'Who cares?' Policy proposals for the reform of long-term care

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In recent years, there have been growing concerns about the design and funding of long-term care. Following its election in May 1997, one of the earliest acts of the New Labour government was to establish a Royal Commission on Long Term Care to investigate this issue. When the subsequent Commission reported in 1999, its diagnosis of the failings of the current approach was scathing:

> "The current system is particularly characterised by complexity and unfairness in the way it operates. It has grown up piecemeal and apparently haphazardly over the years. It contains a number of providers and funders of care, each of whom has different management or financial interests which may work against the interests of the individual client. Time and time again the letters and representations we have received from the public have expressed bewilderment with the system – how it works, what individuals should expect from it and how they can get anything worthwhile out of it. We have heard countless stories of people feeling trapped and overwhelmed by the system, and being passed from one budget to another, the consequences sometimes being catastrophic for the individuals concerned" (Royal Commission on Long Term Care,199, para. 4.1-4.2).

While the Commission's main recommendation (that personal care should be provided free of charge and funded by general taxation) was accepted in Scotland, it was rejected in England, and calls for reform have continued to grow (see Box 1 on page 2 for examples). Most recently, the government has published a "case for change", pledging to consult widely in order to produce a Green Paper on options for reform (HM Government, 2008). According to current analysis, the traditional system of care and support is both unfair and unsustainable, and requires a "radical rethink" in order to "address the challenges and meet the opportunities of the 21st century" (p.23). In particular, key issues include:

■ Greater pressure on the system (through a combination of rising numbers of older people, increased public expectations and advances in medical technology). Arising out of this, the Department of Health estimates that there could be an estimated £6 billion funding gap in 20 years' time.

■ A lack of transparency in the current system, with people unclear about their responsibilities or entitlements.

■ A widespread lack of understanding as to how the system works.

■ A lack of incentives to prepare for future care costs (since the cost of people's homes is taken into account when assessing financial contributions, those who have saved throughout their working lives and own their own homes can feel as if they are being penalised).

While the government is to be congratulated on seeking to tackle such a longstanding issue, the debate to date has been limited by three main tensions:

1. While the government's initial consultation document recognises the need for a debate about the relationship between the state, the family and the individual, these are politically difficult topics – indeed, part of the reason why we have failed to resolve these issues in the past is arguably because it is easier not to have these debates than it is to fully surface all the underlying complexities.

2. Even if some of these controversial issues could be managed in some way, there is currently very little sign of a practical framework that could help policy makers to design and implement a fairer and more sustainable system. Irrespective of how we resolve longstanding debates about long-term care, someone somewhere has to design the resulting new system - and producing something that is practical, accessible and actually works seems a tall order at the current moment in time.

3. In addition to current discussions about the funding of long-term care, other government policies are seeking to improve support for carers and to develop more person-centred adult social care. Unless we are careful, we may end up trying to deal with carers, personalisation and long-term care separately – without acknowledging that they are all part and parcel of the same underlying issues.

Box 1: Growing calls for reform

"The UK has not yet found a clear, fair and adequate system for financing the growing demand for long-term care as the population ages. In the 1990s it shied away from major reform which would have secured a sustainable and rational financing structure… The public finds the present system incomprehensible and considers its outcomes unjust" (Joseph Rowntree Foundation, 2006, pp. 1-2).

"The current systems of funding are perceived to be inequitable, confusing for the consumer, and unsustainable in the long-term" (Croucher and Rhodes, 2006, p.6).

"There is a growing consensus that the UK care system is in crisis. A crisis of funding – can we afford to get old? A crisis of fairness – who pays for our care when we do? A crisis of confidence – is the care system one that people understand and have confidence in?" (Counsel and Care, 2008, p.3).

"Many older and disabled people with physical or mental conditions are being forced to pay for their care. This is wrong. The state should provide for care needs caused by disability. We must end this injustice" (Claire Rayner, patron of the Right to Care campaign).

"There is more than a hint that government has decided how much money should be spent on care funding and has devised a pragmatic way of spending it without regard to patients' needs. This is the opposite of how older people should be looked after" (Sutherland *et al.*, 2003, para. 20).

"All types of participant – older people, carers, professionals - … said that they found the system irrational, confusing and unjust" (National research into the views of over 700 older people, carers and providers by the Caring Choices initiative, 2008, pp. 11-12).

Against this background, this policy paper seeks to respond to all three of these dilemmas, presenting a practical way forward that enables us to engage in debate about underlying complexities and link to related policies. Although none of this will be easy, it is our belief that much of the infrastructure and key concepts necessary to do this are already in place – what is needed now is a simple overarching framework in order prevent the current debate from becoming so complex that we yet again fail to successfully resolve the issue.

The future of adult social care

Under the government's (2007) *Putting People First* agenda, the current system of adult social care is being replaced with a new approach – often known as 'self-directed support'. While this consists of seven key steps (see Box 2 on page 3), the majority of debate so far has focused on the notion of a 'personal budget'. Whereas in the past, people needing support were assessed by a social worker and slotted into one of a number of pre-existing (and often very unimaginative) services, self-directed support involves being clear with the person from the outset how much money is available to spend on their needs, then allowing them much greater control over how this money is spent and over how much control they want over the money itself. Perhaps unusually, the concepts of self-directed support and of personal budgets have not been imposed from the top down, but were developed in the field by a social innovation network known as 'in Control' and have grown bottom-up (see www.in-control.org.uk). Although it is still very early days, all the available evidence (see, for example, Poll *et al.*, 2006; Hatton *et al.*, 2008) suggests that this can lead to:

- Better outcomes for individuals and families, with more imaginative and innovative support that more fully meets needs.

- Support that builds on rather than diminishes existing strengths and family/community networks.

- A more transparent sense of entitlement which enables people to plan more creatively and which increases equity (by making equal resources available for equal needs).

- A more effective use of scarce public resources which (at best) could lead to significant cost savings, but which (at worst) achieves much better outcomes for the same amount of money.

Essentially, self-directed support has the potential to transform the whole of the adult social care system by moving away from a traditional "professional gift" model (in which the state uses the money it receives from taxes to slot people into pre-paid services through the work of professional assessors and gatekeepers) to a "citizenship model" (in which the disabled person is at the centre of the process, is part of the community and organises the support they need and want). This is depicted visually in figures 1 and 2, but it is this shift in the relationship between the state and the individual that is at the heart of self-directed support. While the personal budget is important, it is the underlying emphasis on citizenship and on entitlement that is so central to the self-directed support agenda more generally.
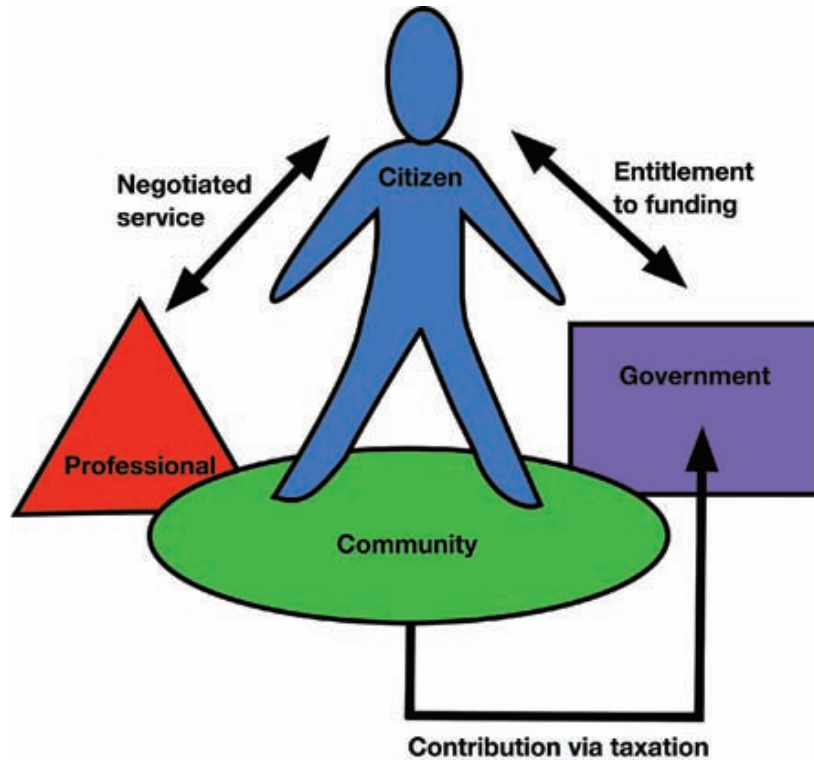
In developing this further, in Control has sought to summarise some of the key differences between traditional approaches to social care and the new system of self-directed support (see Table 1 on page 4).

Figure 1: Professional gift model of social care
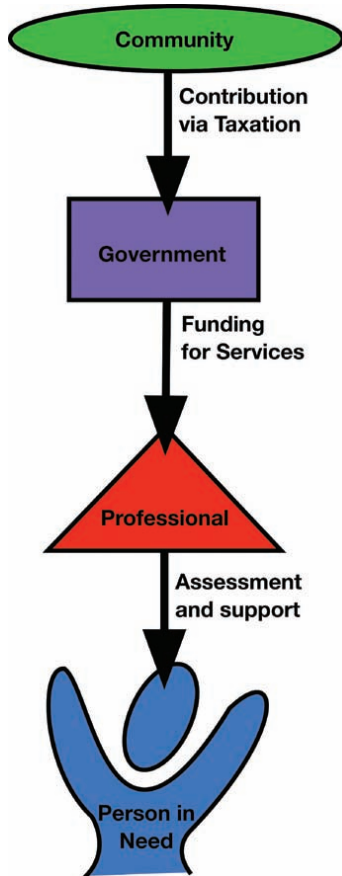
Reproduced with permission from Duffy (2005a, p 153)

Figure 2: Citizenship model

Reproduced with permission from Duffy (2005a, p 155)

Box 2: Seven steps to self-directed support

Step 1: set a personal budget - using in Control's resource allocation system (RAS), everyone is told their financial allocation - their personal budget - and they decide what level of control they wish to take over their budget.

Step 2: plan support - people plan how they will use their personal budget to get the help that is best for them; if they need help to plan, then advocates, brokers or others can support them.

Step 3: agree plan - the local authority helps people to create good support plans, checks they are safe and makes sure that people have any necessary representation.

Step 4: manage personal budget - people control their personal budget to the extent they want (there are currently six distinct degrees of control: ranging from direct payments at one extreme to local authority control at the other).

Step 5: organise support - people can use their personal budget flexibly (including for statutory services). Indeed, the only real restriction imposed is that the budget cannot be used on something illegal (as long as people are meeting their eligible needs).

Step 6: live life - people can use their personal 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: review and learn - 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.

Source: adapted from **www.in-control.org.uk**

Table 1: Social care v self-directed support

Beliefs for social care	Beliefs for self-directed support
Disabled people are vulnerable and should be taken care of by trained professionals	Every adult should be in control of their life, even if they need help with decisions
Existing services suit people well – the challenge is to assess people and decide which service suits them	Everybody needs support that is tailored to their situation to help them sustain and build their place in the community
Money is not abused if it is controlled by large organisations or statutory authorities	Money is most likely to be used well when it is controlled by the person or by people who really care about the person
Family and friends are unreliable allies for disabled people and where possible should be replaced by independent professionals	Family and friends can be the most important allies for disabled people and make a positive contribution to their lives

Source: Duffy, 2005b, p 10

What this might mean for the future of long-term care

Given that the government has now committed to ensuring that all people accessing adult social care in the future receive a personal budget, it seems to us important that any debate about the future of long-term care is compatible with the principles of self-directed support (see Box 3). Adapting the current approach being developed by in Control, one way of funding long-term care would be to:

■ Establish a national resource allocation system (with individuals falling into one of a number of different funding brackets depending on the level of their needs). This could be set annually (perhaps in the same way that social security rates are set), with scope to tailor the national figure to take account of regional variations in costs.

■ Enabling the individual to spend their personal budget flexibly. While the many advantages of personal budgets have been set out briefly above, this would also ensure that the new approach to long-term care was fully consistent with the system for funding community-based support, with no artificial distinctions between support provided in different settings. It would also build on practical resource allocation frameworks already being tested and rolled out across the country, providing a greater sense of financial transparency and greater equity. If self-direct support is the answer for community support (and government policy has concluded that it is), then why should it not also be part of the solution to the current long-term care debate?

Box 3: Seven key principles of self-directed support

■ *The right to independent living*: if someone has an impairment which means they need help to fulfill their needs as a citizen, then they should get the help they need.

■ *Right to a personal budget*: if someone needs on-going paid help as part of their life they should be able to decide how the money that pays for that help is used.

■ *Right to self-determination*: if someone needs help to make decisions, then decision-making should be made as close to the person as possible, reflecting the person's own interests and preferences.

■ *Right to accessibility*: the system of rules within which people have to work must be clear and open in order to maximize the ability of people to take control of their own support.

■ *Right to flexible funding*: when someone is using their individual budget they should be free to spend their funds in the way that makes best sense to them, without unnecessary restrictions.

■ *Accountability principle*: the person and the government both have a responsibility to each other to explain their decisions and to share what they have learnt.

■ *Capacity principle*: people, their families and communities must not be assumed to be incapable of managing their own support, learning skills and making a contribution.

see **www.in-control.org.uk**

How might this help resolve current controversies?

While self-directed support and personal budgets would provide a practical framework for a new system of long-term care, any new approach would have to be capable of responding to at least three underlying political issues:

■ The role of families

■ Charges for care

■ Equity

While the best way of resolving these issues is beyond the scope of this paper, our main argument is that a system of self-directed support could be designed in such a way as to incorporate a full response to each issue – *irrespective of the outcomes of these debates*.

Family support

One of the (often unspoken) tensions behind current debates revolves around the role that families either do or should play in supporting people with social care needs. This is controversial territory, and it is difficult to imagine why any government would want to get embroiled in detailed debates about how families ought to relate

to each other. However, with a system of self-directed support, assumptions about the role of families could be built into the resource allocation system irrespective of the nature of these assumptions. Thus, on the one hand, need could be assessed and resources allocated without any reference to the availability of family support – once people had received their personal budget, those with access to friends and families could decide whether they wanted to spend part of their budget on this form of support, on paid assistance, on directly provided services or on some combination of all three. However, the decision about what kinds of relationship people had with their families could be left entirely up to them, without the need for any state intervention in this debate. While this would be our preferred model, a government that decided the opposite – that families had a duty to support each other – could design a system in which people with access to family support received a smaller personal budget than those without. Either way, the same system of self-directed support could enable any final decision about the role of families to be embedded into the new approach to long-term care.

Charges

A second key issue is about who pays for long-term care. Again, this is often bitterly contested, and a successful resolution is likely to require significant political will and courage. Once again, however, a system of self-directed support could be constructed in such a way as to incorporate whatever compromise or solution is reached in this difficult arena. In our view, long-term care should be provided free of charge and funded by general taxation. After all, this is how our health care is provided, and distinguishing between the needs of a cancer sufferer in hospital and an older person with dementia in a care home seems to us to be both artificial and unfair. We also believe that we get the health and social care services we deserve as a society – in one sense, the predicted £6 billion shortfall in funding for long-term care does not seem very much in the overall scheme of things if we made a conscious decision as a society that this was a priority for public spending.

However, other funding options would be just as possible under a future system of self-directed support – for example,

proposals by Sir Derek Wanless (2006) to fund long-term care on a 'partnership' basis between the state and individual might work equally well. Some commentators might also argue that a greater sense of entitlement around adult social care should be matched by making some current disability benefits more conditional – although not necessarily our personal view, this could also be built in. Finally, individuals could also be persuaded or compelled to take out some form of long-term care insurance to cover their contribution to care costs. While all funding options are likely to involve some crucial trade-offs, whatever approach was ultimately felt to be most appropriate could be built into the new system. In our view, probably the only crucial requirement is that current charges start to focus on the *level* of support being provided – not on the *type of service* that has historically been used to meet this need. Thus, if someone needs support 24 hours a day, then this should attract the same charge (all other things being equal) irrespective of the setting in which the person chooses to have these needs met.

Equity

Also crucial are a series of ongoing concerns about equity. As we have already seen, self-directed support has the potential to be more equitable than traditional social care by allocating equal resources to equal needs. The early signs are also that equity can be increased by more fully tailoring support to individual need and aspirations, and focusing scarce social work skills on those most in need of support to plan. However, the long-term care debate also has other implications for equity. For example, should older people who own their homes be forced to use this capital in order to contribute to the cost of their care, or should younger people (who may already be struggling with the cost of becoming a first-time buyer and of paying off tuition fees) pay higher taxes in order to fund the needs of people with significant money invested in their properties? Equally, should people with a life-long impairment be subject to the same charging regime as people who have worked all their lives before becoming frail in older age? Whereas the latter have potentially had chance to save for future care costs, they have also paid taxes all their life and so contributed to the funding of the current system.

While these issues are likely to lead to controversial political debates, a system of self-directed support has the potential to incorporate the outcomes of such discussions into a new system. For example:

■ Any charges could be based solely on income and savings up until the point where someone has needs that fall into a funding band equivalent to 24 hour support per day. At this stage, the value of the person's property could be taken into account (if we decide that this is fair), with a charge placed on the person's estate to be paid after their death. If this felt like too sudden a transition, the cost of the home could be phased in over several funding bands to make this a smoother process.

■ Depending on what approach is taken to the role of families (see above), this could even act as an incentive for greater family support. Where a family was able to keep a person living more independently and away from 24 hour care, then the cost of the family home would not be taken into account.

■ In one sense, taking the cost of property into account might achieve a degree of equity between different groups of service user. Where someone had been unable to work or prepare for care costs due to a life-long condition, they would be unlikely to have as much money invested in their property. However, a person who had worked throughout their life and only required care in older age would have a higher chance of owning their own home and thus being charged accordingly.

To reiterate again, our preference would be for a system in which long-term care is funded free of charge via general taxation. However, the actual solution is less important (for present purposes) than the fact that a framework of self-directed support would enable whatever solution is chosen to be embedded into the new system.

Summary

Following its positive impact in adult social care more generally, self-directed support could offer a potential framework for reforming the funding of long-term care. By giving individuals in need access to a personal budget, self-directed support could equip people to choose how best to meet their own needs, irrespective of the service or setting that this may entail. As a result, access to resources would depend on the level of need, not on the type of service selected. Crucially, adopting an approach based on self-directed support would also enable us to co-ordinate policies on long-term care, carers and personalisation, providing an overarching framework capable of resolving the various tensions in current policy and practice. Irrespective of the compromises struck over the role of families, charging and equity, a system of self-directed support could be tailored accordingly. By committing now to an approach based on self-directed support, policy makers could free themselves up to focus on the more fundamental underlying political issues at stake, safe in the knowledge that a practical framework already exists to implement the resulting solutions.

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