Personalisation in social care

***Simon Duffy**, Chief Executive of* in Control, *a charity leading the reform of the welfare system to provide citizenship for all, argues for radical reform*

This article explores how the current reforms in social care are rooted in a radically different approach to social justice and welfare to those that preceded them. The initial testing of these new ideas by local government and *in Control* have led to very positive results and the creation of new ideas like personal budgets and self-directed support. However it is unclear whether central government is ready to fully embrace these ideas and begin the process of radically reforming the welfare system to enhance citizenship for all.

In England the government has committed itself to an important reform of social care which will give people information about their social care entitlement in the form of a personal (or individual) budget which can then be used to purchase existing social care services or can be used more flexibly. These practical reforms build on the pioneering work of *in Control*, but raise significant policy questions about the future of social care.

'Social care' is the official term for any kind of non–medical support that enables people to live safely and with dignity. The UK government spends approximately £25 billion on the social care system, which is managed by local government. However, it is likely that a further £55 billion is spent on meeting the same needs by other funding streams, in particular through the benefit system, in education, in employment services and in the NHS.

Defining 'social care'

The complex pattern of funding for 'social care' is just one of the reasons why the British public barely recognise its existence as a distinct part of the welfare system.[1] A second reason is that the entitlement to social care is very weak. Although everyone is entitled to a 'Community Care Assessment' even people with very significant disabilities can find themselves ruled out of eligibility, either because they are not poor enough (the current system is heavily means–tested) or because their needs are not critical enough (perhaps because the individual's family are deemed to be 'coping').

A third explanation may be that the consumers of social care are not organised around any awareness of their common interests as consumers. The largest groups to use social care are divided between older people who acquire disabilities in later life, people with physical disabilities, people with learning disabilities and people with mental health problems. These groups tend to only be organised around those identities and they do not see themselves as part of a larger system where they would have many more allies. Furthermore, many of the leading advocacy bodies are actually major service providers and their advocacy can become distorted into campaigning for more 'services' which is actually inconsistent with the need to help people become smarter consumers of social care.

Fourth, most of the funding is spent on services that people do not want. For example approximately 50 per cent of social care funding is spent on residential care, but in a recent poll the general public stated clearly that residential care was the least popular form of support for older people.[2] Other dominant service forms such as day centres, residential respite services and even domiciliary care are often characterised by offering de –personalised supports that do not build social capital or sustain individual capacity. This probably means that many who should be eligible for support stay away from a system which has traditionally given people little control and has tended to invest money in institutional services.

Social care in context

Today social care is primarily made up of the following forms of provision:[3]

- 267,000 people live in residential care homes (the average size of a residential care home for people over 65 is 34);
- 242,000 people attend day centres;
- 98,000 people receive 'intensive home care' or domiciliary care;
- Many thousands continue to be placed in hospitals (increasingly private) or similar large–scale institutional environments.

It is striking that even the most personalised service, domiciliary care, is often provided in a cumbersome and restricted manner. More than half of all home care services to adults are provided through pre–commissioned block contracts or in house services and the Commission for Social Care Inspection noted that:

'*Most councils restrict the help they will offer to a list of prescribed activities. Care managers draw up individual care plans that tightly specify both the tasks to be undertaken and the time to be devoted to these tasks. During this study, people using services, their families and their care workers told us that it could be difficult to carry out the required tasks in the time available. They also expressed frustration with the inflexibility of this system.*'[4]

Figure 1: 'Professional gift' model

The institutional character of social care is no accident, for many of the roots of social care are not positive. The New Poor Law (1834) led to the growth of workhouses which were designed to be unattractive so that only the most desperate would enter. Later the eugenic panic of the mid–twentieth century led to a further growth in asylums and institutions which explicitly set out to segregate the 'feeble–minded' so that they would not damage the genetic inheritance of the race. However, during the 1970s there was growing recognition that older people and people with varying disabilities had both the right to freedom and support, and that institutional services actually put people at greater risk of abuse and indignity.

The subsequent battle to close institutions and move people into the community was both helped and hindered by a major policy 'accident' of the Thatcher years. In 1980 the government created an entitlement for residential called Board & Lodging, which could be claimed by residential care home owners. From 1979 to 1990 the numbers using this entitlement to enter residential care jumped from 12,000 to 199,000. This funding stream did subsidise the closure of the institutions, but it also erected a new institutional structure in its place. Thus, the very existence of residential care as the dominant form of service provision in the UK is primarily a function of central government's policy –making.[5] Most people using this system had no choice over where they lived, with whom they lived or who supported them.

Pressing for reforms

However, a movement of reform does exist. In particular the Independent Living Movement, which started in the USA, has led to an increased focus on the rights of people with physical disabilities to receive support and to control that support. The Inclusion Movement fought against the segregation of people with severe learning disabilities in hospitals, and there are now many fewer people in long–stay institutions. The Recovery Movement also stressed the ability of people with mental health problems to recover and manage their mental health successfully. There have even been some attempts to build a movement around the demands of older people to dignity and security.[6]

In contrast to the prevalent forms of social care it is noticeable that, when disabled people, older people and families have tried to develop supports and services, these have been more personal and more under their own control. Pressure from these groups led to the development of the Independent Living Fund in 1988 and then to the Direct Payments Act in 1996. Both these legislative changes have allowed some disabled people to take direct control over the cash for services:[7] in 2006 there were 32,000 people using direct payments (growth in direct payment usage continues to be significant)[8] and in 2007 there were approximately 19,000 people using the Independent Living Fund.[9]

However, both these systemic improvements did not involve any more fundamental review of the institutional structure of social care. At the heart of social care is a paradigmatic assumption that the consumer of social care is a passive recipient of services and that the services are properly in the 'gift' of a professional group which is given to people on the basis of an assessment of their needs (see Figure One above).[10]

This Professional Gift Model does not take into account the fact that we should treat each individual as an individual agent, with rights and responsibilities, and who can only flourish as part of a broader community of family, friends and civil society. However, against this there is an alternative paradigm which is the Citizenship Model of Service Delivery, which distinguishes the entitlement to support from the actual delivery of support (see Figure Two below). It is this new paradigm which has inspired the most recent wave of reform.

Figure 2: Citizenship model

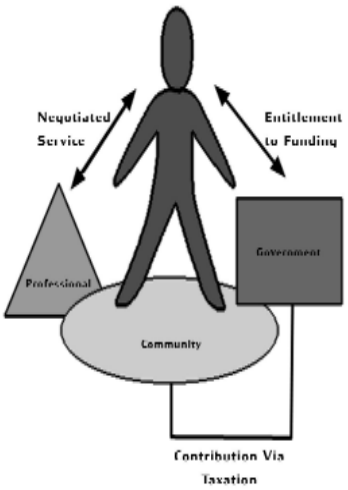

Figure 3: in *Control*'s self-directed model

Self-directed support

In 2003 *in Control* was set up as a partnership between central and local government and some independent organisations working with disabled people. They began work with a small number of local authorities who had come to believe that the current system of social care was utterly inadequate. In its place they developed a new and universal system called 'self–directed support'. The self–directed support process involved seven steps, which can be seen in Figure Three above:

- **Step 1**: Everyone is given an indicative financial allocation and they decide what level of control they wish to take over that budget.
- **Step 2**: People plan how they will use their budget to get the help that's best for them; if they need help to plan then family, friends, social workers or others can support them.
- **Step 3**: The local authority confirms the budget, checks that they are safe and makes sure that people have any appropriate representation.
- **Step 4**: People control their budget to the extent they want; they can manage the money themselves, have someone else manage it for them or have the local authority continue to commission their support.
- **Step 5**: People can use their budget flexibly: they can use statutory services, (the cost of which is taken out of the budget) or other forms of support; if they change their minds they can redirect their budget to more appropriate forms of support.
- **Step 6**: People can use their budget to achieve the outcomes that are important to them in the context of their whole life and their role and contribution within the wider community.
- **Step 7**: The authority continues to check people are okay, shares what is being learned and can change things if people are not achieving the outcomes they need to achieve.

The very early work (2003–2005) focused on 60 people with the most complex needs in six local authorities. But while the numbers and the size of the project was very modest the outcomes were striking and statistically significant:[11]

- Improved satisfaction levels for the people who use services (e.g. satisfaction with support went from 48 per cent to 100 per cent)

Table 1: Results from *in Control*'s Phase 2 Report 2008

	Improved	Same	Worse	Net Improvement
General health and wellbeing	47%	48%	5%	
Spending time with people you like	55%	42%	3%	
Quality of life	76%	23%	1%	
Taking part in community life	64%	34%	2%	
Choice and control	72%	27%	1%	
Feeling safe and secure at home	29%	70%	1%	
Personal dignity	59%	41%	0%	
Economic well-being	36%	59%	5%	

- Improved efficiency (e.g. the lowest reduction in cost was 12 per cent)
- Increasing use of community and personalised support (e.g. use of residential care reduced by 100 per cent)

In 2006 *in Control* extended its membership and started to work with any interested local authority in England. 122 local authorities joined *in Control*'s programme and by July 2008 7,000 people had been given a personal budget. The 2008 report demonstrated similar benefits to the earlier report. The average per capita cost of support had dropped by nine per cent while people identified major improvements across a range of domains (see Table One on the previosu page).[12]

Furthermore the government began its own intensive research of this kind of approach in 2006 in what was called the Individual Budget Pilot Programme. While the research report has yet to be published the government's growing enthusiasm for this approach was set out in the social care concordat *Putting People First* which stated an expectation that local systems would provide 'Personal budgets for everyone eligible for publicly funded adult social care support... '[13]

Conclusions

Despite all this enthusiasm, it is far too early to tell whether there is any real understanding of its policy consequences. So far the government has tried to treat these innovations as if they can be adopted within the current legislative and funding frameworks. However there will be growing tensions between this approach and existing structures. For example, a report commissioned by the government suggested that the natural results of this approach would be the termination and integration of the existing Independent Living Funds programme along with the development of a nationa resource allocation system.[14] However this report has so far not been acted upon. The primary innovation of self–directed support is that people are told their budget before they plan and before they decide how much control they will choose to take. To do this requires the development of a resource allocation system, which is a transparent set of rules that defines a fair allocation of resources for a given level of need.[15] The development of this technology opens up a new range of policy solutions, for example it would be possible:

- To create a equitable national social care entitlement, with local tuning, that was clear and portable.
- To radically reform the current eligibility and means –testing rules for social care.
- To integrate other funding streams, either directly or indirectly, and remove any unnecessary bureaucracy.
- To revisit the contract between local and central government
- To reform the current tax and benefit system combining the many diverse benefits, tax credits or allowances could be combined into one system.

Currently the government is consulting on the future funding for adult social care (children's social care being excluded because they are overseen by a different department) and further reforms to disability benefits.[16] However it is not yet clear that there is any general understanding of the real potential that self–directed support offers to this reform process or to the reform of the whole welfare system. The current Labour Government probably only has a small window of opportunity to exploit the opportunity created by these ideas before the next election. Potentially they offer any government, with a real will to reform the welfare system, the tools to radically improve both equity and efficiency. However it will still require the will to tackle the inertia, and the vested interests, inherent in the management of the current state-dominated system.

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