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Paying for long-term care

CARING FOR OUR FUTURE: WHAT SERVICE USERS SAY

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This paper:

- presents the views of service users on current adult social care and their fears for the future of the service:
- discusses proposed changes, including funding, to the social care system;
- makes recommendations on the future of adult social care, based on the experiences of service users.

The Joseph Rowntree Foundation (JRF) commissioned this paper as part of its programme on paying for long-term care, which aims to influence the funding and creation of a better system for adult social care in the UK.

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Consulting service users on social care reform

There are growing concerns among disabled people and other social care service users that their voices are not being heard at a time when major reforms in social policy are taking place which are particularly impacting on them.

This report shares the results of a consultation, held in November 2011, on social care reform. The consultation was carried out by Shaping Our Lives, in association with the Centre for Citizen Participation at Brunel University, and supported by Joseph Rowntree Foundation (JRF) in line with JRF's commitment to ensuring the voices of service users are heard in national debates about policies that affect their lives. It is important not to over-claim from the views of 27 people, but they do represent a diverse range of independent adult social care service users from different areas in England. The consultation was structured around the six strands of the Coalition Government's Social Care Engagement Exercise. People were also asked to identify other issues important to them; they said:

- Funding
- Damaging effects of public spending cuts
- Hostility towards disabled people
- Fears for the future
- User involvement.

The quality of support and the workforce

Services users in this consultation valued the commitment of many workers, but generally felt the social care workforce is patchy, under pressure, and unsuited to delivering quality support. **They recommended better training, support and supervision; better terms, conditions and career progression; more support for the role of personal assistants; effective user involvement; and social work based on a social model of disability.**

Personalisation, choice and control

Service users raised concerns about personalisation and personal budgets. They felt these were being derailed by public spending cuts, poor preparation and inadequate support infrastructure. Some described a mismatch between the current social care market and person-centred support. **They recommended effective user**

involvement and more support for user-led organisations as service providers.

Prevention and early intervention

Underfunding, rationing policies, means testing and needs-testing were all seen as blocks to prevention and early intervention. Many felt this resulted in higher human and financial costs, as people were left to deteriorate. **They recommended 'that little bit of help' as a cost-effective and rights-based way to meet people's needs.**

Health, social care and wider integration

Most respondents felt the lack of integration between health and social care creates serious difficulties. Some wanted full unification, including funding. Concerns included: whether integration might result in a narrow, medical approach; whether structural reorganisation would deliver; and whether focusing on health and social care was too narrow. **They recommended seeing integration as a wider issue, including housing, education, equipment services, transport and leisure.**

Increasing the role of the private/financial sector in social care

Many respondents were strongly opposed to increasing the role of the private sector in social care, especially financial services but also care services. The private sector's profit focus was felt to be at odds with a focus on quality care. Some cited unfavourable treatment of disabled people as a bad risk for insurers. **They recommended a continuing leadership role for government and adequate funding of care.**

Reforming social care funding

Only a couple of respondents felt the Dilnot recommendations (ruling out fund through general taxation) were a pragmatic although not ideal solution. Almost all the other service users we consulted strongly rejected the Dilnot recommendations as unfair, unsustainable, flawed and ignoring service users' views. **They recommended social care should be publicly funded and accessed in the same way as the NHS, through general taxation.**

Cuts in public services, welfare reform and hostility

Everyone in the consultation reported the damaging effects of public spending cuts on themselves and other disabled people and service users, as services and support became restricted. They felt the debates about welfare reform are having a corrosive effect, stereotyping people as ‘scroungers’ or ‘a drain on society’. **This was resulting in anxiety, despair, feeling scared, insecure and vulnerable, even suicidal.**

User involvement and user-led organisations

Throughout the consultation, service users raised the issue of improving user involvement in social care. Many were worried about the effect of spending cuts in undermining user involvement and the capacity of user-led organisations at a time of growing need and crisis. **They recommended effective user involvement should be seen as a central part of transforming all areas of adult social care.**

Shaping Our Lives submitted a full report of the consultation to the Department of Health in November 2011.

Introduction

The Coalition Government has embarked upon a radical and far-reaching programme of welfare, health and social care reform (Davison and Rutherford, 2012). Both official and other spokespersons have described its proposals for health and social care reform as the biggest since the creation of the NHS. Yet there is an increasing sense among disabled people and other service users that their voices are being lost in this storm of change. The authors of the report, Responsible Reform (also known as the 'Spartacus Report'), a group of 'sick and disabled people', wrote

Our input and opinions have all too often been ignored when, in fact, only sick and disabled people can know exactly how disability affects them. A return to a model that takes even more control out of our hands can only ever be regressive.

This report aims to give a voice to the millions of sick and disabled people who rely on effective support to live productive lives. It aims to present a strong evidence base on which to build effective reform (Diary Of A Benefit Scrounger *et al.,* 2012).

This is also the aim of our report, which sets out the findings from a consultation with 27 disabled people and service users carried out towards the end of 2011 to feed into the government's own consultation about the future of social care.

While the service users consulted here are a relatively small number, they include people from a very wide range of circumstances and experience and living in different parts of England. It is important that their views are heard, especially since the reforms taking place are particularly affecting them and the official rhetoric emphasises the importance of listening to service users and putting the service user at the centre. This is reflected in the Coalition slogan for the NHS, 'nothing about me without me'.

The wider context: adult social care in England

Adult social care is at a time of major change and difficulty. There has long been recognition, extending to government, politicians and policy-makers, that the present system is defective, inadequate and untenable. Most recently, the Health Select Committee Enquiry Report on Social Care (February 2012) concluded that existing social care arrangements were confusing, fragmented and wasteful (House of Commons Health Committee, 2012). It stated: 'The Committee is clear that a new offer needs to be made to older people' (op. cit., 2012, pp9–10). However, the committee did not seek verbal evidence from a single service user or service user organisation.

Adult social care has long been recognised as facing major problems of inadequate funding and inadequate and sometimes inappropriate services. However, the difficulties facing it have been brought into even sharper relief by the severe cuts that are currently being made in public services under the rationale of reducing the public deficit. These have significant consequences both for specific social care provision, upon which service users are reliant, but also upon more general public services on which they tend to have greater reliance than other members of the population. At the same time, while the prospects of increasing expenditure in social care are generally seen to be greatly curtailed, the problems associated with social care have emerged with even greater force recently. These include:

- Problems in the reliability of service providers, highlighted by the collapse of the private equity company Southern Cross that provided for more than 30,000 people, and the increasing loss and insecurity of social care service provision more generally.
- High-profile cases of abuse and neglect, epitomised by the Winterbourne View hospital scandal in Bristol.
- Reports of widespread poor conditions and treatment for older people in NHS hospitals in Care Quality Commission and other reports.
- The tightening of eligibility criteria significantly reducing the number of people with support-needs able to access local authority support
- A Care Quality Commission report finding up 25 per cent of domiciliary care provision was not up to standard.
- An Equalities and Human Rights Commission report highlighting the denial of human rights of many people receiving domiciliary care.

Thus while government spokespersons frequently speak of the 'many examples of good practice' in adult social care and highlight the increasing numbers of service users now accessing personal budgets as part of the government's policy of 'transformation' to personalisation, a picture is also reported of conditions in social care that for some service users are extremely poor and hazardous.

Past and present governments have been exploring major reform for social care. The present Coalition Government plans to publish a white paper setting out proposals for reform in Spring 2012. The aim of this is to draw together proposals for change that relate to the funding, legislation and provision of social care. These will build on the findings and recommendations of the Dilnot Commission on the funding of social care (Department of Health, 2011a); the Law Commission proposals for law reform (Law Commission, 2011) and policy developments for the ‘personalisation’ of social care, with increasing reliance on personal budgets – see for example Putting People First (HM Government, 2007) and more recently in Thinking Local, Acting Personal (PPI Consortium, 2011).

Although each of these developments has been accompanied by its own round of public consultation, the government also decided to undertake an additional consultation in preparing the white paper. It has called this Caring For Our Future: Shared ambitions for care and support (Department of Health, 2011). Given the scale of changes taking place, it is especially important to ensure that the direct voices of a wide range service users can be heard – and disappointing that more has not been done by the Department of Health, the Health Select Committee or others to seek directly the views of social care service users and user-led organisations.

Current concern has been with establishing a system of adult social care that is both sustainable in the long term and will achieve some significant consensus of support. This sits uncomfortably with economic and other pressures that are currently reducing resources for social care and related public services. Given that the political concern is to set in train legislation for social care which is intended to have a substantial shelf life, the present government consultation has to be seen as having a long-term rather than short-term purpose and the feedback that it receives as being of value and relevance in shaping longer term solutions for adult social care.

This report’s first purpose was to feed into the ‘Caring for our Future’ consultation, offering the viewpoints of a range of service users, and seeking to inform longer-term solutions for adult social care. The aim has not only been to make it possible to provide independent evidence from as diverse a group of service users as possible, but also to include the perspectives of service users who are networked and in touch with others and therefore able to speak not only from their own experience, but also with familiarity of the broader picture as it is being experienced by many more. It also adds to the significant body of evidence about service users’ views about social care recently provided by the four-year Standards We Expect project supported by the Joseph Rowntree Foundation (Beresford *et al*., 2011).

Brief note on the 2011 government consultation on 'Caring for the Future'

The government describes the consultation as:

'an engagement with people who use care and support services, carers, local councils, care providers, and the voluntary sector about the priorities for improving care and support. [It] is an opportunity to bring together the Law Commission and the Commission on Funding of Care and Support with the Government's Vision for Adult Social Care, and to discuss with stakeholders what the priorities for reform should be. This could include help getting out of the bed, cooking meals or getting out of the house – the day-to-day activities many of us take for granted but that some people find more difficult. It might include emotional support at times of difficulty or stress. This help is what we call care and support. Care and support is something that affects us all.' (Department of Health 2011b, p2)

The consultation identified six areas for which it particularly wanted feedback. These were:

- **Quality**: how could we improve the quality of care and how could we develop the future workforce to do this?

- **Personalisation**: how could we give people more choice and control over the care and support they use, and help them to make informed decisions? Shaping local care services: how could we ensure there is a wide range of organisations that provide innovative and responsive care services and that respond to people's needs and choices?

- **Prevention**: how could we support more effective prevention and early intervention to keep people independent and in good health for as long as possible?

- **Integration**: how could we build better connections locally between the NHS and other care services?

- The **role of the financial services**: what role could the financial services sector play in supporting care users, carers and their families?

- **Making changes to the funding system** for care and support, as discussed in the Commission on Funding of Care and Support's report, would impact on all aspects of the care and support system.

So we also want to consider the implications of the Commission's recommendations as part of these discussions.

Six 'key leaders from the care and support community' were selected to help lead discussion over these six key areas. One came from a carers' organisation. There was a representative from the private insurance industry, and from the Association of Directors of Adult Social Services. There was not one service user or representative of a service user-led organisation. This, despite the government's frequent mention of 'user-led services', 'choice and control' and 'co-production' with service users.

Similarly a 'reference group' was also established for each 'workstream' to reflect the broad set of interests in social care reform (http://caringforourfuture.dh.gov.uk/2011/10/04/reference-group-members/#div). Yet of 44 people listed as making up these reference groups, only one was identified as a service user.

Consultation by Shaping Our Lives

The consultation reported here was carried out by Shaping Our Lives in association with the Centre for Citizen Participation at Brunel University and supported by the Joseph Rowntree Foundation.

This report draws upon a small-scale national survey of social care service users in England, supported by the Joseph Rowntree Foundation. The survey was based on the six areas of inquiry set out in the Department of Health consultation to maximise its helpfulness. It also addressed other issues that service users and their organisations repeatedly highlight, for example, benefits and welfare reform. This survey also built on an earlier consultation which was also carried out with support from the Joseph Rowntree Foundation that focused particularly on what service users had to say about the future funding of social care (Beresford, 2010). There was some significant overlap of participants between the two studies. On this occasion, however, constraints set by the timescale of the government's consultation and increasing concerns among service users about retaining anonymity has meant that the studies have been carried out in different ways. The first one brought together some service users for a group discussion and interviewed others. In this case all participants have been interviewed individually, some through telephone, but most through electronic interviews.

The service users included in this consultation were diverse in terms both of the nature of their service use and conditions/impairments and according to equality issues (see Appendix 1). Many were also strongly networked with other service users and locally involved in policy and practice issues.

Quality of support and the workforce

The first question that the Department of Health asked in its consultation concerned quality. It asked, ‘How could we improve the quality of care and how could we develop the future workforce to do this?’ In our consultation, we did not ask a specific question about improving the quality of care and support, although service users taking part had many comments to make about this. We focused on the workforce, asking people if they thought the present workforce was suitable for ensuring good quality support, and if not what changes were needed in it to improve the quality of support service users receive.

Most service users who participated in the consultation felt that the workforce was not suitable to provide good quality support. Two thought it was, one ‘guardedly’ and another said that they didn’t know. Some participants presented a mixed picture, anxious to give credit to the efforts and commitment of some workers often under difficult circumstances:

I think in fairness this is a mixed picture. Better training and management of staff would certainly help, as well as raising the status and rewards of social care staff, particularly home care and residential staff who tend to be a very neglected, over-worked and under-valued group of workers who do an incredibly important job.

It can be good in certain circumstances, for example, where people have control through a direct payment.

Where care support is provided through direct payment or individual budget, under the control of the benefiting person, with choice of action paramount, experience is generally positive. The major flaw in this mode is the low monetary rates allowed to purchase appropriate help.

However some service users who took part interpreted this in terms of the continuing ‘patchiness’ of the workforce:

No, the workforce is definitely not suitably and adequately able to provide good quality support for service users. There is a tremendous variation from area to area around the country and there is not consistency to ensure the availability of good quality support everywhere. In this country there are pockets of exceptionally good practice and others where the services provided are appallingly bad. There needs to be more robust regulation and inspection as well as a portability which empowers the individual to *take their support package with them if they move, if not a guarantee to have the same level of service wherever they are. This would be very difficult to achieve due to the cultural and geographical differences.*

No, from personal/family experience.

There was a clear desire among respondents to highlight the efforts and commitment of workers. At the same time they emphasised the problems of the workforce's poor terms and conditions and poor or inadequate training:

No. I'm not saying they're not capable, I'm saying they're over-stretched and underfunded.

No, the current workforce is underpaid and poorly trained, especially in terms of an understanding of the social model of disability and the concept of independent living.

Whilst there are many dedicated and well trained staff delivering mental health services there are also too many exceptions to this. Too many BME [black and minority ethnic] and other minority mental health service users experience worse treatment and discrimination. In addition cuts to local authority and NHS budgets is creating negative pressure on the quality of the staff delivering care.

How can we expect good service from such a badly paid poorly supported workforce? Low rates of retention and under recruitment show this. It abuses workers.

I needed a personal assistant and advertised through my local care provider. They sent me a list of 'suitable' people to interview. One of the candidates was a young lady… who I had known when in hospital and knew how potentially disturbed and violent she could be. The care providers who recommended her had no idea of her background and her care manager was pushing her to get work. She was not a suitable person to be working with vulnerable, disabled people in my opinion.

Agency staff are expensive even though they are poorly paid by their employer. Often they are poorly motivated displaying the outdated health model of care in 'knowing what's good for you'. This attitudinal bias, at odds with the social model of care, results in a loss of control by the client; sadly it remains commonplace.

Some service users connected the limitations of the workforce directly with broader policy:

How many inquiries, scandals etc., do we need before people get the message about how vulnerable people are not being cared for because of the attitude being fostered by government that vulnerable people are a burden to society?

Anyone can be a care/support worker, no training required.

Relatively low pay, few career prospects and lack of status, and high turnover all have a negative influence on maintaining a high-quality workforce.

Whilst many workers do provide an excellent service to their users, particularly workers who are employed through direct payments, there is evidence that some workers find it hard to adapt to the more flexible personalised way of delivering support to disabled people. Emphasis from government and statutory bodies focus on regulation and training which in my experience often has little bearing on quality of support. Indeed the recent abuse scandals occurred what there was regulation and training. The incidence of abuse of direct payments users is significantly lower even though many local authorities consider PAs [personal assistants] to be unregulated and not trained.

Improving the workforce

Service users' proposals for improving the social care workforce follow logically from their concerns about its shortcomings. They saw a clear need to improve the terms, conditions and training of social care workers:

Better training, better wages, hope for future so people want to do it.

Better rates of pay, wider awareness amongst society of the value that social care workers provide in enabling Disabled and Older people to live the lives they want, more flexible and personalised training opportunities for staff that promote the empowerment of service users.

More staff and more money.

Service users involved in the consultation stressed the need for social care workers to be *valued* more:

We know that what is needed are better terms and conditions, better pay, more valuing, better and more training and supervision.

The workforce could be improved by valuing and supporting them properly. They work very hard in often unpleasant jobs, unsociable hours with huge responsibility for very low pay and little society recognition. It's regarded – falsely – as an unskilled job. All this must be remedied to improve the perception of the job and the self-worth of social care workers.

The care plans set up by social service departments are unrealistic – requiring paid carers to travel long distances which then means they are only making 15-minute calls which in turn means they provide minimal care. Social interaction is completely missing. Care workers are themselves 'blowing the whistle' on standards of care. Service users are often afraid to speak out and many people do not have family to speak up for them.

Particular importance was attached to training that supporting person-centred working and which was based on a social model of disability approach:

More training needs to be given to ensure that people, regardless of their background, receive the best care. More needs to be done to support people in the community to achieve their ambitions, rather than contain them in inappropriate, and expensive, settings.

An education process that puts the social model of care at the heart of the care service. And this education should be mandatory on all providers across all levels including the policy makers and administrators, with compulsory refresher courses at bi-yearly intervals. Service users should be engaged in developing and delivering the training scheme.

People who work in services need to understand that disabled people are the experts in their own lives. Training staff to know what's best for people is anathema to that philosophy. Training for the social care workforce should be about independent living and led by user-led organisations, not by the care industry protecting the interests of service providers.

Social care staff need to have a value base which is based on empathy, rapport and the right attitude in order to work with service users appropriately. Relationship-building is all important to the tasks which are carried out.

Service users made the case for careers to be developed in social care:

The workforce needs a proper career structure with good training, pay and prospects. Support workers/carers need comprehensive training in both practical skills needed for care and support and in an understanding the social model and independent living to underpin the practical.

There needs to be proper, nationally-available training for personal assistants, delivered at least in part by disabled people experienced in employing PAs [personal assistants] and by experienced PA's, and this training should be seen as essential training for people working in this area. This is particularly important given the roll-out of personal budgets, as many more people will, we hope, be offered the opportunity to employ their own PAs.

Participants stressed the shared interests of workers and service users – and the importance of both being taken better account of.

The most fundamental change that is required urgently is for the autonomy of both service users and caring professionals to be emphasised over the corporate profit directives that impose sanctions upon people not wanting to be conscripted into being elements of a 'reserve army of labour' – whether the role of the conscripted be that of a sick or disabled person driven into work that is beyond their competence and/or sense of vocation, or a care worker recruit facing lack of training support and remuneration.

At the heart of achieving improvement, in this as in other areas, service users saw greater user involvement:

CILs [centres for independent living] should be involved more in mandatory staff training.

Personalisation, choice and control

We did not ask service users any specific questions about personalisation, choice and control, or about personal budgets, direct payments and self-directed support. Nonetheless, they did raise these subjects in their comments and responses. As might be expected, there was a strong commitment to choice and control among the service users with whom we consulted. A significant proportion of them were in receipt of personal budgets and direct payments.

The Government has committed itself to ensuring that, by Spring 2013, every service user should have the offer of a personal budget. However, the service users consulted here raised serious concerns about the progress and direction of personalisation. Some highlighted problems which were emerging as government sought to take forward personalisation at a time of severe spending restrictions:

Local authority departments responsible for delivering social services have hastily undergone restructuring to meet the demands of loss of finance imposed by the government. Well established and understood processes by both provider and recipient have been replaced with poorly understood practices by all parties. This causes confusion, distress and needless anxiety to the vulnerable seeking help.

One older woman spelled out how she felt personalisation policy had been taken forward without sufficient care and preparation.

Personal budgets should not have been rolled out before there was adequate universal understanding and training for statutory, voluntary sector and disability organisations' understanding and when the marketplace was not fit for purpose.

Proper individual budgets could help integrated working between health and social care services with the person at the centre choosing their providers. However, the Resource Allocation System [RAS] limits the opportunity for people having real choice, control and independence.

Other service users who took part highlighted the difficulties there still are accessing and running direct payments. We know that while there has been a large increase in the number of service users identified as having personal budgets, the number accessing direct payments – which are most associated with increased choice and control and improved quality of life – has increased much more slowly. Direct payments were still seen as an option that was not generally readily available:

Direct payments are hard to get but being supported to buy your own care package that suits you should be the way forward.

There needs to be in-depth training provided to the workforce in self-directed support and the roll-out of personalisation, and this training should be under the leadership and control of service users and carers. There would also need to be regular monitoring and evaluation of the workforce. The status of the workforce and the important work they are doing should also be raised so that the value of the support which is being provided is appreciated, understood and funded appropriately. There needs to be a cultural change to change the mindset of many of the social care workforce. We now have a different approach with the introduction of direct payments, personal budgets, etc., where it is not a question of fitting the service user into a service box but adapting the service to the very needs of the individual who is receiving the service. This is too much of a quantum leap for many of the workforce. It needs to be drummed in from the outset. Strong messages need to be put across. The workforce is there to support, empower and liberate service users, not to intervene and restrict users. There needs to be a balanced approach about risk-taking, health and safety and safeguarding issues which do not impinge upon or violate the rights of the individual.

[What's still needed is] quick access to direct payments and peer-led advice on how to use them.

The social care market was also seen as still running far behind enabling real choice and control for service users:

Despite the rhetoric of personalisation and service directed support these services are not available to all. The market dictates its own needs and these are not always corresponding to the individual needs and wants of an individual, as the market in financially driven. It lacks the qualitative perspective of good quality, flexibility, service users satisfaction, control and choice. The markets are more interested in finance and profit than in services and individuals. I think there is a big dilemma here and the big lack of understanding.

I think that there are not enough incentives currently available to assist disabled employers to find employees [personal assistants] who are suitable to cater for specific individual needs.

Cuts in both public services and welfare benefits were also seen as having damaging effects on personalisation and its progress.

On a simple, more practical level, lots of people are getting the amount of respite care paid for them being substantially reduced. This isn't just bad for their informal carers, it is bad for the disabled people themselves, who need and deserve breaks from their everyday routine and care structures. It is getting more and more difficult to get funding for respite care.

I'd say the cuts, or the prospect of them, are stifling innovation in the public sector in terms of social care provision. Things are going backwards rather than forwards.

The changes occurring that impinge upon the process of hurrying up the target of getting 30% of services users receiving personal budgets is becoming disasterous. Direct payments, if built upon, would have produced far better outcomes. What is happening is that personal budget holders are being isolated out – it is an individual model, whereas direct payments produced a collective model. On their introduction people came together, supported each other through peer support, advocacy, and a whole range of knowlege-gathering and sharing experience. Personal budgets are producing many issues that even care managers and others do not know how to manage. This, together with the huge change in financial contributions policies, is pushing people out of the social care system, or leaving people to struggle on small amounts of personal budget money that does not enable them to meet their needs. Much of what is happening is because disabled people's organisations do not have the capacity to bring people together to discuss issues and build knowledge, etc. Only the success stories are being highlighted through media outputs.

Whilst personalisation is a welcome concept, it is now being seen as a convenient cover to justify cuts. In order for personalisation to truly work, we need a cultural shift from social services staff. With an increasingly demoralised workforce that will be difficult to achieve.

The [welfare] reforms and the processes on moving people into employment (what jobs? I say) are completely moving away from policy regarding more choice, control and Independence for disabled people and service users.

We have no money to do anything nice like a coffee in a bar. We are heading towards sordid poverty as the effects of the cuts take set.

The social care market

Moves to personalisation, self-directed support, personal budgets and direct payments have highlighted the need for development in the social care market, to ensure that the kinds of services and supports that service users themselves might want and prefer are more readily available. We did therefore ask them questions about this.

To check out developments from service users' perspectives, we asked them:

Do you feel the kind of services and supports you would like to have are readily available in the market?

At least one participant felt uncomfortable with this market-based way of thinking about support services:

[Services and support] should be made readily available as a public service… not in any 'market'. Human health is not a commercial commodity.

Only two people thought that the services they wanted were available, but even their answers were qualified:

Yes, to a limited extent.

Yes, in [the city where I live, where there is a strong and long-standing disabled people's organisation]. We seem to have a flexible diverse workforce to recruit PAs [personal assistants] from. Many community facilities are relatively accessible although poor public transport can be a barrier.

While a few others thought the services might be there, they did not feel they were readily available to them or others, either because they weren't easy to find or because they were too expensive:

Yes, the services are there, but the information and help needed to access them are not.

Maybe, if you have loads of money and an advocate who knows. but not really. it's still mainly the same old thing and what's good is *only there if you've got the cash. Things just aren't reliable. You don't know what you are getting.*

They may be in the market, but I cannot afford to pay for them - in my case, [I need] help to keep well in work.

With a handful of exceptions, people do not see the kind of support they want as forthcoming or available to them on the market at present. They did not see the market as appropriately developed:

As the market has shown little ability to understand the need, how can they be expected to provide? For example, a visually impaired person in my authority wishing to use shop-ability, where adequate provision is made for the less mobile, but little thought given to supporting people with sensory loss.

No they are not! People have to wait far to long for care packages to be provided leaving them at unacceptable risk services can often be unreliable inconsistent and of poor quality.

Not yet. I would like to see more smaller consortia of disabled people coming together to commission services. Also I would like to see more user-led initiatives to recruit and train personal assistants.

As one residential care service user said:

No. Individualised budgets/direct payments only work when the market is there such that people can buy the sort of services that they require. There are nowhere near enough supported living services etc., such that many people are left in inaccessible houses, having the minimum of care at fixed times to the home care's convenience, or being forced into poor quality or inappropriate residential care.

Some service users who participated in the consultation saw the situation getting worse rather than better, with the major cuts currently being made in social care and other public services:

Note also that the 'cuts' and privatisation agendas are distorting the functions of social care. … It is potentially disastrous for local authorities to put services for vulnerable adults out to tender on the basis of the cheapest provider gets the commission, leaving vulnerable service users even more vulnerable, their feelings in matters that directly impact their lives completely disregarded.

No – because of the cuts.

Improving services and support for the future

We also asked service users what they thought would help ensure a better and wider range of services and supports being available. Again service users made connections with broader issues. Some once again highlighted the importance of better funding for social care as key to such improvement:

However, unless more money is put into social care we are all going to end up institutionalised.

Proper and serious funding and the involvement of client groups. After all we know our needs, even the most vulnerable.

Some highlighted the importance of increased user involvement to make this possible:

Listening to service users/more user involvement.

There needs to be more involvement at the outset by service users in the early planning and design stages in order to develop a wider range and perspective of different services and support which will reflect the diversity of the different communities. This process needs to be fully inclusive and accessible to all. There needs to be a systemic approach in this and it means real involvement, co-production and planning and not consultation or preplanning before the disabled individual or service user.

There needs to be role models around training people to do the jobs in an accessible way. Get disabled people involved in training. There should be a direct link to an advocacy agent in every town so that problems don't become a crisis.

Others stressed the importance of changed attitudes and values in social care and the need for fundamental culture change:

Different attitude. Old and disabled people are seen as having less worth.

A better understanding among all providers, including private providers, of mainstream services, of the needs of disabled and older people.

There's no quick fix. I get very angry about this. There needs to be a change in mindset and priorities at the top and at every level *throughout the political system in this country. A mindset change to rights, not charity, to recognising the inherent worth of every person (not burdens/layabouts) and that what they are asking for (or what they've been trained by the system not to ask for!) is completely reasonable. I talk about 'Careland'. If you move into care or become a service user, suddenly you are expected to be happy with a different standard of living than every other citizen. Suddenly things that would be considered totally unacceptable in everyday life are considered perfectly acceptable and routine, at least by the establishments that provide the support. This must be challenged at every level.*

Avoid stereotypical assumptions. Listen more.

A few respondents articulated the view that better services would come if the private sector played a less important role:

Less influence for private sector

Essentially, clamp down on influence of private sector lobbyists, and allow service users greater access to self-advocacy skills.

And some argued that a greater emphasis needed to be placed on prevention and earlier intervention to improve provision:

A change in attitude, that prevention is better than cure. I feel my physical care needs are well catered for but my mental health needs are woefully inadequate. All the services that help prevent relapse have been closed for economic reasons - a false economy, certainly in my case as my admission rate has soared since these services have been closed. There is no accounting for the social exclusion and isolation I suffer, but then there is no-one to tell about that.

Two participants identified specific services which they thought needed to be more readily available:

What is needed is a service that will manage someone's personal budget[PB]/direct payment for them, as I do for a neighbour who uses a personal budget. Such a service needs to hold their PB in a bank account, keep the timesheets and records, pay the invoices etc. This is a different service from a payroll provider, to which I also contract the payroll for my neighbour's PA [personal assistant]. A service which manages a person's personal budget/direct payment for them, as I do for my neighbour, would enable many more older people and others to experience the choice and control that direct *payments can provide, even if they can't take on managing the admin and the money.*

I'd like to see more gyms suitable for people with disabilities.

One service user felt that the state had to take a lead if the social care market was to improve:

Investment by the public authorities in a foundation layer of services that people can rely on to fall back on while sustainable markets are shaped that better reflect what people want. good quality information directories of services, including disabled people offering the skills they have gained from running their own packages, such as help with support planning. Sharing of ideas born of service users' experiences in different ways to use personal budgets.

However, the single factor that was most often mentioned as making possible better services and support was ensuring that user-led and disabled people-led organisations were in a position to take on a greater role as service providers. Such user-led services were thus seen as a key route to improved provision for the future. Unfortunately while successive governments have highlighted their commitment to a plurality of service supply, user-led initiatives – co-ops, social enterprises and small firms – have not been enabled to develop a larger role in social care service provision:

The better funding of user-controlled organisations who can come up with creative and workable solutions that are user led outcome based. We need more brokerage, advocacy and general DP [direct payments] support from ULOs [user-led organisations] in personalisation work.

Active encouragement and support for disabled people in particular to roll out services to meet the needs of service users who have personal budgets/direct payments. This would essentially be the same support services as are needed by start-up businesses but would include support to identify and meet the needs of social care service users.

By providing easier tendering services so that DP/ULOs [disabled people's/user led organisations] could bid.

Asking service users and listening to what they say. supporting their groups and organisations and other local not-for-profit ones who *might really care and be interested and aren't just interested in the money.*

To ensure that ULOs [user led organisations] etc., can improve the market they need to be supported, happening now.

How much disabled people’s and older people’s organisations need secure funding in order to …develop the market place in this new age of austerity. Many of our organisations are struggling for survival and others who have some monies need time to develop the range of knowledge and skills required in what has become an extremely complex and diverse society.

Prevention and early intervention

In its consultation, the government identified ‘prevention’ as one of the six areas on which it particularly wanted feedback. It asked:

‘How could we support more effective prevention and early intervention to keep people independent and in good health for as long as possible?’

To address this issue, we asked service users who participated in our consultation:

‘What do you think would make it possible for service users to prevent problems and difficulties get worse for people who need support?’

Service users were sensitive to the importance of prevention and early intervention in social care. For example:

To assess adequately for the support a person requires and to major on prevention. So much research has been done on preventative measures and these should be drawn upon. For example, Professor Norma Raynes 'That little bit of help'.

Offer appropriate services to people at all levels of need so that people's needs don't have to reach substantial or critical [levels]. These services should include basic help with housework and garden maintenance, as these are often the first areas of difficulty for someone whose needs are likely to increase. A bit of help early on can save resources by stopping people's circumstances from deteriorating further.

Some service users highlighted the need for better planning and resource management to make possible more preventive provision:

Proper long-term financial planning and funding. Bring back ring-fencing to stop syphoning off of promised resources.

Present reliance on means testing was seen as a key barrier to a more preventive approach which could encourage helpful early intervention in social care:

Less emphasis on means testing and putting up barriers to eligibility, more focus on what people need. Good quality, accessible information on arranging your own support.

Refusing services to somebody who only needs one service or who is only at low or moderate risk (or even substantial) will only result in their escalating up the ladder and becoming at severe risk and thus eventually needing more intensive services, to say nothing of their poor quality of life and the derogation of their human rights in the meantime.

Investment in prevention work; lower FACS [fair access to care services] criteria for social care users to have more people cared for before they become more unwell and into the hands of health services; more responsive crisis help for mental health users by social workers.

Ending narrow eligibility criteria that cut people off unless they are desperate. That is about rationing. So it is down to money again. Proper funding which means free social care.

Service users' concerns about the unhelpful effects of means testing blurred into their wider concerns about social care funding. Rationing through eligibility criteria was seen by some as at root following from the inadequacy of funding. Thus many saw the present approach to accessing and funding social care as discouraging early intervention and prevention. More than half of the service users with whom we consulted raised the need for better funding and more resources for services to achieve more preventive policy and practice, expressing this in a range of ways:

Better trained staff with more time to fulfil their duties effectively.

A lack of investment, as we are currently seeing, coupled with increased demand as we are also seeing, as people lose benefits, increasingly face unemployment and unaffordable housing.

Social care budgets need to be protected and ring fenced to ensure that adequate funds are protected. Scrutiny committees need to be robustly watching this with the co-production of service users. Local authorities all need to be signed up in protecting front line services, which support people in the community. The Government needs to ensure that these services are maintained despite the current economic crisis.

Giving care and support at an early stage before a person's situation becomes critical. If left they are going to require more services at greater expense for a longer time. False economy.

Better funding from government and providing support through DPULs [disabled people's/service user led organisations].

I am also finding that local authorities are trying to claw back any unspent direct payment in people's account leaving no scope for buying additional support if their needs increase at short notice.

But while adequate funding was seen as important, problems in the way of prevention were not seen as only financial ones. Participants highlighted the need to value both service users and workers:

The obvious answer is to resource the service sufficient for the task. But it's more than that, it is to value the service and both those delivering and receiving it, properly. In doing this the enormous contribution that can be made by peer engagement and support should not be underestimated.

Appropriate assessments which are person-centred are needed, with the proper length of time taken with people. Assessments are now very limited in the amount of time the social worker spends with the service user during assessment and review processes. People should be listened to regarding their needs and these needs should be heard at the right time. In this way the focus would more likely be on the preventative rather than crisis intervention. Advocates or supporters should be routinely offered and involved.

More user involvement was seen as crucial to achieve this. Prevention was seen as something that needed to be addressed both at individual and at broader policy level. Correspondingly, user involvement was seen as helpful to make this possible, at both an individual and an organisational level. A first step was to ensure that people were in a position to seek help at the earliest possible opportunity, before things got worse:

A better knowledge of the role of social services could help both potential service users and their family, friends and neighbours to identify where they can go with their concerns about not coping, i.e. when low-level needs become apparent.

People must be informed and helped to have an advocate working with them as a representative of the person's interests.

Listen to people who use the services. Money and services can be saved. Forwarding planning, e.g. ask people in their forties what services they would like when they reach sixty.

Authorities responsible for care services should have a well defined prevention strategy with emphasis placed on early action, again rooted in the engagement of and contribution of the user community.

Keeping up to date with service user groups and knowing what happening to the people who use the services. Talking to all stakeholders in social care.

One service user felt that ultimately it would take action by service users and their organisations if a real shift to prevention was to be achieved:

Campaign and march and raise public awareness of the situation.

Health and social care integration

The issue of ‘integration’ has assumed increasing importance in health and social care debates. The Prime Minister has increasingly stressed the need for integration between health and social care. Improved integration to save money and improve services is a theme at the heart of the 2012 Health Committee inquiry into social care (House of Commons Health Committee, 2012, p4). There is a major concern to overcome the problems and financial waste currently caused by a system where the two services frequently connect badly. This has most often been framed in terms of ‘bed-blocking’ – people having to be held in hospital beds at great expense, because support is not available in the community. But it is also highlighted in terms of inappropriate and repeated hospital admissions for want of adequate community support in times of crisis or difficulty and through people’s problems becoming exacerbating and needing health care treatment as a result of the failure of preventive care provision and approaches. Understandably, therefore, integration was one of the issues on which the government sought to gain feedback in its consultation. It asked:

‘Integration: how could we build better connections locally between the NHS and other care services?’

To address this issue, we in turn asked service users:

‘**How do you think health and social care services can work better together to meet people’s rights and needs**?’

Interestingly one service user felt it was important *not* to integrate the two services, concerned about the negative impact of the medicalised thinking of the NHS on social care:

Keep them separate! The attempt to shoe-horn social care into health-related structures brings about a poorer service. We [as disabled people] have always predicted that social care would be treated as the poorer, less important sibling to health services; and this has been borne out everywhere it has occurred – registration standards, CQC [Care Quality Commission], etc., etc. They have two different aims; whilst they do of course have to work together and communicate, I think it is vital to realise that they have two different standpoints and objectives in ‘treatment‘/support. This separation would actually enable them to work better, both individually (social care support skills are very different from medical support skills!) and together (knowing, understanding and *respecting the skills of each sector).*

This reflects broader concerns that moves to integration which reinforce the dominance of the NHS and medical models that still underpin it, over social care, could actually be counter-productive. Instead of shifting the balance to community-based and more social approaches to people's needs, they might actually undermine these, weakening social understandings of people's needs.

Some concerns were also expressed that new reorganisations might make things worse rather than better:

The current commissioning structures are being disbanded, so how will primary care work with social care when it comes to jointly providing care, to panel and back, to and fro – what a waste of time. Lets have joined up thinking for a change.

Generally the inadequacy of integration was seen as a problem:

There is too much separation between the two [services]. This makes budgeting for the service user/employer very difficult.

1. The lack of integration creates delays particularly when people are being discharged from hospital and may need additional funding over the transition period.
2. People who have continuing health care needs are often denied a personalised support package, such as direct payments, as personal health budgets are not yet implemented.

Integration, as service users saw it, emerged as something complex that might entail different kinds of change at different level. There was an emphasis on both structural and relational change. Some service users highlighted the need for organisational change to overcome problems:

Actual integrated and partnership working, and not tokenism by having teams which don't operate under the same line management, supervision, record keeping or accountability structures. They need to have CQC [Care Quality Commission] inspections on their operational methods and accountabilities to the population they serve.

There needs to be greater inter-disciplinary working alongside recognition of specialties. As an example, social care should reintegrate adults' and children's services. Social care, like the health service, should be 'from the cradle to the grave'.

However, integration was not just seen as an organisational issue. People who took part in the consultation stressed the need for improved collaboration:

They could stop passing the buck and start actually working together. For example, I have physical and mental health issues and the two sides fought like cat and dog over who should fund services that both agreed I needed to manage at home, but neither wanted to pay for. I was left feeling like an utter [parasite] for needing any help at all.

It's simple. Communicate well and act honestly in the true spirit of an integrated service. The rhetoric is fine, the action not so. Talk to one another with an open mind, not influenced by an agenda where one party assumes superiority.

Better training was seen as a route to achieve this:

Staff need to be trained to assess both health and social care needs and to understand that usually, the disabled/ill person is the expert.

Another was ensuring that there were key people with a responsibility to bring about integration/better joint working:

…by having a focal person in each area that can communicate with the teams on both sides. Those people must have power.

Service users also talked of the importance of improved understanding and cultural change to achieve this:

…of each other and of the health and social needs of service users.

ALL health care staff should have a working understanding of social care services – it is depressing that GPs, for example, appear to know next to nothing about direct payments, personal budgets etc., even though these services are essential for their disabled and older patients.

There also needs to be a huge cultural shift particularly by health to sign up to human rights approach to people's services and needs.

More and improved user involvement was also identified as a route to improved integration and coordination between health and social care:

…by ensuring that the service user is at the centre of commissioning and delivering care.

To look at management structures and involve service user and carers at the beginning of planning changes. Acknowledge the expertise each person can bring to the table.

Listen to us, act on our recommendations. Don’t consult and then ignore us.

For some service users integration between health and social care would best be achieved through their unification. Significantly, about a quarter of participants mentioned unifying the *funding* system of health and social care (from general taxation) in order to achieve effective integration:

I think health and social care services need to be integrated so that ideally a seamless service can be provided in a multi-disciplinary agency manner this would provide a much more holistic service that hopefully would prevent gaps in service provision that often can happen currently. I think a more focused approach help better promote the interests of users and carers.

I think that there have been so many years of failed attempts to integrate health and social care services that it is time to conclude that the only solution may be to just have one organisation responsible for people's health and social care support in the community. One improvement would be to make both sets of services free at the point of delivery.

Community care could have one budget, then it would not be a fight between two services for scant resources. It was my impression that they were to have merged with shared care, but my experience is very different. Having targets certainly made the physical care team pull out the stops as they did not want to lose their star ratings.

They need to be linked at every level, from bottom-up and top-down. Better support for multi-disciplinary working, but most of all they need to be funded and organised on the same basis.

Wider integration of policy and services

While the Government’s consultation focused on integration specifically in relation to health and social care, we did not confine our attention to these two services in our consultation. We also asked services users about other services which they felt might need to be linked more closely with social care services and support. This followed from recognition of the long-term concern of the disabled people’s movement to ensure equal access for disabled people across all policies, services and institutions in society as part of its independent living philosophy.

One service user highlighted the need for better integration even *within* the health service:

Mental health and physical health need to work together. Lots of people with physical [impairments] have mental health problems, but the two services are so far apart, never the twain shall meet. Going into psychiatric hospital causes severe damage to my physical health that leaves me more or less immobile and needing more support when I come out, yet the two services will not even speak, let alone work, with each other.

Some participants identified specific services that they felt needed to be much better linked to meet the needs of service users. This included a wide range:

Especially important is housing and that is getting really bad.

Transport also needs to be part of the equation in terms of ensuring accessible transport systems to enable disabled people move around appropriately.

The voluntary sector.

Wheelchair service and ‘access to work’ [services for disabled people].

Gyms, exercise classes and social groups.

The benefits office needs to be linked into social care services and education.

Housing and lifelong access to education. Social services should also work more closely with job centres.

I think housing support nursing medical services and appropriate voluntary sector support need to be networking together to comprehensively meet peoples needs.

Advice and information agencies.

Arts, entertainments, transport, volunteer, access courses to present a full range of possibilities for a person to feel nourished with a potential for growth and extension of friendship groups

Such responses highlight that for service users, integration is a much broader issue than improving health and social care coordination and is really concerned with the need to develop an holistic approach to meeting their rights and needs. Some service users talked about particular groupings of services whose coordination needed to be improved. For example:

1. Housing – disabled people often live in inaccessible or inappropriate housing which can significantly affect their support needs. Poor housing can also make working conditions difficult for support workers/personal assistants leading to problems with retaining staff;
2. Equipment services – disabled people often experience long delays in accessing even very basic pieces of equipment which could help themselves or the people supporting them.
3. Transport – accessible public transport is a particular barrier outside the bigger cities.

[Especially] employment, housing and equipment.

For other respondents, the issue was ultimately about ensuring that all services were integrated effectively.

Other local authority services which provide a service to the community.

Everything that people without disabilities have access to, we need access to these things too.

All agencies should have an overall remit to deliver a healthy society where people are supported to achieve their potential for the good of themselves and the wider community. Specifically public health powers, soon to be returned to local authorities, should be used to build resilience and give people the tools they need to take more responsibility for their well-being.

Housing, employment support such as Access to Work, benefits provider (DWP) [Department for Work And Pensions], financial and benefits advice services, leisure and adult education services and, importantly for disabled parents, schools, nurseries, out of school provision, education welfare services, children and families *services. However, DLA/PIP [Disability Living Allowance/Personal Independence Payment] should NEVER form part of social care provision, as these benefits represent the most personalised support available, giving disabled people maximum choice in how to spend the money to meet their needs.*

Service users tend to see things in terms of their overall lives, which do not fit into separate administrative categories or different organisational structures. This has historically been reflected in the thinking of disabled people's and service users' movements, which have long challenged traditional bureaucratic divides:

Placing services in different compartments is arbitrary and diminishes the impact of essential services that may play an even greater part in a person's quality of life than health and social care. Health and Social Care is too narrow a field; well-being should be king. All environmental and wellbeing services such as housing, transport, education, training and the quality of 'open space' beyond the home have a major impact on the persons quality of life; as does employment opportunity. They need to be more closely linked to the delivery of an integrated health and social care support service. Equally agencies addressing issues of poverty and disability awareness must be more closely integrated in the support services. The relevance of these services was embraced in the 2006 Disability Equality Duty which required public service providers to undertake an impact assessment of all new services prior to delivery. In my authority this proved of little value and the multi-disciplinary board which included service user members has not met in the last 18 months. Clearly another tick box lip-service initiative!

Where do you stop? To be holistic, I would take the Southampton 12 basic rights for disabled people: access to the environment, transport, education, housing, personal assistance, education and training, income, employment, accessible information, advocacy, counselling and health care provision. Too often social care is seen as the nuts and bolts of physical provision – getting up, going to the toilet, going to bed, the occasional wash, meals on wheels and if you're lucky a trip to special day centres. For it to work properly though, as legally required (Chronically Sick and Disabled Persons Act) and to actually provide a decent quality of life, all of these things need to interact. So the local housing department, the council access departments, colleges/schools/adult education, the DWP [Department for Work and Pensions] /Council benefits departments, Government policy-makers /JobCentre Plus/the EHRC [Equalities and Human Rights Commission], libraries/web service providers, *health providers, Uncle Tom Cobley and all, need to work together to enable this to happen in any meaningful way.*

An increased role for the financial/private sector in social care?

The Dilnot Commission report on funding of social care saw an increased role for the private sector. This was particularly for financial services, including the insurance industry, if social care was to secure the additional funding which there has been general agreement it needs. When we asked service users their views about increasing the involvement of the private sector in social care, only a few shared Dilnot's view that it could be helpful:

For-profit is not all bad, as long as it is transparent and profits go back to services after paying decent wages and delivering good customer service.

I'm in favour of it – if a non-profit making set-up contributes to services that wouldn't otherwise be available because of a lack of public funds.

Increased involvement by the private sector was greeted generally with suspicion and concern by service users:

Will it be a benefit to service users or is it just money saving by government?

Service users who participated mostly saw such a role for the private sector as negative, creating problems rather than solving them and ill-designed to meet their needs. Generally the making of profit was not seen as either consistent with or encouraging good services and support:

The private sector has ONE priority – profit and is accountable to one master – its shareholder.

The driving force must be excellence of care not excellence of profit

They make a profit and therefore at a time when there is little money in the system and little money in people's pockets, I don't see why money should be leached out into the pockets of profit making privateers, often trying to cut corners on services so they can make a bigger rake off. It just feels unethical, and poor use of limited public money.

Dreadful idea – the sharks are already gathering to take on the bits that make a profit – those that don't will be dropped.

It will be a moral disaster, but the government will do it anyway.

Service users' overall attitudes to the involvement of the private sector in social care seemed to be influenced by their existing experience of its involvement in service provision. Generally this was seen as unhelpful:

I am opposed to this because the tenders that were the cheapest would win and this could result in very bad care. Also how would we monitor best practice?

Opposed. General taxation should pay for care provided by the state, voluntary sector and social enterprise groups.

We only have to see what happened to the Southern Cross residential homes to see the warning signs of this, when people's lives and quality of care are being speculated in the financial markets. We also saw the shocking Panorama programme exposing the horrific violence, abuse and violation of disabled people's rights. What happened at the Castlebeck home, Winterbourne View, is a blatant reminder how social care can go drastically wrong. It has also been brought to our attention regularly over the last five to ten years about some of the bad practices which are implemented in particular by certain domiciliary care agencies, many of whom are private, in terms of the bad quality of care and the abuse that has happened.

Some service users who took part in the consultation highlighted the need for a very cautious approach. They felt the private sector would need to learn to provide more appropriate provision:

There is already a move to more private sector groups providing services. We have a duty to educate these groups about the principals of independent living and the social model of disability

Given past experience controls on it would need to be increased. If the private sector is involved, it needs to be tightly regulated and able to demonstrate that it can deliver RELIABILITY and value for money. With regards to insurance provided by the private sector, regulation is extremely important as the problem with insurance is that providers are mainly concerned with avoiding having to pay out, which will be disastrous if such insurance is relied on to enable people to get the care and support they need, when they need it. The potential for a mis-selling scandal is very great.

There was much suspicion of the extension of private provision of social care insurance and little belief in its workability. This seemed to follow from specific concerns about private insurance as well as broader anxieties from experience of private sector intervention:

In terms of the private sector involvement in the funding solution, I feel unsure as to whether 'private insurance' type models will be able to be made attractive to consumers in terms of affordability, simplicity and offering a relevant product. Disabled people and other people with health conditions already experience much discrimination from the insurance sector, for example, increased premiums, being denied cover, hidden get-out clauses. They will therefore be sceptical that insurance will be the answer to their social care funding needs. Social care recipients are more likely to have lower incomes, higher expenditure related to their impairment experience, more discrimination in the workplace, and therefore are less likely to be able to afford insurance. Conversely, people who are not in receipt of social care will probably not understand its importance and will not access the insurance market voluntarily as they will not recognise the need or the consequences of not doing so.

Also, it has emerged that one of the companies most in position to benefit from such shifts in funding is Unum – a company that has been 'advising' successive UK governments on welfare reform since 1994, despite several law suits against it in other countries' courts. http://www.socialworkfuture.org/index.php/articles-and-analysis/articles/193-the-truth-behind-welfare-reforms

I think it is naïve and dangerous to assume that profit-making companies will act in the interests of service users when in fact I think it likely that people will be left without the means to fund the support that they need. Disabled people have for a long time faced discrimination by the insurance industry because they are seen as a 'bad risk' to insure without enough assurance that premiums will cover the cost of claims. I think it is reasonable to assume that, however well regulated government may think it has made the system, insurance companies will find ways not to insure on an equal basis, groups such as older people and people with higher support needs.

I think involving private companies in the funding of social care is not a good idea. Many private companies do not fully understand what social care is all about. I believe they have their own agendas and do not and will not address the needs of the individual which should be at the heart of any social care service. It is still very *difficult to get this message across even when the government supposedly promotes it in its literature and document.*

Private insurance was seen as an inferior alternative. There was instead a commitment to a public-service ethic:

A better way would be the provision of a social insurance scheme - a bit like NI [national insurance], whereby people pay into a government fund and have assurance that it will pay out if they need care in the future. To introduce this, the government would need to hugely raise awareness among the general population of how social care is currently funded and provided, explain the chances people face of needing social care services (whether publicly-funded or self-funded and whether residential or community-based) in the future and ensure that the fund is limited to the provision of social care and acts like a proper public insurance scheme.

Most service users express very strong negative views about the private sector. While this view might be seen as narrow and extreme, two key points should perhaps be borne in mind. First many of these service users had first hand experience of the operation of the private sector in social care as recipients of its services. Second, only they perhaps have as good an understanding of what it can be like to be dependent at times of vulnerability on services from poor suppliers that can have an intimate impact on people’s lives.

Making change in the funding system: the rejection of funding from general taxation

In our earlier 2009 consultation with service users about social care funding, almost everyone said that they thought social care services, like the NHS, should be free at the point of delivery and funded from general taxation. This was ruled out by the Dilnot Commission and in this consultation we asked service users what they felt about it. Almost all participants were opposed to Dilnot's decision and thought it was a negative and unhelpful one.

One person accepted the Dilnot position for pragmatic reasons, but made clear their view that government really needed to embark on a proper programme of public information about social care rather than undertaking repeated consultations if it was to get public support for the policy:

I think Dilnot ruled this out as he was realistic that unfortunately there is no political party support for this option. I would have liked to have seen an extension of the National Insurance scheme to include social care as well as health care. I feel if this was explained clearly to the electorate what this money was going to be used for, there would be an increasing amount of support for it. The general public are very naïve about how social care is currently funded and rather than issuing countless consultations all on the same subject, the government should embark on a wider awareness raising/education campaign about the challenges facing us.

Another participant reinforced this point:

The complete lack of understanding among the general public of how social care services operate and how they are funded is part of the problem, but is also a reason for the problem. Government and politicians need to do all they can to ensure that the general public understand the issues and can make an informed contribution to the debate, and voluntary sector organisations need to find a way to make the media consider these issues in news programmes, other political and current affairs programmes and the press.

While one respondent adopted a more pragmatic position, they expressed concern about the possible consequences of the Dilnot recommendations:

In an ideal world social care and health services should be free at the point of delivery. We cannot afford to do this so we must make *sure that we do not create a two tier system those that can afford to buy in and those that cannot. We must also remember those that are currently in receipt of services that do not have savings.*

Most others, however, were much more critical of Dilnot's recommendations. They weren't seen to offer a long-term sustainable solution:

…Just about short-termism.

I think this is a grand opportunity missed.

…Just because social care isn't 'sexy' doesn't mean that it should be underfunded by the state.

What were Dilnot's reasons for not suggesting [funding from general taxation] – because politicians of all parties say it cannot be afforded and therefore should not be part of his remit. They seem not to want to be persuaded otherwise – closed minds.

I think this is a dangerous precedent to set just because there happens to be an economic recession at the moment. It erodes a central principle of the welfare state, that is universal entitlement to a safety net of support when people need it. Means testing has also led to a more bureaucratic system, with people now routinely having assessments of their finances before they receive an assessment of their needs.

The recommendations were seen as inherently unfair:

I think this is unfair and the Dilnot Commission needs to rethink its recommendation. Many disabled people are taxpayers, so have already/are contributing to their care costs through taxation. Disabled people are the most vulnerable in society and are being targeted by this government as pariahs and leeches

I think it is unfair as loads of money is wasted in the NHS which could be used to fund social care. Also everyone pays for children's education until they leave further education. but not all of us have children. Even working disabled people pay for them through general taxation and this feels unfair, if they also have to pay for social care too

I think that this is a mistake. it is difficult to see how any system that doesn't connect the funding of social care and health will ultimately work. I also don't see how it will work to meet the needs of everyone who needs care and support.

Dilnot’s recommendations were felt to ignore service users and their views:

I think it demonstrates that the people who are consistently not listened to in the debate are disabled people/service users and their organisations. However, this is not surprising as we don't have much of a voice, as demonstrated by the lack of interest shown by politicians and the media in our views on welfare reform and other issues that affect us more than anyone else.

Most service users involved in the consultation did not think the Dilnot Report would offer an adequate or acceptable solution to social care’s funding problems:

This is appalling; the only moral and sustainable route is through general taxation. It is the only respectful socially responsible action in that it affords respect and dignity to all citizens. Indeed it is an obligation of civilised good governance.

A civilised society can be judged on the degree to which it cares for disabled and vulnerable people.

How should social care be funded?

A few service users accepted either the current principles underpinning social care funding or those proposed by the Dilnot Commission. Some distinctions were drawn between disabled people of working age and those becoming disabled with older age. Only one person opted for a scheme that resembled the Dilnot proposals:

In the future social care should be funded by part taxation and part private – there could be a benign means test.

Another saw the Dilnot’s proposals as the only politically viable ones:

Realistically I think the closest we will get to an acceptable outcome for disabled and older people is if Government can be persuaded to implement Dilnot's recommendations. Whilst I think social care should be funded on the same basis as healthcare, in the real world *this isn't going to happen and Dilnot offers our best hope of a reasonably fair solution, which is a great improvement on the current situation which is a postcode lottery and expects too much from those who need care and support rather than requiring everyone to contribute fairly.*

What is, of course, interesting is the very hesitant response that there seems to have been from government, and particularly the Treasury, to the Dilnot funding proposals, given their general attractiveness, the level of support they have commanded outside of service users and also the modest public funding implications they contain.

A few other service users we consulted also saw a role for some kind of state insurance scheme:

A large number of people that acquire help from social care are of working age or they have to give up work to care for someone, this results in a loss of working hours and additional costs to a company. A scheme where there is a contribution from employers and those on benefits (have a contribution similar to the reduced NI contribution).

Through general taxation for disabled people and through an insurance scheme for older people with age-related issues.

Funding for social care will realistically probably need to come from a variety of sources. Central taxation or an extension to the current National Insurance system should be a core part of the funding solution.

By general taxation for the reasons given above. It is fair because it is scaled to level of income and all one day will draw upon it. Alternatively it could be linked to National Insurance contributions. There may be scope for a national insurance scheme, specifically targeted upon providing social care but care will be needed to ensure we do not allow this to fracture into a two tier scheme where provision for the poorest results with a poor service.

Most service users, however, argued for the funding of social care through general taxation. They saw progressive general taxation as offering the fairest and most effective system of funding:

It should be funded in a fair way, that means out of a progressive system of general taxation so it is like the NHS.

From central government taxation through higher direct taxation i.e. the rich should pay more than the poor.

There is no fair and viable alternative. We have effectively been paying into our own care via NI and this is a good basis for funding care.

For many involved in the consultation, but not all, this meant that social care should be free at the point of delivery:

Free at the point of delivery.

Some parts of health care can be or has to be paid for and this could apply to social care. The basic elements, such as being clean, warm, having opportunities to shop, cook, and, where necessary have support to enjoy good nutrition, to have basic domestic tasks undertaken, etc. should be free and then some other things might be paid for privately according to assessed individual needs.

It should never be made mandatory for disabled people to hand over their care component of DLA [Disabled Living Allowance] as this was not what DLA was for.

Reform along these lines was seen as important because of the predictability that certain proportions of the population (which were generally expected to grow) would need social care support:

The Marmot report [on health inequalities] tells us that everyone faces a period of disablement where we will require social care, the length depending upon the wealth of the individual. The final 20 years for the poorest and the last ten years for the richest. So we have the disabled and the yet to be disabled.

And yet we remain in the umpteenth consultation period. Where is the political leadership so strongly required to tackle this need to provide a fair level of social care to vulnerable people? In my view social care and health care are inextricably linked; the so-called divisions are arbitrary and do not stand up to scrutiny. How can you be well when you are treated badly?

Service users did not assume that such funding reform could take place without a more general and radical review both of how people's support needs were met and how money was spent. There was recognition of the need for such reform if progressive funding arrangements were to work well:

Through general taxation but with more intelligent and flexible allocation of funds from different areas of public expenditure. for example, rather than local authorities having to find all of the money for peoples care and support, where social care is clearly saving money for the NHS, that money should be transferred across from NHS to local government to pay for better preventative services in the future. Also, disabled people's lives should be looked at holistically and funded in a streamlined way, with different funding streams from public services covering employment, housing and equipment coming together as one payment to the service user, as in the Right to Control trailblazer.

Not everyone assumed that moving to a system of funding through general taxation would necessarily be very costly or off-putting to taxpayers as has constantly been stated:

This would not necessarily be huge costs to individual taxpayers in their salaries.

Participants also had suggestions to make about how the effective funding of social care could be paid for – by progressive redistribution:

Additional funds should be raised through increased inheritance tax on large estates and a 'mansion tax' on properties above a certain value – this has the advantage of making it much harder for the wealthy to avoid tax.

Over £123 billion is lost in tax evasion and avoidance every year. If this money was collected it could be well utilised for this purpose and also funding could come from a Robin Hood tax on market trading transactions.

By the state from taxation proportionately equal from those with personal and corporate wealth.

Cuts in public services

When the Coalition Government originally announced the need to make cuts in public expenditure in order to reduce the public deficit, it emphasised that it would seek to protect ‘the vulnerable’ from any effects such cuts might have. Disabled people and people with long-term conditions have generally been recognised as among those the government was talking about as ‘vulnerable’. We asked service users if they thought current cuts in public services were having any effect on disabled people and social care service users. All the people we surveyed thought that they did. In every case they thought the current cuts were having seriously damaging and destructive effects on service users. Indeed some service users thought that disabled people were being made a particular target of cuts:

Unfortunately, I think disabled people and social service users have been targeted disproportionately in terms of the amounts of cuts being made on services which affect them as well as benefit reduction. I am seeing it on a daily basis or hearing stories of disabled people at the moment currently terrified of what is happening and big fears of what might happen in the future. People are losing benefits and losing services without any consideration of the long-term impact on the lives. It is obvious this will affect their quality-of-life in the future which means it will be getting worse than at the same time they will become more impoverished.

Service users we spoke with highlighted the day-to-day effects current cuts were having on them and people like them:

Reduces being able to go out independently more housebound.

Services are being cut as a result of privatisation.

Eligibility criteria are becoming harsher.

Seeking help for my wife who is coping with Parkinson’s and dementia has been and remains fraught with stress. Securing helpful service is difficult. When challenged, the common refrain is the need to acknowledge the cuts in expenditure faced by the service provider.

Yes, they are having an extremely detrimental effect on this group in particular. the availability and quality of care packages are being reduced; discretionary Freedom Passes, day centres, lunch clubs *and other council provided facilities are disappearing; and many are being effected by multiple and cumulative cuts.*

The closure of the ILF [independent living fund] is a significant setback to disabled people with high support needs. This puts in jeopardy many people, including those with learning difficulties who are finally being liberated from institutional care.

They also talked about what they saw as the far-reaching and broader effects that the cuts were having:

The cuts proposed are going to decimate the structure as we know it if the government gets its way. The political class need to make sure they meet and speak to disabled people every week to find out what's going on

I think there are highly negative effects, as people are having to make difficult decisions about aspects of their everyday lives, such as food and heating, as well as employing people to support them to carry out tasks for them such as shopping.

The monitoring of disabled people and service users being mounted under the guise of supporting them back to work has had the impact of labelling them as benefit scroungers, giving Society 'permission' to stigmatise and discriminate more against disabled people and service users.

They seem to want to punish us.

Insecurity for the future, there's no transparency or clarity of what's happening.

There were numerous references to the stigmatising effects the cuts were seen as having:

Disabled people are being portrayed, in the media, as a drain on society's limited resources rather than as a valuable contribution to the richness of society.

Disabled people are being made to feel responsible for the public deficit and that if we could be got rid of, society's problems would disappear. I have heard that many people have committed suicide because their benefits and care packages have been withdrawn. I don't know what will happen to me if my care package is withdrawn as I am totally dependant on it for survival and my quality of life is not so great.

Many participants felt that disabled people and service users were being driven into despair and suicidal thoughts:

Disabled people are feeling suicidal because of the new tests for ESA [employment and support allowance] and DLA [disability living allowance]. When an ATOS employee [reviewing people on disability and incapacity benefits] asks, 'How long have you had Cerebral Palsy', I can see why.

People are very scared. People have said they will commit suicide. People are having their community services cut back and lost completely. I've seen people made more ill due to the stress of public service cuts.

The cuts are having an horrendous effect on people in terms of their emotional mental and physical health and in some cases are leading people to become so depressed they are taking their own lives Apart from cuts in services and benefits the stress of under going WCA [work capability] assessments are also very damaging.

People are frightened and don't feel they can face the future.

Social care and welfare reform

When we raised the issue of service integration with service users, some referred to the benefits system. They did not think social care could be considered in isolation from benefits and welfare reform. The government consultation did not address the benefits system or welfare reform. However, we knew from service users and their organisations that these have been a major concern to them. At a recent seminar, Richard Humphries, Senior Fellow of The King’s Fund commented that ‘welfare reform changes have potentially profound impact on social care’ (Humphries, 2012). Therefore we asked service users about these in our consultation. First, we asked them if they thought social care reform could be undertaken without taking account of welfare benefit reform. As one person said:

those most affected by social care reform are going to be in receipt of welfare benefits.

This reflected an almost unanimous view [apart from two participants who said they were not sure] that social care, social care reform and welfare benefits reform could not be undertaken in isolation from each other. They were inseparable in people’s lives:

They are inextricably linked. Except the social care reform should provide the benchmark, the specification of minimum standards to which benefit reform relates. We have the opposite and unfair scenario operating at present where benefit reform is King!

You have got to have them both going in the same direction. You can't go on about supporting service users and then attack them through the benefits agency.

Social care needs to become more a part of the welfare state in the sense that people should be entitled to support rather than being subject to discretionary decision-making that lacks transparency.

The two are inextricably linked when so many disabled people are unemployed and on benefits. This is a sad situation and an indictment on the negative consequences of the structures of society which prevent disabled people from working. It is not a question of disabled people being scroungers and not wanting to work, which the media and press have portrayed so badly over the last year and have done an injustice to the reality of the situation for disabled people. It is not uncommon now for the general public to believe these false stereotypes.

To give a simple (though hugely important) example, the government is talking about stopping mobility allowance for people in residential care on the basis that social care services should be meeting residents' mobility needs. This frankly isn't happening, as proven by the Low review. This idea of 'double funding' is frankly ridiculous and is a concept invented by the Government. It does not happen in practice.

While some service users who took part in the consultation felt it was not necessarily clear what the effects of welfare reform would be, they thought this in itself was making things worse:

[It's] hard to establish the effects as it is still early days and some of the reforms are not yet in place. However, the uncertainty and the government rhetoric on the subject is unhelpful and leading to increased stress and anxiety. The media portrayal is also not helping.

The benefit changes were seen as cuts, not reforms:

So far [benefits] reform = savage cuts.

Particular concerns about the need to consider both areas of reform together were raised in relation to mental health service users:

Welfare benefit reform is having a significant impact on many people with mental health issues who are at risk of losing meagre incomes and social housing. It is important that social care reform is informed by this.

Terrible. I think especially for mental health service users, people living in fear, terror and dread. It will mean more attacks and violence, more hatred, hate crime. People either thinking about or actually killing themselves. It's already happening. It is wicked.

We asked people what effects they thought welfare benefit reforms were having on disabled people and other service users. All the service users we consulted thought that the effects were serious and negative. The words 'fear and despair' frequently cropped up:

Poverty, stress and despair.

What I am hearing is that disabled people are living in fear whether their benefits have been changed or cut or left the same. People feel there is little they can do and so it leaves them in a position of continual worry.

People are worried that they will have their benefits reduced and they will experience extreme hardship. The media is more than ever promoting the long-term sick as scroungers.

They have unleashed a ticking bomb with regard to disabled people being able to play an equal role in society.

It's taking us back to Victorian systems of the 'worthy or unworthy' poor and disabled… We the vulnerable and disabled take the brunt of these savage cuts.

Disabled people were being made to feel badly about themselves:

Disabled people are already being 'checked' and re-assessed for benefits they had previously been told they were entitled to for life, to the point that people are worried to the point of considering suicide.

The already inadequate benefit system is now being pulled away from under our feet, de-stabilising our ability to live in and contribute to our communities.

Cuts such as removing the lowest care rate of DLA [disability living allowance], reducing the DLA budget by 20% (when they know fraud is a tiny percentage of that…) stopping all new applications for ILF [independent living fund], making people uncertain as to whether their ILF will continue (so they're concerned they will be forced to move back into residential care), the move to the new universal credit etc. etc., all leave vulnerable disabled people very uncertain as to what will happen to them in the coming years and how it will affect their quality of life. This is real, genuine, palpable fear which is having a major effect on people right now in a very real way.

The welfare reforms were also reinforcing highly negative stereotypes of service users and encouraging their exclusion:

As a result of what is being proposed we are being locked out of society. David Cameron promised he would not do anything that would harm disabled people at the general election. All his policies to date work against disabled people being active members of society. The localism agenda is his pipedream not our reality.

Apart from the impact on all members of society i.e. 'heat or eat', disabled people and service users are experiencing greater *discrimination and stigmatising under the label of benefits scroungers.*

The Work Capability Assessment which is linked to welfare benefit reforms is destructive, debilitating and demoralizing for many disabled people and services.

The reforms and the processes on moving people into employment (what jobs? I say) are completely moving away from policy regarding more Choice, Control and Independence for disabled people and service users.

Disabled people and service users are perceived as a cost only and not as benefitting our society.

Service users involved in this consultation generally adopted a similar view to that evidenced in the Spartacus/Responsible Reform report produced by disabled people. They saw current welfare reforms as based on unreliable evidence and primarily motivated by hostile attitudes towards disabled people which framed them in negative terms as dependent and scroungers. This does not deny that there may be some people who claim welfare benefits inappropriately. Research has consistently shown that the proportion is very small and much less significant than is implied in anti-claimant campaigns (Briant *et al.,* 2011). We can expect that like any other group, whether members of parliament, journalists or the rich, there may be some people in receipt of benefits whose honesty and ethics can be called into question. But this does not justify the large-scale stigmatisation of service users or their division into categories of ‘deserving’ and ‘undeserving’.

User involvement

Part of the purpose of the government’s consultation was to enable service user involvement, through getting feedback from service users. This of course was also the purpose of our independent consultation. In this, we did not ask service users any specific questions about user involvement, but it was an issue that cropped up again and again throughout their comments, in relation to all the issues that both the government and we had asked them about. It cropped up mainly because participants either felt it was not being adequately addressed, or they saw it as a solution to problems that they identified. They expressed a constant concern that service users should be listened to more and earlier. It is interesting that after 20 years of provisions for user involvement in social care, starting with the 1990 NHS and Community Care Act, there still seems to be a widely held view among service users that this is not working well enough. As one disabled woman said:

At each step decision-making must involve the client and all processes must be transparent.

The big challenge for all organisations that support service users is to find a way to persuade politicians and the media to listen to our point of view and to acknowledge the fact that any person could become disabled at any time, due to accident, illness or the ageing process. We also need to find a way of widening the debate from older people needing residential care, to ensure people understand that the issues affect disabled people of any age and that most social care services are in fact provided in a non-residential setting.

Service users who took part in our consultation saw more effective user involvement as the route to a better workforce and improved service quality:

No, I think at the moment there is not enough service user involvement in workforce regulation and decisions about what is important when training and recruiting people to support service users are made all too often by non-disabled people. Too much emphasis is placed on 'care' rather than independent living, choice and control. Too much importance is placed on safeguarding.

Respondents emphasised the importance of supporting user and disabled people-led organisations as service providers to ensure the market better fitted the new goals of self-directed support and personalisation. For example:

The adoption of a user-led and controlled social enterprise for the provision and delivery of the service would yield positive results. It would be well informed on need and how best to meet it in a way that is respectful and recognises the dignity of the person being served. It would also understand the logic of a proper reward for a responsible job.

Service users saw enhanced user involvement and the values and philosophies associated with it as key to improved integration:

There also needs to be a huge cultural shift particularly by health to sign up to human rights approach to people's services and needs. We need prescriptive social care/health legislation which incorporates this approach. Health also needs to allocate more of its resources both financial and social into the community settings.

Give a greater role to user-led and controlled organisations in developing and delivering integrated services by recognising their expertise. Indeed such action is imperative.

There needs to be a big cultural change in the way that the health authorities plan and deliver their services, and a new approach to adopt and understand patient and user involvement from design into implementation and finally delivery. In other words, the whole process. Both health and social care need to take on board an approach using co-production with service users and carers.

Improved user involvement was raised by service users in the context of prevention and early intervention:

Service users need to be at the heart of everything which affects their lives including service planning, design and delivery.

However, some service users felt that user involvement was currently being further undermined through cuts, although government says that it is committed to such involvement and co-production. Such cuts were also seen specifically as putting user led organisations at risk:

Other cuts such as cuts to funding of user-led organisations are also having effects. There is concern that the above changes are being pushed through without transparency and without genuine involvement of the people it will most affect, i.e. disabled people. By reducing funding to ULOs, this further reduces the possibility for disabled people to have a genuine say or impact upon the support services they receive.

While welfare reform and the rhetoric surrounding it was a growing problem for service users, their capacity to respond to it was felt to be increasingly restricted:

While there is a need to re-evaluate and reassess welfare benefits because of the way in which the system has become so complex, even for people delivering the service, the way in which people are receiving information is leaving them in fear and, often, to worry in isolation. Those who are getting a good service are often unwilling to share their experience because they are fearful much will be taken away at some point. So, whether life is good and enabling independent living for some, others are impoverished but neither knows how to manage these polarised situations any more because there are few strong disability organisations left to provide the pro-active support required.

Instead of user involvement, service users felt under the threat of increasing exclusion and stigmatisation:

The Government, through the media, is perpetuating this myth of many disabled people being workshy malingering layabout scroungers. The welfare benefit reforms are making this perception stronger… People in residential care are compared to helpless people in hospital; they are expected to have meaningless existences. This constant barrage of unfair and untrue negative characterisations of disabled people wears disabled people down. It perpetuates their feeling of being worthless and unable to do anything. Paradoxically, it means that people aren't given the support they need to achieve more in life, to contribute more to society, and/or that they don't have the confidence to do so. It is mean, counterproductive and has a hugely negative effect on disabled people.

Service users: some key concerns

Finally we asked service users if there were any other points they would like to make or issues they would like to raise. Most responded to this request and they largely used it as a forum to raise their broader and overall concerns. These fell into a few key categories.

Concern was again raised about social care funding:

Why are we still having this debate about how to afford social care? Beveridge bit the bullet for health care – we need another Beveridge for social care.

Service users highlighted the damaging effect of current public spending cuts. For example, causing the loss of good social care workers:

So many amazing and creative people are being thrown out of jobs who made a real difference to disabled people's lives.

There was a repeated plea for supporting real personalisation, choice and control:

I believe that care and support structures must promote the move towards personalisation and schemes such as personal budgets and the Independent Living Fund already demonstrate that high-quality care and support can be delivered in a very cost effective manner. Financial resources can then go directly to people needing care and support rather than being eaten up by maintaining buildings and facilities (e.g. day centres, institutional care). This also means that funding requirements can be easily altered and flexible to meet the ever-changing needs of the population. Any funding system must ensure national consistency, so that care and support is maintained evenly across the country and so that one area of the country is not disadvantaged financially purely because it has a particular demographic profile. Central funding of care and support needs also would assist disabled people, who currently experience major barriers.

Most common and perhaps most important, was service users' sense of coming under increasing attack. They highlighted their sense of inequality, with people who were the poorest and least powerful coming under the greatest attack:

How far is this government prepared to go to get the most vulnerable in society? Why are they not pursuing the tax evading bankers and high earners who caused this economic crisis? A society is only as strong as its weakest link. We are now a very weak society. So much for the idea of big society.

We seem to own several banks now that 'had' to be nationalised, during the banking crisis. These are now making huge profits and I don't see that money coming back into to public purse. Our spend on foreign aid is better than some European countries yet we choose to ignore poverty and illness at home it seems.

[There is now] an atmosphere of fear and depression such as I have not seen since I was a child. People are losing hope.

At the basis of all these problems is the stereotyping and characterisation of disabled people. Convenient boxes include ‘helpless and in need of pity and care’ and ‘malingering lazy scrounging layabout’. There doesn't seem to be the assumption in fact that most disabled people are genuine, surviving and achieving whatever they do against the odds stacked against them by an unforgiving and penalising society with no genuine understanding or respect for their inherent worth or their rights.

They communicated a strong sense of fear for the future:

As a disabled person for most of my life now almost entering retirement age, I am extremely concerned and fearful of the future. We just don't know where it is leading… The government has not done an equality impact assessment on the long-term effects these cuts will have on the quality of life of disabled people in the future. They need to address this situation soon.

Participants reiterated a shared sense of high-level political retreat from a civilised society:

The older generation have bought into what they believed was a caring future. This generation is under no illusions; they have seen their parents having to cope with an inadequate care service in the past with high levels of distress. Now their expectations of being properly cared for are dashed. Instead they have the prospect of a poorly funded care service. This is cheating them of their rights; indeed it is fraudulent. So we have the absurd outcome in my case where as a blind person I’m left to administer numerous daily medications to my wife (coping with Parkinson’s and dementia) five times a day without any certainty that I’m giving the right one or that *they are being taken. This on top of cooking, cleaning and toileting; indeed all health and welfare requirements for both of us. Surely this is an injustice.*

For some service users, this highlighted even more the importance of increasing user involvement and people's say:

Organisations that are set up by the grassroots should be supported as they are more credible in the community and people trust them to get things done.

It is vital that service users are given the resources they need to make more decisions for themselves. Empowering people to have a say in commissioning and delivering services is the best way to improve services, make them more efficient and give people confidence.

Users and carers should be central to all decisions and plans regards service reform and development 'No decision about me without me'. Users, carers and health and social care workers need to stand together to support their need for comprehensive caring compassionate services that respect people and promote dignity. Sadly the present government is doing the exact opposite to this and dragging us back to the dark ages, we need to fight this oppression and injustice with all that we have in a united front the consequences of not doing this are to horrible for words.

The powers that be must work closer with user-led organisations. At national level they must look at bringing in new faces and ideas

A key route identified for service users to break the impasse now seen as facing social care was to improve public attitudes and understanding:

The most important challenge for organisations supporting disabled people is to turn the tide of public opinion, so that the increasing disadvantage faced by disabled people is recognised for the national scandal that it truly is. Until that happens, the government appears free to do as much damage as it likes as it is not being held to account by either the public or the media.

Conclusion

In this consultation report, we have mainly tried to enable service users to speak for themselves, rather than drawing our own conclusions. However, what does seem to emerge is a worrying and increasing disconnect between what service users (and often carers) say and related evidence, and the thinking of government and policy-makers and what they seem to be doing. This is powerfully illustrated in the present consultation by the massive discrepancy that there appears to be between the Dilnot recommendations for social care funding and service users' preferences, and also between current government thinking and proposals on welfare benefits and their impact on disabled people and service users. Such a gap between service users' experience and realities, and policy perceptions and proposals, looks likely to be highly destabilising. If there is such a gap between the grassroots reality and policy perceptions, it has worrying implications for the likelihood of policy being successful, acceptable, sustainable and effective. The current very difficult economic times may mean that there needs to be recognition that the possibility of establishing long term sustainable social care reform has receded. This may impose delay, but such a time of crisis should not be used to prevent the introduction of more sustainable arrangements for social care for the longer term.

Continuing barriers

In a recent national research and development project exploring person-centred support, funded by the Joseph Rowntree Foundation, two fundamental and inter-related barriers were identified by participating service users, carers and face-to-face practitioners. These were barriers of culture and funding. The prevailing social care culture was identified at odds with person-centred support. This was exacerbated by chronic and major funding problems (Beresford *et al.,* 2011).

The need for culture change

These two major barriers were also highlighted in the present consultation. This was reflected in the responses of participating service users to the issues that we raised with them. These repeatedly pointed to large-scale problems in the way of developing a more person-centred social care culture. This was reflected in their frequent view that:

- The workforce is inadequately supervised and supported, with poor conditions of work.
- Personalisation policy is being undermined and not achieving the goals associated with it because of the unhelpful ways in which it is being implemented.
- Private provision is preoccupied with making profit rather than meeting people's rights and needs.
- Opportunities for prevention are being lost through reductions in access to support and perverse incentives linked with needs and means-testing. These are resulting in people only get help when their conditions are very serious and/or have deteriorated.
- Severe cuts in local public services mean that 'total place' approaches where all statutory resources are focused on meeting local needs have been put in jeopardy.
- Integration is narrowly interpreted in terms of organisational change within health and social care, without sufficiently challenging the unhelpful dominance of medicalised approaches, or taking adequate account of the importance of wider service integration.
- Arbitrary and stigmatizing welfare reform is resulting in increasing fear and anxiety among service users. The consequent negative stereotyping of disabled people and service users flies in the face of their mainstream involvement in society and the policy aspirations of personalisation.
- There is still a widespread failure to develop positive policy and practice for user involvement, to make possible more user-led services.

The need for funding change

The views of service users included in this consultation reflect the views of other service users which have been obtained, but are strongly at odds with current policy proposals. There seems to be wide agreement, if not political consensus, that there needs to be more money in the social care system. The Health Select Committee inquiry into social care added its voice to the Dilnot Commission in coming to this conclusion. There is little agreement, however, how this money is to gained, whether it should come from the state, private sector, or service users themselves. The closest we have come to consensus is the view of the Dilnot Commission that some kind of partnership funding arrangements will be needed. But the service users who took part in this consultation are far from convinced that the Dilnot recommendations will actually provide a safe and sustainable system for all.

Proposals for funding social care along the same lines as the NHS out of general taxation have been ruled out, notably, by both the last

Labour Government and Dilnot, as too costly to be politically acceptable or sustainable. Recently Andrew Dilnot commented:

‘Why didn’t we recommend general taxation? Because it wouldn’t have happened. If it had, it wouldn’t have lasted. Even if Sutherland’s [Sutherland Royal Commission] recommendations had been implemented, we wouldn’t still have it. All the countries that have done it have given up’ (Dilnot, 2012).

However, no serious attempt has yet been made to check out the actual costs and the cost-effectiveness of such a move. More needs to be done to generate convincing evidence about social care costs in the medium and long term. Yet evidence does suggest that short-term economies and the chronic and continuing underfunding of social care work against goals of prevention and injecting ‘that little bit of help’ that can delay or stop major problems, resulting in high level costs. The evidence from the POPPS (Partnership for Older People Projects) programme is that putting money into social care schemes can make subsequent savings in health bills (Windle *et al.*, 2010). Prevailing social care discussion has been fixed on narrow approaches to financial modelling and accounting. Instead, we need to take a broader focus, for example, exploring how:

- Social care spending can help disabled people of working age and who are older to continue to contribute to society and the economy.
- Social care jobs and provision can be part of a sustainable environmentally positive economic growth strategy, which can support and encourage the private, third sectors and user-led sectors.
- Funding for social care can play an enhanced role at social as well as individual levels in encouraging self-management schemes for physical and mental health in older age.
- Funding for social care can enhance social opportunities and social contact which evidence now shows older people prioritise as key to maintaining their wellbeing (Hoban *et al.,* 2011).
- Increased funding can enable carers to continue to develop their skills and qualifications, maintain paid employment (and funding for their own pensions and welfare benefits) as well as contribute in other ways to society.

Getting voices heard

While the government has stressed the importance of its current consultation, it has to be said that it follows on from a number of others. These include the ‘Big Social Care Debate’ which the previous government organised (this got the largest response to any such social care consultation) and the consultation linked with the Dilnot Commission on the future funding of social care. In both cases, funding social care from general taxation was ruled out even though this was the approach that had major support from service users, carers and many third sector and advocacy organisations .

Given this, and the wider context of welfare reform and public spending reductions, it is difficult to see what trust service users and their organisations can be expected to place in further consultations on social care.

One of the most important messages from service users in our consultation is that they must be listened to much more than they feel they have been to date. However many barriers funding restrictions impose, it is always helpful for policymakers and politicians to listen – directly – to what service users tell them – in both the short and long term.

Currently much rethinking is taking place among disabled people and other service users about both their goals and how to achieve them (Morris, 2011). Significantly they now seem to be turning increasingly to other methods of making their voices heard, rather than relying on government consultations. They are engaging with the mainstream political process and new forms of direct action as well as developing their own campaigns; service users and disabled people are a visible presence in broader struggles and demonstrations. They are using the law, lobbying, media and formal structures of representative democracy, at national and local levels. They are developing their own new forms of accessible and inclusive collective action and individual protest. They are particularly making creative and innovative use of new social networking and information technologies, blogging, vlogging, podcasting, tweeting and communing within their own Facebook groups (Beresford, 2012).

Recommendations

Workforce and quality

- A greater valuing of the workforce's role and contribution.
- More support for the role of personal assistants.
- Development of social care careers.
- Increased user involvement and a shift to a social model of disability based approach to social care work.
- Improving the funding, terms and conditions of the social care workforce.

Advancing personalisation and person-centred support

- Government support for user led organisations to:
    - provide an effective voice for service users;
    - provide an infrastructure of support for self-directed support and co-production;
    - expand the role of user-led service providers in social care thereby helping to build a social care market which will give them choice and control.

Improving prevention

- A changed mindset, improved funding and the removal of barriers that arise through needs and means testing.

Advancing integration

- A more collaborative culture at all levels, improved user involvement and a move away from a narrow medicalised model.
- Organisational change to make integration between health and social care a positive possibility.
- Putting the funding arrangements of social care on the same footing as those of health.
- A much wider approach to integration, including a wide range of other services (particularly housing, transport and equipment and adaptations), to ensure that all services are supportive of and consistent with the rights and needs of service users and fully accessible to them.

Improving the social care market

- This means a social care market more suited to personalisation and prevention.
- A person-centred culture.
- More support for user led organisations to play a bigger role as service providers.

Future funding of social care

- Service users do not think that partnership models or an increased role for the private financial sector offers a basis for sustainable social care for the future.
- Instead they are largely committed to a model of funding from progressive general taxation and feel that costings for such a model should be thoroughly examined and explored.

Improving user involvement

- Service users identify increasing effective user involvement in relation to all issues concerned with improving social care, from improving service quality, the workforce, the social care market, integration of services and a preventive approach to policy and provision.

Linking welfare reform with social care reform

- Social care reform needs to be considered in close association with welfare reform, as current welfare reform proposals are having serious negative effects on many disabled people and service users – increasing their exclusion and insecurity and increasing hostility and negative perceptions of them.

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Appendix 1

Make-up of service users consulted

Demographics

Gender

Male	17
Female	11

Sexuality

Heterosexual	15
LGBT (lesbian, gay, bisexual and transgender)	6
Not known	7

Ethnicity

White	20
BME	8

Location

Northern England	2
Southern England	5
London	8
Midlands	6
West of England	3
East England	4

Age

Under 30	1
30s	3
40s	6
50s	7
60s	7
70s	4
80s	-
Total of service users	28

Service user characteristics (self defined)*

Older person (65 and older)	8
Physical impairment	9
Sensory impairment	4
Mental health service user	8
Person with learning difficulties	2
Wheelchair user	2

Alcohol or drug problem	1
Epilepsy	1
Long term condition	4
Residential service user	1
Living with HIV/AIDS	2
Total	**42**

*this is based on how people described themselves. There are more impairments and descriptions than people as a number of people included themselves in more than one category.

Service status

Receiving personal budgets	3 plus one in process
Receiving Direct payments	14
Currently using health and social care services	26 (one person currently not accessing services, another awaiting the result of their assessment.)
Total	**28**

A diverse range of service users were identified to take part in this consultation. Most completed the survey electronically although offered the option in a number of cases of a telephone interview. This was chosen by one service user. In line with our commitment to valuing the work, contribution and expertise of service users, a payment was offered to all taking part in this consultation, although not everyone wished to receive it.

Appendix 2

Consultation Schedule

Social Care Funding And Support Consultation 2011

Thank you for agreeing to complete this schedule survey as part of a Shaping Our Lives user-led consultation on the present state of funding and services for disabled people and service users in England. This project is independent of government and being supported by the Joseph Rowntree Foundation.

We are seeking to involved a diverse range of service users/disabled people in this consultation, which we will be feeding into the government's consultation/listening exercise 'Caring For Our Future', which is meant to inform their planned social care White Paper.

Because of the big changes now taking place in social care and other public services we believe that this is an important opportunity to feed in service users'/disabled people's views.

This consultation follows on from an earlier exercise we carried out in October 2009, which you may have been involved in. This was reported in 2010 and you can check out what people said there through these links:
http://www.jrf.org.uk/publications/funding-social-care
http://www.jrf.org.uk/sites/files/jrf/care-service-users-views-summary.pdf

We are anxious to feed in accurate and up to date information from disabled people/service users who are well networked to help balance the contributions to the consultation. We know that in the past there has not always been a full involvement from a wide range of service users/disabled people. We hope that the Joseph Rowntree Foundation will also publish the findings independently. Shaping Our Lives will also publish them on our website.

In completing this schedule please draw upon your own experience, experience in your area, from other service users/disabled people you are in contact with and more generally

Please can you ensure that you return this schedule NO LATER than Monday 21st November 2011 so that we can

submit our evidence to the Department of Health's consultation before its closing date shortly after that. With many thanks.

Please return completed schedule to: Eamon Andrews at:
eamon@shapingourlives.org.uk
(Direct line: 0845 241 2128)

Questions to be completed

Question 1
In our last consultation in 2009, almost all disabled people/service users said that they thought social care should be free at the point of delivery and funded from general taxation. This has been ruled out in the recommendations of the Dilnot Commission. What do you think of this?
Detail

Question 2
How do you think social care should be funded in future?
Detail

Questions 3
The government is keen for the private (for profit) sector to be more involved in social care (funding). What do you think of this
(in favour/opposed/don't know)
Detail

Question 4
Is the present workforce suitable for ensuring good quality support for service users?
Yes/no/don't know
Detail

Question 5
If NO, what changes in the workforce are need to improve the quality of support received by service users?
Detail

Question 6
How do you think health and social care services can work better together to meet people's rights and needs?
Detail

Question 7
What other services do you think need to be linked closer together with social care services and support?
Detail

Question 8
What do you think would make it possible for social care services to prevent problems and difficulties get worse for people who need support?
Detail

Question 9
Do you feel the kind of services and supports you would like to have are readily available in the market.
Yes/No/Don't know
Detail

Question 10
What do you think would help ensure a better and wider range of services and supports being available?
Detail

Question 11
Do you feel that the cuts in public services currently being made with the purpose of reducing the public deficit are having any effects on disabled people/social care service users?
Yes/No/Don't know

Question 12
If **YES**, what effects do you think these cuts are having?
Detail

Question 13
Do you think social care reform can be undertaken without taking account of welfare benefit reform?
Yes/No/Don't Know
Detail

Question 14
What if any effects do you think welfare benefit reforms are having on disabled people/service users?

Question 15
Are there any other points you would like to make or issues you would like to raise?
If YES, detail:

Finally

Could you also complete this information about yourself as we want to have a clear picture of the range of experience included in this consultation.

- Your Age…………..
- Gender……………..
- Sexual orientation (if you are happy to describe)………..
- Ethnicity (as you would describe it)…………..
- Nature of your impairment/kind of service user you would describe yourself as being……………
- Do you receive a personal budget……………….
- Do you receive a direct payment…………………
- Are you currently using/receiving social care/health services…………

Continued…

THANK YOU

Please return completed schedule to: Eamon Andrews at:
eamon@shapingourlives.org.uk
(Direct line: 0845 241 2128)

NO LATER THAN Monday 21st November 2011

This paper was commissioned as part of the JRF programme on Paying for Long-term Care, which aims help create a better adult social care system http://www.jrf.org.uk/work/workarea/paying-for-long-term-care

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