why sensitivity to each person’s unique situation is necessary.

There is growing evidence that it is critical that we do not underestimate people’s ability to take control (given the appropriate support) and that taking control can have a radical, transformative effect on their lives. It is this flame of inner resilience that is the central and most important dimension of what we call real wealth. In the development of Self-Direction we need to consider how to nurture each individual’s real wealth. Offering someone control over money without considering what use they can make of that money in the context of their other strengths, assets and connections can be futile and wasteful.

To capitalise on real wealth, we need to:

- increase people’s understanding of risks, options and good strategies
- strengthen people’s skills and confidence
- help people to stay connected to each other.

Personal Health Budgets

Acknowledging that individuals are whole people who have their own whole and unique context, as discussed above, 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 flexibly shape treatment and support
- a recognition and valuing of people’s differences so that unique strengths can be supported and diverse needs can be met
- effective and inclusive systems of support, information and advice
- a range of effective ways to hold the money
- appropriate systems for professional input and monitoring
- a real shift in the balance of power between an individual and the NHS.

Nevertheless, many people would acknowledge that money is a powerful tool and can be an important lever for change in the ways people relate to providers of services and to professionals. The fact that health care money cannot currently be given directly to some individuals creates significant problems for them. For example, there are a number of situations in which people have been in control of money 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 funding. They then lose control – even to the extent that they lose the paid support staff who have helped them to live their lives. This situation surely merits urgent attention and change.
Defining a Personal Health Budget

One important element of Self-Direction in Health is the use of a Personal Budget. This is an important tool for changing the relationship between professionals and those who use services. In Control’s working definition is as follows.

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

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

The person must:

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

The budget must be:

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

We can see from this definition that, while money is important, it is not sufficient on its own to enable useful change. Nor is it essential to always receive money directly in one’s hand. This is important, since it is currently legal for Primary Care Trusts to give people Personal Health Budgets but not yet legal for these budgets to be given in the form of a direct payment. The alternative ways of ‘holding’ the money are outlined below and can work well, provided that the transfer of power and decision-making is genuine.

The Department of Health has defined several ways in which a Personal Health Budget can be held: notional, a real budget held by a third party or, for a limited number of pilot sites, health care direct payments. It is expected that the Secretary of State will be able to authorise

Different ways of delivering a personal health budget

FIGURE 5. APPROACHES TO HOLDING A PERSONAL HEALTH BUDGET (SOURCE, DAWN STOBBS, DH)
pilot sites to use direct payments beginning in summer 2010. These different approaches to holding a Personal Budget are illustrated below.

The Department of Health has also set out some basic rules covering what a Personal Health Budget can and cannot be used for. The Department has left room for great flexibility which will enable maximum creativity. There are a few exceptions: ‘Personal Health Budgets should not include emergency care or primary medical care. Any goods and services purchased should be appropriate for the state to provide. Gambling, debt repayment, alcohol and tobacco are not permitted.’ (Personal Health Budgets First Steps, DH 2009)

Additionally, the Department has stated that a Personal Health Budget should meet an individual’s agreed needs in full, not in part. Therefore, individuals may not directly top up their Personal Health Budget from their own resources to purchase additional care. If, for any reason, an individual wants to purchase additional, private care, they would need to do this separately and not in combination with any Personal Health Budget funds. (Personal Health Budgets First Steps, DH 2009)

Real lives

Self-Direction in Health is new and there are only a handful of examples of how individuals and families are using a Personal Health Budget. The four real-life, snapshot stories below illustrate how a Personal Health Budget can improve people's lives. You can find more real-life stories at www.in-control.org.uk. In its second phase of work, Staying in Control is actively gathering video stories to share.

Heather

In order to manage a complex lung condition, Heather was provided with a CPAP (continuous positive airway pressure) machine to help her breathe at night. But each time she needed the setting changed she had to travel to a London hospital to get it done.

Using a Personal Health Budget, Heather bought a variable rate CPAP machine which automatically adjusted to her breathing. A local supplier was provided with funding for servicing the device. This saved the cost of NHS transport and specialist professional time and meant that Heather was able to spend her ‘well’ hours as she wished – not travelling or in hospital.

Mary

As someone who enjoys spending time with her family (who live some distance from her), Mary found a new way to meet her complex health needs. She previously had personal assistants funded using continuing healthcare money, provided through a nursing agency. This arrangement did not work well because it meant she couldn’t travel to visit her family as the personal assistants were not allowed to work outside the county in which she lived.

A Personal Health Budget allows Mary to use a third party to employ her personal assistants. This arrangement 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 personal assistants in a much more flexible way and choose who comes to support her and when.
Jane

After living independently all her life, Jane developed cancer in older age and was in hospital. She needed a hoist in order to move from her bed to a chair and to the toilet, so was assessed with a view to moving into a nursing home. She did not want to make this move and preferred to return to her home but needed considerable support to achieve this. The nurses felt she would be safer in a nursing home.

Using a Personal Health Budget, Jane was supported to plan for her future and discuss all the risks around her return home. As a result, an occupational therapist visited her house to assess what work was needed to accommodate the hoist and electric wheelchair. As Jane would need her bathroom enlarged to accommodate the hoist, she was asked to consider going into a home while the work was done. She did not want to do this, so a compromise was reached: she would use a commode in the bedroom until the work had been carried out. This approach allowed Jane full choice and control and satisfied the necessary safeguarding issues for all concerned.

Sally

While continuing to enjoy life as fully as possible, Sally has had to deal with ups and downs in her health. She has multiple sclerosis and is no longer able to speak. She has a team of personal assistants who support her at home. They know her well and understand the things that matter most to her. When she was unexpectedly admitted to hospital, Sally wanted her personal assistants to help her with communication and personal care while she was there. The Primary Care Trust would not allow help with personal care as the personal assistants would not be insured to use hospital equipment and Sally was not allowed to bring in her own equipment. There is also no room for the personal assistants to stay during the night.

Using a Personal Health Budget, Sally was helped to write a support plan outlining the support she needed each day. The Primary Care Trust worked with the personal assistants before Sally went into hospital to carry out an assessment of their handling of the equipment to ensure all safeguarding issues were satisfied. This means that, when Sally is admitted to hospital in the future, her personal assistants 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 personal assistants in the event of a hospital admission which will get around the problem of their accommodation at the hospital.
In Control’s approach to Self-Direction in Health

In Control’s work in Health, Staying in Control, began early in 2008, predating Lord Darzi’s report, *High Quality Care for All*, that made the idea of piloting Personal Health Budgets the legitimate ‘business’ of the NHS. Based on the first phase of Staying in Control, we have identified five key issues that define our unique approach to Self-Direction in Health. This chapter discusses each key issue in turn, highlighting what we and our members learnt in our first year of working on Self-Direction in Health and outlining how we will take action as we move into our second phase of work.

The Department of Health is also now running a Personal Health Budget Pilot Programme. As part of this Programme, the Department is advancing the Government’s proposal to pilot direct payments for health care. Under the authority of the Health Bill passed in 2009, the Department has developed regulations that will allow direct payments in authorised pilot sites, starting in summer 2010. This is a very significant step for Government, even if only a few people will initially be able to use this new form of power and control over their health support needs.

In Control is a strategic partner with and member of the Department of Health’s Personal Health Budget Pilot Board. Staying in Control’s second phase complements the Department’s work, and also has In Control’s unique approach, values base and aims as set out below.
Key issue 1: **Changing relationships, improving decisions and outcomes**

The aim of our work in health is to improve the quality of:

- the conversation between people and health professionals
- decision-making and support/treatment planning to enable people to organise their support in ways that make sense to them
- health outcomes – through shifting power and decision-making closer to the person directly affected.

We are committed to acknowledging people as part of whole systems – both those requesting help and those seeking to provide that help. A change in one part of the system affects the other parts. Our membership work is therefore focused on supporting people to renegotiate their relationships, and calling for change in the power and control between commissioners, providers, professionals and people seeking support and treatment.

In order for this change to work, it is important to acknowledge that, for some people, previous experiences of discrimination within the health system will have an impact on their starting point when engaging with professionals. In some instances, a community’s lack of access to or different experiences within services will affect people's expectations and levels of trust in the system – for example: people from the black community who have experienced discriminatory access and treatment within mental health services; or failings in respect for and treatment of people with dementia or frail older people in acute health care settings. Such experiences will need to be taken into account if we are to ensure that people have confidence in the possibility of a shift of power.

We need to tilt the balance of power further towards people directly affected by ill health, enabling them to be more actively engaged. Their personal experience of illness needs to be respected and perceived as an essential component of decision-making. We want to further develop an alternative to the NHS's current **professional gift model** in which it is assumed that professionals know best not only about clinically proven treatment but also what is best for someone's life. This traditional approach leads to a familiar situation in which professionals and commissioners work out what they believe people need and buy it for them, or a prescription for medicine is written but may remain in the cupboard. Individuals have to slot in and accept the prescription and, while they may feel grateful for the ‘gift’, they remain a passive recipient.

In a **citizenship model** of health care, citizens are actively engaged. They know what they are entitled to receive and they are fully involved in negotiating the care they want with professionals and commissioners. Their care takes account of their personal context, their **real wealth** and the community in which they live. This shift from a gift model to a citizenship model is illustrated in Figure 6 below.

Simon Duffy, Director of the Centre for Welfare Reform, has developed a model that illustrates the role that professionals, commissioners, providers, individuals and families play in a **citizenship model** and the important steps in the process of having a Personal Budget. (See Duffy S, *Briefing Paper on Self-Directed Support*, 2009)
Simon has also created the graphic below to illustrate **Total Place Commissioning**, an integrated approach, described in his latest paper *Personalisation in Mental Health*. This report describes a model for integrating health and social care support for people with mental health problems. The model is designed to promote personalisation, empowerment and citizenship. Drawing on the latest thinking, this report provides a model for development and implementation in the Yorkshire and Humber region. It also provides a framework for the integration of NHS and social resource allocation systems. (See Duffy, S, 2010)

**FIGURE 6. THE PROFESSIONAL GIFT MODEL (LEFT) AND THE CITIZENSHIP MODEL**

**FIGURE 7. TOTAL PLACE COMMISSIONING**
There will always be health situations in which we seek to leave power and decision-making with expert professionals. Some people may never wish to change this for themselves. In emergency situations, for example, 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 professional. At critical moments, having trust in others and their expertise can be essential for our health and well-being.

On the other hand, if we suffer, for example, from dementia, schizophrenia or 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 or diabetes, we cannot wait for a magical cure. We need to do something ourselves. We want professionals to share best practice with us, to inform us about NICE guidelines and discuss the latest clinical evidence. But, frequently, the evidence is not entirely conclusive. We may also have a range of health conditions which interact so that treatment options are inter-related or in conflict. There is often more than one possible course of treatment and our preferences matter.

To understand the deeply personal and unique perspective of how an individual views and experiences an illness, we have to seek out that view and open a dialogue. We cannot assume we know, for example, that someone would always rather be pain-free regardless of the impact of pain relief medication on their life and the important roles they want to fulfil. The NHS and its professionals will know the top recommended treatment. Only we can ever know what matters most to us as individuals.

Figure 8 below illustrates the different kinds of knowledge that individuals and professionals bring to the planning process and how both are necessary in the development of an effective personal health plan. If individual preferences and knowledge are not taken into consideration in treatment planning and decision-making, the NHS is at risk of wasting some of our hard-pressed public money on care that people do not want, or treatments that people will not keep to, and that may therefore not best improve their health. (Waste of medication is but one worrying example.)
LESSONS LEARNT

In the context of changing relationships and improving decision-making, these are some of the important lessons we have learnt in phase one of Staying in Control.

Cherishing as well as changing

It is vital to retain best practice as well as change the relationships. We want to make sure that everyone’s voice and their evidence of what works for them is taken into account alongside clinical evidence. Having a Personal Health Budget need not mean ‘all or nothing’. Individuals should not be expected to cut all ties with existing services. Having a Personal Health Budget should offer the opportunity to take control of those aspects of a person’s life that make sense to him or her and should not necessitate the loss of services that provide helpful and timely support.

While we shift our focus towards outcomes and keeping processes around Personal Health Budgets as simple as possible, we must also sustain current good practice and build on what we have learnt from implementing Personal Budgets in social care. Thus we must ensure we have:

- a fair process for allocating resources to individuals so they know how much they have to spend
- a clear process for authorising plans to agree that they will keep someone healthy and safe
- expert clinical input alongside an individual’s own views and ideas
- continuous appropriate monitoring and review of someone’s health condition over time.

Careful consideration must be given to plans that support people whose condition means their health will inevitably deteriorate. If a person becomes increasingly unwell as a result of their condition, this should not be seen as a failure of someone’s Personal Health Budget. It may be important to counsel a person about how their ideas and views can be incorporated at every stage in a way that reflects where they are in relation to their illness.

The importance of listening to people and families

Mitchell is a young man with complex health needs. Two years ago, his family took control of his care using a Personal Health Budget. Mitchell’s family’s direct experience of putting Self-Direction in Health into practice highlights the importance of listening to people and families, as his Mum, Jo, explains.

‘The process of developing Personal Health Budgets so far highlights the need to listen intimately to what people and families have to say. Being listened to and understood very early on in the process of developing our son’s personal health plan was especially transformative for us as a family. It enhanced our self-belief, enabled us to clarify our thoughts and crystallised our vision. I know this to be true for other families too which suggests it is an integral part of the process which cannot be negated or hurried.’
It is widely acknowledged that clinicians and services will experience and need to embrace a huge culture shift as Personal Health Budgets are introduced; this is also true for people and families. After years of being “done to” by services, having the opportunity to talk intimately about their experiences will help people explore what a Personal Health Budget could mean to them and unlock their full potential. From the dark place we were in four years ago, the biggest shift in terms of our family’s process occurred when we began to see that there was an alternative to the way we were living. Suddenly, there was a light at the end of the tunnel.’ (Jo Fitzgerald 2009)

The transfer of power to people must be real

‘It isn’t enough to choose whether to go shopping or where to go on holiday. Involving people in planning their own support is not the same as sharing power. We learnt this lesson when we entered into a third party arrangement based on a false set of assumptions. We assumed that what we meant by being “in control” was the same as the organisation we had appointed to hold our son’s budget. Sadly, within two or three months, it became clear that we were talking a different language. From their point of view as the third party, they were responsible for the budget and for all important decisions. So what we actually experienced was no shift in power; it felt like what we were getting was no different to the service we had left behind. We have since brokered a new arrangement based on shared values and aspirations which is working as we had always imagined.’ (Jo Fitzgerald, 2009)

Translating understanding into action

Below are actions that In Control is committed to taking in order to translate understanding into action:

- In Control will work with Staying in Control members to explore how we can create guidelines or tools to support individuals and families to be allowed sufficient time for the process of listening described above. Time and a sensitive approach are needed to support someone to explore and come to an informed view about useful change being possible and about whether they would like to use a Personal Health Budget. This listening and sharing of possibilities does not only have to be done by a health professional, though their involvement in some aspects may be important. Advocates, peer supporters and voluntary sector user-led organisations could offer this important, exploratory first step. Raising expectations and aspirations (within a practical and well-informed understanding of what is feasible) is a key part of Self-Direction.

- In Control will work to support individuals and families to share learning about support planning which starts with an exploration of what is important to someone as well as considering what is important for them in terms of their health. Support planning differs from care planning in that it starts by identifying an individual’s hopes and dreams about how that individual would like his or her life to be and goes on to explore how those hopes may best be realised or approached. Personal Health Budgets enable this planning to use both the knowledge of what public money is available and also to focus on each individual’s real wealth.
In Control will work with all its members and through public presentations and publications to share a clear approach to health support planning which emphasises the importance of a changed dialogue between individuals and health professionals. This dialogue will enable the best possible clinical knowledge and professional contribution to health outcomes to be integrated with an individual’s own personal life priorities and commitment to those agreed health outcomes.

Jo Harvey of Helen Sanderson Associates in partnership with PCTs in the West Midlands has created a draft set of criteria for support planning in health which is now available, and also a workbook to support people developing their health plan. (See investing for health: *Support Planning Toolkit*). In Control will work with individuals and families and also with decision-makers in PCT member sites to share such good practice that describes useful criteria to apply when agreeing a support plan. This work will include how risk is managed and what training and workforce development needs to be undertaken to support a person and meet their health needs. It will be essential to ensure that not only are clinical tasks performed expertly and safely but the way the tasks are carried out conforms to the person’s support plan.

In Control will work with its members to find effective ways to measure whether the transfer of power to individuals is genuine. These ways will be created by individuals and family members working with provider organisations and commissioners to agree what would be a useful set of criteria that can be developed over time and through use. We will also work to connect those people who wish to link up locally, regionally and nationally in order to promote power-sharing through collective solutions and support for one another.

**Key issue 2: Whole people in a whole context**

Our focus is on the whole person in his or her whole social context. We aim to enhance real wealth, working with people’s strengths and skills as well as the needs they see as most important to them and which are most important for them.

In Control's overall message is one of determination to promote the view that people are whole people – perhaps with a range of complex interacting needs but also, crucially, with potential to contribute and creatively engage in change, often in ways which amaze and confound our traditional patterns of relating.

In Control’s view, based on our work in social care and on a clear ideological commitment to people having a right to an ordinary life as full citizens included and valued in society, is that many people, over time and with sufficient information and support, will want to take more control for their own health as an integral part of their lives.
LESSONS LEARNT

Approaching people as whole people in their whole context, these are some of the important lessons we have learnt in the first phase of Staying in Control.

Timing is crucial

People with long-term or complex health conditions experience many peaks and troughs in their lives. There can be huge variation in how people experience their condition over time, which suggests that we need to think very carefully about timing. As people start to be offered Personal Health Budgets, we need to ensure the process is not prescriptive. We need to refrain from offering a Personal Health Budget only on discharge from hospital, for example. Paying attention to the real wealth concept of the ‘inner flame of resilience’ may be most helpful.

For some people, the experience of living with a health-related condition leads to a sense of grief and loss as well as a loss of self-esteem and self-confidence. Whilst the ideological goal is to enable people to have an ordinary life as full citizens, we must remain sensitive during the planning process. We must not force people to take on more control than they desire. Individuals must not feel judged if the focus of their support plan is less on playing an active citizen role and more on feeling understood, safe, cared for and comfortable.

’Again, I am drawing on our family’s initial feelings of relief when our son was discharged from hospital after twelve months. At that stage, we would not have wanted or been ready for a Personal Health Budget. However, things felt very different two years down the line. What seems important is for those involved in offering budgets to be sensitive to where people are in relation to their health condition. Rather than being prescriptive, people need to remain open to the fact that people change their minds and that should not be a barrier to having a Personal Health Budget when the timing is right.’ (Jo Fitzgerald, 2009)

Translating understanding into action

In Control will work with members to find simple ways of ensuring that the option of holding a Personal Health Budget (either directly or through a third party) is made available to people in timely, accessible ways, not offered as a ‘tick-box’ exercise which prevents take-up and excludes certain people. We will also be alert to the threat that any targets that may be set by Government may unintentionally disrupt or destroy the free choice of people over a decision about whether and when they wish to take control over their health plan.

Key issue 3: Working together

The Staying in Control programme will work with individuals and family members, alongside professionals, to put in place sustainable ways of working together (co-production) and of growing peer support, locally, regionally and nationally, as part of developing a social movement for change.

The move towards Self-Direction has been driven by disabled people themselves demanding change and has rapidly become included in the latest Government policy initiatives. It is
important to remember people’s own call for change and the obstacles to independent living that Self-Direction seeks to address, in both health and social care. Self-Direction in Health is a whole-system approach specifically designed to enable better decision-making and to make best use of public money by shifting information, power and control closer to people. This cannot happen effectively unless people with direct experience of health care services drive the process alongside providers and commissioners.

In Control believes that there is already sufficient evidence that shifting power and control to people directly affected, when done sensibly and thoughtfully, is useful. Our work is therefore focused not on whether to evolve Self-Direction in Health but, rather, to work out with our members how best this can be achieved and to measure and evaluate the impact.

**LESSONS LEARNT**

In the context of working together, these are some of the important lessons we have learnt in the first phase of Staying In Control’s work.

**We need to invest in people and families**

Not only do we need to listen to people and families, we also need to invest in them, remembering that people and families are what Personal Health Budgets are all about. However, investing isn’t simply about acknowledging people’s own innate resources. It is also about investing in innovative mechanisms that support people to take control. For example, there will be those who want to set up a social enterprise as their third party mechanism because it makes sense to them both as a means of managing their finances but also as a source of support. Pooling resources may give people what they need in order to manage complex packages of care using local knowledge and expertise.

We also need to think about toolkits for families. We hope that, while the Department of Health and In Control are working to develop Personal Health Budgets, people will be empowered and supported to find their own solutions.

A good example is provided by a family in the north west of England. Family members have negotiated their own third-party arrangement with a third-sector organisation. It was agreed by the commissioner and began in January 2010. We need toolkits that enable people to negotiate what they want and need from a third-party arrangement alongside what is needed by the third party for a co-produced contract. We will need to invest in people brokering their own arrangements, recognising that, in essence, they are citizen commissioners. We must ensure that this support is available and accessible to all people, irrespective of their level of education, cultural background, beliefs or language. Supporting citizen commissioners must be worthy of investment and pump priming.

**Recognising the urgency felt by some people and families who need a Personal Health Budget as soon as possible**

There are a number of people who, having had an individual budget in social care, have been reassessed for continuing health care. They experience a profound loss of choice and control. They had built strong relationships with personal assistants only to be told that arrangements
that had been working well could not be continued due to a change in funding. Sadly, some of the people who are keenest on having a Personal Health Budget do not live in an In Control or Department of Health pilot site. How do we support these people to have a dialogue with commissioners and to articulate their sense of urgency? There are people who simply can't wait for us to work everything out. We need to have opportunities to learn through practice and to link up people around the country.

Translating understanding into action

Below are actions that In Control is committed to taking in order to translate understanding into action:

- In Control will work with all stakeholders to co-create a toolkit to support the four partners needed to make Personal Health Budgets a workable reality for the maximum number of people. These four partners are: those wishing to use a Personal Budget; professionals; commissioners responsible for agreeing and monitoring the plan; and providers who wish to have a role in either direct input or a support role in 'holding' the money or employing staff on someone's behalf. This work is urgent and critical, especially since it appears that legislation to allow direct payments in Health will only be available in a few PCTs for several years. Also, many individuals and families may not immediately (or perhaps ever) wish to directly hold money themselves nor to employ staff directly but will wish to have control over their health plan and over how resources are used. Flexible options with effective information and support systems to enable people to have the degree of control they want offer a way of ensuring that personal health plans can be used equitably across diverse communities by people in a range of circumstances – including by those who lack capacity (by means of clarifying who else can act on their behalf).

- In Control aims to join with members to demand change and to communicate the distress caused by some parts of the current public health and social care systems. At the same time, In Control seeks to work constructively with policy makers and Government to support strategic decision-making and sustainable developments. Building confidence and resilience throughout public services as well as within individuals and communities may best enable the necessary shift in power.

- In Control will work with all its members to ensure that the resources developed through Staying in Control are accessible to all and support individuals and families from all backgrounds to take control. This work will include, for example, developing approaches to support planning that take into account the importance of culture, faith, family and other relationships. Where appropriate, In Control will also work to involve community organisations in the development of Personal Health Budgets that can provide support to individuals with diverse language and cultural needs.
Key issue 4: Community

In our work, we will aim to find ways to make the context within which people are seeking to establish Self-Direction conducive to the process. We will, for example, work with a **community focus** as well as a creative service delivery focus; and create tools for **support providers and commissioners to shift power and control closer to people.**

**LESSONS LEARNT**

**The importance of keeping flexible options**

One important dimension of community context is the potential for alternative sources of supply in the community that offer wider options for individuals and families as citizen commissioners. Self-Direction creates an opportunity, by opening up choice and control, to develop a market that extends beyond traditional health and social care services to include community-based activities and use of mainstream resources such as libraries, colleges and leisure centres.

We will need to remember that people themselves often create alternative solutions that professionals may never have considered. People’s creativity will be best engaged by enabling the most flexible approach to planning ideas and by stimulating a market, including small and micro-enterprises and user-led organisations, rather than by offering a restricted menu of choices based on what is available in current service provision.

**The importance of recognising, valuing and supporting family carers**

Carers are a vital resource in communities. Most care and support is provided unpaid by families or friends (support of more than 50 hours per week to over 6 million people). Self-Direction can be an ideal framework for both enabling the effective integration of paid support, help from family and friends and other natural supports available within the community, and for taking into account carers’ need for choice and support, their health needs and whole-life plans.

**The importance of community power-sharing concepts such as participatory budgeting**

There are already examples of communities coming together to bid for and vote for how best to use Health funding to improve the health of their local community. We can build on this work and explore with Public Health professionals and community workers how Self-Direction might evolve within communities.

**Translating understanding into action**

In Control will consider a range of ideas with members, including the potential use of participatory budgeting and health promotion initiatives, alongside small-scale but vital market development work, and exploration of links with *shop4support.*
Key issue 5: **Evaluation**

We will learn by doing in small-scale actions. We will evaluate developments by gathering the views of individuals, family members and professionals.

**LESSONS LEARNED**

Below are some of the important lessons learnt about evaluation in the first phase of Staying in Control.

**Self-Direction is not a universal panacea and won’t resolve financial constraints**

Self-Direction in Health and Personal Health Budgets are not a universal panacea. They will not be appropriate across the whole of the NHS nor will they resolve the financial issues of a limited budget. However, Self-Direction can enable an open debate about health priorities and how to connect the provision of resources to need in the most efficient and effective ways. It can also transform lives.

It can be argued that people themselves have the highest vested interest in getting best value for money. In considering efficiency, we must factor in the current wastefulness of providing services that people do not want or use, which cut them off from natural community supports and increase dependency. We must, at the same time, pay attention to safeguarding services that people value.

**Self-Direction in health should be evaluated fairly**

Any move towards Self-Direction in Health will need to demonstrate value for public money and sustainability in the long term. This is appropriate provided that Self-Direction in Health does not have to bear an unreasonable degree of testing which other commissioned services do not. It will be essential to evaluate not simply different purchasing arrangements but also changes in people’s lives from the perspective of individuals, carers and professionals at the same time as addressing the wider strategic issues of resource use and effectiveness across the whole public health and social care system.

**Translating understanding into action**

We will learn by doing and evaluate as we proceed. We will use the evaluation tools we created in our first phase of work to capture baseline information and to gather together information on any changes in people’s lives once they have had experience of using Self-Direction. ([Available at: www.in-control.org.uk/StayingInControl-celebratingoneyearofwork](http://www.in-control.org.uk/StayingInControl-celebratingoneyearofwork))

Since we all use Health services, we all have a stake in developing the NHS and sustaining its best qualities. We will continue to connect people to share ideas about what is possible and the new solutions they have found. We will continue to share stories in writing and on video of how people can and do transform their lives and communities when power and decision-making are shared.
References, resources and the Health Planning Tree

This section lists publications in print, publications with web links, resources and the Health Planning Tree. Many weblinks referenced in this report are long, so, rather than list them here, we have created a web page where you can access the documents through live links www.in-control.org.uk/citizenship-in-health

The Health Planning Tree, reproduced in full at the end of this document, can also be downloaded from the In Control website.

Publications available in print


Publications with web links

www.in-control.org.uk/citizenship-in-health


Duffy S, *Personalisation in Mental Health*, The Centre for Welfare Reform in association with the Yorkshire & Humber Improvement Partnership (YHIP) Care Pathways & Packages Project (CPPP) and the Association of Directors of Adult Social Services (ADASS), 2010.

Investing for health, *Support Planning Toolkit for Health*. There are five downloads that make up the Toolkit.

General web resources

- Centre for Welfare Reform
- Department of Health Personal Health Budget Pilot Programme
- DH Care Networks *Personalisation Toolkit*
- In Control’s Staying In Control Programme
- West Midland Strategic Health Authority, *Investing for Health Personal Health Budgets Toolkit*

The Health Planning Tree

An organisational development tool for Self-Direction in Health

This new *Planning Tree* document was created for our second phase members of Staying in Control. It is a tool to enable organisational change. (It is not for individual support planning). It uses the image of a tree since we believe that the development of Self-Direction in Health is a living, growing development that needs nurturing and time to take root. We also believe Self-Direction in Health can best be grown with the active input of people with direct experience and family members, alongside health professionals, commissioners and providers. It is available for use by our wider In Control membership community and can be downloaded from our website.
The Health Planning Tree

An organisational development tool for Self-Direction in Health

Our Team
Roots and team building

If we are to take forward a meaningful and sustainable change in the way individuals relate to the Health Service, it will be essential to have people on board who have experience of being patients. They can help us drive forward this evolution, as part of a small local team with all the necessary partners. We will need this voice to be heard to help us all actively counter-balance the dominance of the traditional way of relating, and negotiate a new relationship. To be successful, some changes in both professionals and people who are used to being patients will be necessary.

How do we make sure from the start that people with direct experience of health conditions, themselves or as family carers, take an active part in leading this work locally? And how do we make sure that all the other essential people who need to be included in developing how Self-Direction in Health will work locally, are also part of it (Health professionals, providers, our colleagues in social care)?

First, we need to agree what we’re aiming for, so we need to agree: What will this local leadership team look like when we’ve grown it, and how will we know it’s working well?

When we come to do this work, what skills knowledge and experience can we draw on personally, locally and regionally to help us make sure that we have people with experience of being patients leading this with us? (Things we’ve done already, relationships we’ve built, contacts we have, organisations we know about, skills and experience – our ‘real wealth’).
What do we need to do next? And what/who can help us with this? – each other in our local team and people from other member sites, regionally or nationally.

What might we find useful to help with this?
Working out what money can be made available for someone to control

Self-Direction in Health will work best if the individual is told at the start how much money is available with which to create their plan. The sum of money calculated to meet their particular health outcomes needs to be demonstrably sufficient to meet the outcomes agreed. Because everyone’s situation is unique, it needs to be open to some renegotiation once the plan is drafted.

We are at a very early stage of connecting health money to individual outcomes so we will be learning together as we make these calculations. The individual needs to be assured that they will not be losing access to any essential care and treatment through taking control.

How do we make sure that we can identify some health money for an individual to control?

First we need to agree which people we are considering inviting to take control of resources, since this will help us look for options that are possible in that part of the Health system. For example, if someone has been assessed as having their health outcomes met through continuing health care funding then there will already be an identifiable sum of money to control. In other parts of the NHS, predicted average service use for someone with a particular illness may need to be costed as a starting point.

Then we need to find out what we can learn from social care’s early work (before resource allocation systems were created) as a good enough way of starting to take action. Then we need to consider whether all the people in the NHS locally who have to calculate and agree spend are included, so that we can guarantee any offer made to someone is achievable and sustainable. We need to find useful ways of beginning to connect needs, costs and outcomes instead of simply identifying needs and services.

When we come to do this work, what skills, knowledge and experience can we draw on personally, locally, regionally and nationally to help us identify some Health money for someone to control? (Things we’ve done already, relationships we’ve built, contacts we have, organisations we know about, skills and experience – our ‘real wealth’).
What do we need to do next? And what/who can help us with this – in our team or beyond?

What might we find useful to help with this?
What will the processes be to authorise, implement, monitor and review support/care plans? And who will do these tasks?

It will be essential to clarify the ‘deal’ or the ‘rules’ under which we are offering people control of public money to meet their health outcomes. These rules, and who will be responsible for ensuring that each essential part of the process happens, must be worked out before we invite people to join in and consider taking control.

This is necessary because the person who is being invited to take control, needs to understand and have full information about the whole process. In social care there were occasional examples of poor practice where people were given very little information and there were different assumptions about what was acceptable in a plan, leading to distress and disappointment. We can avoid this by learning from those mistakes and putting in place a clear process with accessible timely information; and with opportunities for discussion and clarification. (The next section will consider how the criteria set to create these essential processes, informs the options made available of ways to hold the money).

When we come to do this work, what skills, knowledge and experience can we draw on personally, locally, regionally and nationally to help us work out how we will put in place these essential processes to authorise, implement, monitor and review support/care plans, and who will fulfil them? (Things we’ve done already, relationships we’ve built, contacts we have, organisations we know about, skills and experience – our ‘real wealth’).
What do we need to do next? And what/who can help us?

What might we find useful to help with this?
We need to make sure there are readily available options for how the money can be ‘held’ (alongside any direct payment option if this is legal locally)

Whilst some people will welcome the opportunity to take responsibility for having direct access to and control of Health money, others will be keen to take control without having the money paid directly to them. For some this will be a choice (those in the DH Personal Health Budget pilot sites). For many, it will remain the only option. In Control has consistently highlighted that it is entirely possible to have control of money without it having to be paid directly. Experience to date has already made clear that we need to consider carefully how ‘third-party’ options of holding the money can be made available, and how the shift of power and decision-making can remain valid.

When we come to do this work, what skills, knowledge and experience can we draw on personally, locally, regionally and nationally to help us work out how we will put in place options for how money can be ‘held’ and control remain with the individual? (Things we’ve done already, relationships we’ve built, contacts we have, organisations we know about, skills and experience – our ‘real wealth’).
What do we need to do next? And what/who can help us?

What might we find useful to help with this?
Support planning

Individuals and families are likely to need tools and other resources to draw on with which to create their support plan. Experience has shown that many people are incredibly creative and can write their own plans. However, everyone will need good information and a framework with which to make the plan – including what are the essential elements for a plan to be authorised.

Many people will find it helpful to talk with others who’ve gone through the same or a similar process, and to be given ideas about what other people have done with their money. (How can people choose blue if they have only ever known red and green?) Timescales need to be given careful consideration, especially for someone unused to having their opinion sought or heeded. People need time to begin to believe in the possibility of a better life (or even a better death) before establishing the outcomes that matter most to them and discussing how these interact with best professional health advice. The varying needs of our diverse population must be considered if we are to offer fair access to choices about planning, so that everyone who is invited to take control is enabled to take up that choice if they wish to, and is not excluded through lack of, or inappropriate, support. For example, if someone has no family and lacks capacity to make their own decisions at that time, someone fitting needs to be appointed and authorised to speak on their behalf.

When we come to do this work, what skills, knowledge and experience can we draw on personally, locally, regionally and nationally to help us work out how we can ensure that the tools and resources people need with which to plan, are available and that everyone has equal access to taking control through consideration of their unique circumstances? (Things we’ve done already, relationships we’ve built, contacts we have, organisations we know about, skills and experience – our ‘real wealth’).
What do we need to do next? And what/who can help us?

What might we find useful to help with this?
Evaluation and stories

How will we know we are making a useful difference in the lives of individuals, family carers and professionals?

In Control and our first phase Staying in Control members have created some evaluation tools which we believe will provide useful baseline data and then ongoing data about the impact of Self-Direction in Health. We hope that all member sites will complete these. We can also talk with people and write up stories of people’s experiences. We can potentially film people speaking directly about their views too (where this is agreed).

What skills, knowledge and experience can we draw on personally, locally, regionally and nationally to help us work out how to make sure we evaluate and gather stories? (Things we’ve done already, relationships we’ve built, contacts we have, organisations we know about, skills and experience – our ‘real wealth’).

What do we need to do next and who can help us?

What might we find useful to help with this?
Summary

What are we going to do next?

What do we want from In Control?
In Control Partnerships

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