

Personalisation and the future of adult social care: the views of Hampshire residents, submitted to the Hampshire County Council Commission of Inquiry

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Abstract

The personalisation agenda and the crisis in social care funding necessitate major reshaping of the adult social care system. 'Putting People First' requires that, by 2011, adult social care services undergo a transformation, facilitating greater choice and control for the individual and a more personalised response to their care and support needs. To help determine its approach to transformation, Hampshire County Council created a Commission of Inquiry. To find out people's experiences of social care in relation to the personalisation agenda, their ideas on the way forward to transform services and their views on how care should be paid for in the future, the Commission put out a call for evidence across the County. This article identifies key messages submitted in response by Hampshire residents and local organisations. It highlights issues that need to be dealt with to meet the personalisation agenda including: paternalism; the relevancy of current services; provider fears; regulation; partnership; the lack of preventative services; lack of information and advice. The article reveals the diversity of views on how care should be funded. It concludes that local authorities should be mindful of the importance of engaging all stakeholders in partnership at the beginning of the process to take forward the agenda.

Keywords: Personalisation, adults, local authorities, funding

Introduction

The government concordat *Putting People First: A Shared Vision and Commitment to the Transformation of Adult Social Care*, published 10th December 2007 (Ministers *et al.*, 2007), made manifest a commitment to transforming care services by 2011. Building on the principles of choice and control set out in the 2006 White Paper *Our Health, Our Care, Our Say* (Department of Health), transformation involves moving to a more person-centred or 'personalised' adult social care system which emphasises the individual's dignity, right to self-determination, choice, control and power over the support services they receive. The vision gives greater recognition to the importance of prevention and requires a whole system change. Local authorities are charged with implementing this

transformation but have a degree of autonomy in the detail of how they might respond to the personalisation agenda. Concurrent to this period of expected change, demographic pressures have made the present funding system for social care unsustainable, prompting the Government to undertake a major consultation exercise to inform a Green Paper on options for reform. In January 2008, recognising the need to respond to the personalisation agenda proactively, and wishing to identify ways of tackling the failings and unsustainability of the current system in England, Hampshire County Council set up a *Commission of Inquiry into Personalisation and the Future of Adult Social Care*. The aims of the Commission were to: obtain evidence and expertise on which to base the transformation, including personalisation, of adult social care in Hampshire; provide a model for change which might be drawn

upon by other local authorities; make recommendations to Government on national implications for achieving services that put people first; and contribute to the Council's response to the consultation for the Green Paper on the future funding of adult social care. In order to facilitate informed debate in which stakeholders, including Hampshire residents, could 'have their say' in shaping the future of social care, a call for evidence was made. This article aims to highlight some key issues regarding the way forward on personalisation and the future of adult social care identified in evidence submitted by those respondents either resident in Hampshire or representing businesses and organisations with an interest in the County.

Methodology

It was decided to run the Commission in a similar format to a Select Committee. The Commissioners were selected from the Council and from a variety of external organisations and interests, including community stakeholders, academia and national organisations. In keeping with the 'select committee' approach, the Commission sought qualitative evidence on people's experiences of social care in relation to personalisation, their ideas on how to transform services, and their views on how care should be paid for in the future. Having obtained research governance approval, an invitation to contribute evidence (including views, ideas and narratives of experiences) on four themes within the overarching topic of personalisation was drawn up – people and carers, partners and funding, the care market, and the local authority. It was publicised in the Council's magazine (delivered to every household in Hampshire), in local newspapers, on local radio, on the Council's website, at public buildings in the community, via stakeholders, at community events, and sent via email, letter and in person to individuals and organisations with a known interest in

adult social care.

In response, 120 Hampshire residents and 17 local organisations submitted their views, experiences and ideas in writing, through the post and via email. Thematic analysis (Boyatzis, 1998) was undertaken to identify key themes amongst responses received. The process of analysis involved reading and re-reading the submissions, identifying themes within them, developing and attributing codes for each theme, grouping similarly coded statements, and describing and abstracting common themes. Throughout the process, emerging themes were compared with relevant literature. Many responses contained personal material of a sensitive nature and a small number of respondents wished their submissions to be given to Commissioners in strictest confidence. Those responses were thus omitted from the analysis and this paper.

A number of organisations with national remits, including voluntary organisations, and social care associations also submitted previously published reports to the Commission and these were incorporated into literature reviews for the Commissioners (Dittrich, 2008 a,b,c,d). In addition, a number of people with views, experiences and particular expertise representative of the scope of the issues involved in *Putting People First* and the future funding of adult social care were invited to present evidence to the Commission at four public hearings. As they were purposely selected, their presentations have been omitted from this study.

As all submissions in this study were the result of self-selection, the views and experiences contained should not be considered representative of the views and experiences of *all* Hampshire residents. Nonetheless, their messages have made an important contribution to the evidence base for determining the future of adult social care in the County.

Key findings

The concept of personalisation

The majority of respondents who expressed an opinion on the personalisation of care welcomed, supported or endorsed the concept in principle. Particular support was given to the principles of increasing choice in daily life, being treated as an individual, person-centred planning, self-assessment, personal or individual budgets and direct payments. Most respondents felt that they themselves were the best person to make decisions about their own care. However, most respondents suggested caveats for personalisation and specified requirements needed to counter the potential of personalisation to further burden people. These included the need for a safety net if suitable carers cannot be found or are suddenly unavailable through sickness, the need for support to make decisions and manage finances, and the need for sufficient funding to ensure personalised care would be available for all who need it.

A comparatively small number of respondents were opposed to personalisation. One disabled respondent felt that reform was unnecessary as the personalisation agenda was already being met through direct payments. An older carer whose wife has Alzheimer's felt that Adult Services provide a good service and if carers were given control of funds the system could be open to abuse.

Issues that need to be addressed to achieve personalisation and transformation

Whole systems change
Putting People First expects local authorities to take the lead in working with local statutory, voluntary and independent sector partners to transform social care via a system-wide approach (Department of Health, 2008b, p.11). This should involve making a contribution towards community

and social capital development in order to improve prevention, well-being, social inclusion, independence and enablement. Paralleling these expectations, local voluntary user-led adult care organisations stressed the need for change across all local authority departments and beyond as part of the shift towards personalisation:

Believe it or not, there is more to life than Social Services! ... All too often Disabled People are viewed as a Social Services issue, when in reality Disabled People need all of Hampshire County Council's services to be inclusive of their needs if they are to realise the ambitions of the Personalisation Agenda.
(User-led organisation)

What about the places where we live? Our surroundings, the infra-structure society depends on? Local transport, the built environment, shops, cafes, cinemas, pubs, restaurants, further education facilities etc., all are partners, all can play an important role in enabling an inclusive and active lifestyle. ... We live in supposedly one of the wealthiest parts of the country and yet much of our built environment, public transport and other such everyday facilities remain inaccessible. This is not just a matter of ramps, level thresholds, wider doors and so on, but a much broader, more inclusive understanding: a greater tolerance, accommodation of the deaf and partially sighted, affordable facilities and so on. These are facilities, attitudes and provisions designed to sustain, to include, to nurture community.
(User-led organisation)

Collaboration between agencies, particularly between social care agencies and transport providers, was cited by respondents as an important area for improvement in order to ensure that services are accessible to people who need them.

Workforce culture and skills

Putting People First requires a shift from care management processes to self-directed support and person-centred planning. According to *Putting People First – working to make it happen: adult social care workforce strategy – interim statement* (Department of Health, 2008a), this will mean the workforce will need to be remodelled. Currently, social workers spend much time assessing need, commissioning services, gate-keeping resources and managing risk. In the new system of social care geared towards enabling people who need care to have more control, social workers will continue to have a major role in safeguarding and will have a role in managing personal budgets on behalf of those people who cannot, or do not wish to, have a ‘hands on’ role in managing it themselves. However, in all instances, the social worker’s role will be to work in co-production with the person needing care, supporting the person’s decisions rather than determining care for them.

A number of respondents in this study highlighted lack of power and choice for individuals in the current system, and expressed the view that personalisation necessitates a shift away from the paternalistic roles and culture existing in both local authority services and in services provided externally:

Care managers put words in my mouth. It’s about what they think I should do, such as leave home and they don’t listen to me. (Disabled Service User)

[Our son] moved into a 5-bedded residential home in 2002. He has substantial learning disabilities, autism, and very little speech to aid communication. ... New residents moved in ... also staff, including management, has been subject to many changes. Throughout our son has had no say or choice in these matters which seriously affect his day to day life. ... Some

providers still want to do it ‘their way’. (Carer)

Areas for change mooted included a shift from financial gate-keeping and a ‘gift mentality’ where the professional knows best, to one in which people’s self-determination and individuality is respected and supported:

As someone who uses Direct Payments, I really welcome the move towards personalisation. I feel frustrated with the current system, where I am only able to use my money on ‘personal care’. I would often prefer to have the choice of being able to use it to cover things that meet my wider objectives. The paperwork attached to justifying my spending is incredibly time consuming, complicated, and quite frankly a waste of everyone’s time! I hope that personalisation will end this and allow me to be trusted to spend the money on the things that matter most to me (and hence improve my lifestyle and general well-being), without having to continually justify my actions. (Service User)

Two respondents, one a carer, the other a provider, highlighted the need for more training in person-centred planning as particularly important. Other respondents suggested that the shift towards self-directed support as part of personalisation means fewer local authority social care staff might be needed, and employees would need different skills than previously.

Workforce commitment is necessary for the success of personalisation (Stephenson, 2008) and thus it is essential that the workforce are brought on board as partners rather than set up as scapegoats for the failings of the social care system. Nationally, some care managers and social workers have welcomed the shift from care management as an opportunity to do ‘real social work’ (Goldingham, 2007; Community Care, 2008). In Hampshire, a

public sector trade union suggested employees want to support personalisation:

Personalisation means flexibility and responsiveness to individual needs and wishes; a task which Hampshire members feel they are up to given adequate resources and imaginative management.

However, it was also indicated that there is a degree of scepticism about individual budgets and concern amongst staff that the personalisation agenda would be used to close in-house services, reduce and de-skill the workforce and mask cuts in the budget for services. Positive engagement with the workforce is needed to counter any unfounded fears.

Information and advice

The exercise of choice and informed decision-making depends on up-to-date, accurate, accessible information about available options. Hence *Putting People First* requires that local authorities establish a universal information, advice and advocacy service for people needing services and their carers, including self-funders. The need for this is demonstrated in the evidence received in Hampshire. Several respondents mentioned the difficulty of making decisions regarding their own care or that of older people they know. They highlighted the lack of information and help with exploring care options and options for paying for care together with lack of means to find out about entitlements that may make their financial situation easier:

In 2002 my aunt became ill with dementia and was no longer able to look after herself. ... My aunt's property (in London) had to be sold to pay her fees, which at the time of her death in April 2008 were just under £3500 per month. It was not until September 2007 that I discovered that I could claim attendance allowance on her behalf. (Carer)

Many of these respondents were self-funders, or relatives of people self-funding, disadvantaged by a perceived unwillingness of statutory services to offer them any kind of help:

My mother was in (names) Hospital after a stroke, where the Consultant advised that she would not be able to walk unaided, feed, dress or wash herself again and that we should find a nursing home for her, suggesting that we talk to the Hospital-based Social Services team. We did – and on hearing that she would be self-funding, the shutters came down and the help/information offered was zero. (Carer)

Shift from current to new services

Personal budgets, one of the main features of the new personalised system, devolve control of money from the local authority to individuals needing care and support. Individuals may choose to obtain traditional group services, such as day care or residential care, or commission something more individualised e.g. live-in help. In Hampshire, some people who receive self-directed support may decide that their outcomes can be best met by entering residential care in which case Hampshire County Council will use the individual's personal budget to purchase this for them. Currently people cannot receive a Direct Payment to purchase residential care themselves. If any money remains in the personal budget 'pot' after residential care has been purchased an individual can choose to spend this in any way to meet their outcomes, including receiving this as a Direct Payment. They can choose to source and pay for provision of care and support directly themselves or via a representative, or ask the local authority to pay on their behalf once they have chosen. This means that, although providers may still have contracts including block contracts with local authorities that are acting on behalf of an individual or groups of individuals, they may increasingly have direct contracts with

each individual or their representative.

Private and third sector providers who submitted evidence expressed concerns about personalisation and the implications it would have for their organisations. They were particularly anxious about the potential shift towards contracting with individuals instead of the local authority and the effect this would have on their sustainability:

To ensure 'real' choice LA's are going to have to recognise the risks involved for small providers especially as they are often the ones that bring diversity to the market place. We as an organisation are very positive regarding personalisation but we have identified that personalisation could be a risk to our sustainability. Small organisations like our own will not be able to withstand variable purchase from individuals as we will still have to provide annual budgets, salaries, pensions, training, overheads whilst also developing appropriate strategies/services. It is obviously guaranteed income, which makes all this possible. (Voluntary Organisation supporting disabled people)

If service user needs are to be addressed on an individual basis, how will the needs of groups of people be identified in order for any strategic or service development plans to be put in place i.e. how do we stop the market becoming totally reactive as against a mixture of reactive and proactive? (Voluntary organisation supporting disabled people)

A number of respondents mentioned the likelihood of an increased demand for personal assistants and carers who would work flexibly and there was concern that people would face difficulty in finding such staff:

It is no good being given money if the service you need is not there. I have found it very hard to find a carer for my

father locally as to get a carer for an hour is hard when the bus service is so poor. This excluded several who applied and I have currently been forced to use an organisation to provide help. (Carer)

Personal budgets will allow people to spend, within financial constraints, some of their money on mainstream items or services instead of personal care and segregated services if such resources meet their needs or improve their quality of life. Pilots of individual budgets have seen service users using mainstream services such as leisure centres and taxis (Leadbeater *et al.*, 2008, p.59). Many older people in the pilots have used their individual budgets partly on conventional care services and partly on services or items from mainstream markets outside of the remit of the local authority, such as hairdressing or pub meals (CSIP, 2007, p.5). This could impact on both mainstream services (e.g. leisure) and providers of segregated services, e.g. drama classes for people with learning disabilities.

One respondent in this study provided information on how service users in Hampshire were exercising choice and successfully accessing universal services in the local community, such as mainstream adult education, in preference to traditional services such as day services. However, some respondents felt that mainstream services are not right for everyone or expressed concern that people would be expected to access universal services without being given sufficient support or funding to do so:

A further risk and fear is that personalisation could covertly collude with a prevailing fantasy economically driven and supported by those more able people that there is employment for all, that all day opportunities are unnecessary and intrinsically bad and that everyone can live and wants to live independently and are able to access their communities with support. What is

perhaps not being recognised is that the taking up of choice and control is a transitional process requiring personal development, skill acquirement coupled with confidence and self-esteem and is not attainable for everyone. We also need to remember that our communities are not always the warm, friendly and welcoming places we would like to believe they are and it often takes a brave and confident person to tackle covert discrimination and negative attitudes. (Voluntary organisation supporting disabled people)

A user-led organisation supporting independent living highlighted the need for the local authority to make providers aware of their potential personal budget-holding customers to ensure that mainstream services are sufficiently accessible to make them a real option:

The local authority must use its considerable financial and political influence to ensure a greater awareness of the changes and their implications. We want to see a rapid acceleration of inclusive measures being taken by the goods and services industry.

Some respondents felt that there will be a continued market for traditional services such as day and residential care but it was also suggested that changes to these services would be needed to meet the personalisation agenda:

The Government has misled the public into believing that care in the community is best for everyone and it is what they want. My experience is that this is not necessarily the case, especially with the very frail. ... [However] although the physical care we give our elderly has improved beyond all measure with better bedrooms etc. and more choices, in some ways, emotional and intellectual, we continue to warehouse our elderly people, which is in marked contrast to

other parts of the world. ... If this Commission is serious about the future quality care and choice for elderly people it must change its mindset about the place of residential care so that it is not seen as last resort for those who are a danger to themselves at home but a positive experience for those coming to the end of their lives. (Carer)

Assumptions have been made that there is no longer a demand for traditional day services with people desiring more social inclusion through use of universal services such as leisure centres and libraries. Whilst this appears to be intuitively correct in other care groups such as learning and physical disability, it does not ring completely true in older people's services, particularly in the area of dementia care. This view is certainly contradicted at older people's carer group meetings, where there appears to be a high level of anxiety about the possible reduction in provision of day services: ... we could extend our opening hours beyond 4 p.m. in the afternoon and into the weekends. ... We could link more closely with the residential units on site to provide combinations of overnight and short stay (weekend) respite to complement day services provided and could rotate staff to work in both the residential and day service settings so that people experience some continuity of staff. In this way, trusting relationships can be formed with individuals and their carers which will fully support people to remain in their communities. (Manager, local authority)

Quality and regulation

It is often mooted that greater choice and control for services users has the potential to bring them greater risk (SCIE, 2007; IFF Research, 2008; Lombard, 2008). Risk management for individuals receiving state-funded personalised services remains the responsibility of the local authority, even where a provider might have a direct

contract with the service user. However, local authorities are not currently responsible for ensuring the quality of externally provided services, including any services purchased by people who fund their own care. Several respondents expressed concern about the quality and regulation of personalised services and for people self-funding care. A number of respondents in receipt of home care cited the closure of local authority in-house home care services and shift to use of private companies as an example of how outsourcing can result in a deterioration of quality for the service user even when services are subject to regulation. Service users have experienced poor time-keeping, lack of consistency in staffing, and unreliability: a depersonalised service. It could be inferred from their experiences that, if personalisation results in the closure of other local authority services and an increase in privatisation, the service user experience may get worse unless greater effort is made on quality control:

Anecdotal reports indicate that service quality is at best erratic and at worst poor. Regulation enforcement from CSCI has been disappointing. This begs the question of how the new regulatory body will respond to a decentralized market and a possible large rise in individual complaints. What sanctions if any will be implemented against poor providers? Currently the regulatory framework focuses on 'risk', POVA, etc. The benchmark of 'quality' is set low; provided adequate risk management is in place you can provide a poor quality service. This needs to change. ... The new regulatory body (CSCI ends April '09) will have to adapt and provide a clear customer-focused service that is responsive to individuals as well as regulation of statutory bodies and enforcement. (User-led organisation supporting disabled people)

Respondents expressed particular concern about the current lack of regulation for

personal assistants and support brokerage, citing potential problems with standards of service and training, awareness of the law, lack of emergency cover, and abuse. Various measures were suggested to safeguard against such problems including: a 'Kite Mark' for services or providers considered by the local authority to provide good service; 'licensing' staff; accrediting agencies; a local authority-run website listing available carers/personal assistants who have had CRB checks and providing complaints procedures and advice on legal and training matters for both employers and employees. One respondent felt it would help if the local authority acted as an agency for personal assistants:

People having live-in care currently pay about £70 to £120 weekly to an agency that introduces live-in carers to clients. They provide training to self-employed carers (who have to pay for the training themselves). Why can't Social Services run an equivalent scheme? Presumably such agencies run at a profit? (Carer)

Another respondent highlighted the fact that lack of regulation regarding personal assistants can mean that the personal assistants themselves experience poor working conditions or are put at a disadvantage:

I was a close friend of a profoundly disabled person. ... When he died he owed the Bank about £12,000. ... His full-time PA therefore lost a month's salary, her job and as she was a joint tenant, her home, all at a time when she was personally bereaved. Fortunately the Benefits Agency were able to help until she got back on her feet, but the Bank was completely unsympathetic. I believe that a consortium approach to contracts and payment of PA's could reduce transaction costs and provide some protection in the circumstances described. (Friend and advocate of a Service User)

Prevention

I'm 81 years old and live alone. My heart valves are diseased. I have Diabetes and a catheter. The day I was discharged from the (names) Hospital in October last year a person from Social Services came to ask if they could do anything for me. I asked if someone could look in on me to see if I was O.K. The person seemed unsure, I then asked if someone could phone me once a week to see if I needed anything like shopping. The reply was short and to the point, we don't supply people to do shopping. I told the person to forget it. (Older Person)

A number of respondents lamented the lack of state-funded 'low-level' services such as 'home help', gardening help, advice and advocacy, and several stressed that such services would help prevent crises and thus the need for more costly care that results from loss of independence. Several respondents also emphasised the need to provide respite solutions to help prevent carers, particularly those caring for people with dementia, reaching crisis, which would help avoid being forced to resort to expensive residential care services:

If there could be a service whereby the carer's charge could stay in a suitable respite home for two weeks at a time – once, twice, three or even four times a year: - FREE of charge to the carer, having recharged batteries would have time to more willingly, patiently and lovingly be able to ensure a dignified and happier life for their loved one. (Carer)

The view is often expressed that attendance at day service sessions, particularly for those caring for a person with dementia, is the thing that enables people to continue to care for their loved one at home. ... Given that social care relies so heavily on the unpaid, informal care provided by these individuals, it is nonsensical to reduce access to a service which can make such a significant

contribution to the prevention agenda. ... Carers would like to be able to use the services for part sessions across the week and into the evenings, in order that they can have breaks from the caring role to be able to do the things that keep them connected to their community e.g. meeting friends, visiting the hairdresser etc. (Manager, local authority)

Respondents also suggested that training of carers to help them look after themselves would also prevent crisis and the need for 'formal' care services.

Funding

The personalisation concept will not change the existing barriers until greater resources are available, and there is a danger that the publicised success of a small number of special cases may be seen as of benefit to the whole, whereas it may only divert resources. (Carer)

Respondents stated that, for people who currently receive state-funded help, often only the most basic personal care needs are being met. If inadequate funding is supplied to meet needs there is a danger that people who have personal budgets will be forced to act as rationers of their own resources, having to restrain or reduce quality of life to meet priority needs (Jones, 2008, p.45). Furthermore, evidence submitted supports the conclusion that, unless there are national changes made to how social care is funded, personalisation will only be achievable for a minority as fewer and fewer people qualify for state funded social care. The difficulty that local authorities will have in reconciling the opportunity for choice with insufficient funds and eligibility criteria could mean even the most modest of people's needs will not be met:

Never mind the glossy brochures, the enlightened promises, our daily experience tells us a different story. ... How many times do we have to hear a bewildered voice on the phone

exclaiming, 'it never dawned on me that they would do nothing!' as yet another family member discovers that a much loved relative does not qualify for help.

(User-led organisation supporting disabled people)

Approximately 70 respondents referred to the issue of funding care. A considerable proportion expressed anger at the unfairness of the current system, many stating that people who save are penalised, whilst those who waste money benefit from free care. It was also highlighted that self-funders are unfairly having to effectively subsidise state-funded places in care homes. Furthermore, those families using care suggested that the system, including the 'benefits system', is focused on minimising payouts rather than helping, and is confusing. Many did not understand why the NHS would not pay for care for people with dementia – this was seen as unmindful of people's dignity as well as unfair:

The first thing you can do to ensure dignity is to scrap means testing, or at least raise the thresholds to something that acknowledges that people should be encouraged to save during their working lives. ... And when it comes to applying for NHS continuing care, we don't want three-year battles and umpteen appeals before we get our dues. We need sympathy and understanding and not money put first but my wife put first. (Carer)

It can be a real struggle – finding out what benefits they are entitled to, claiming the benefits, etc. ... There are elements of the claim procedure which can be very upsetting, i.e. I found out that Mum would be entitled to a council tax discount because Dad has Alzheimer's – she did get the reduction but the form says that it's because Dad is a "disregarded person" – a horrible expression. (Carer)

Responses were split between those who felt that care should be free for all at point of delivery and those who felt some or all should contribute the same as, or more than, they would now. Many felt that universal entitlement to a basic degree of care would be more fair; they had paid their 'dues' through income tax and national insurance and therefore should be entitled to state-funded care:

Of course the state should pay all regardless of whether the person is rich or poor; why should one section of the community get justice and the other not, just because they have managed their finances better all their life and/or been more sensible. (Member of the public)

It was suggested that as the wealthy paid more towards care through taxation, they had a right to be as equally entitled to state-funded care as poorer people. Several suggested that money should be taken from other pots, such as other Council services or defence, to enable free care. Some respondents displayed awareness of the funding crisis in social care and an expectation or acceptance of the need to make additional contributions to deal with the crisis. However, several respondents, consisting predominantly of people whose elderly relatives had no option but to enter residential or nursing care and who did not initially receive state funding, expressed shock that their relative's assets were needed to pay for care resulting in the depletion or loss of their inheritance. This suggests government needs to better inform the public about the financial expectations associated with continuing care.

Some felt that means testing should be retained and it is notable that they thought that this should mean only the very rich pay for their own care. Of those who thought some or all should make more contributions, some said they wanted quality and value for money in return. Several ways in which people could make a greater contribution

towards the cost of care were suggested. Some felt that the deficit should be funded through taxation or national insurance. Another suggested compulsory savings would be a good idea. Two suggested equity release schemes would help. One stated that the state pension should be offset against the costs of paying for care oneself. Two suggested that tax relief on care would help enable more people to pay the fees themselves. One respondent said they were willing to pay 80% of the cost of care. Another said it would be reasonable to contribute 50% of one's income towards the care of a spouse. Respondents reported experience of barriers that make it difficult for people to make a financial contribution to care, including difficulty of obtaining power of attorney from the Office of the Public Guardian to enable selling the home of someone who has Alzheimer's, and the lack of regulation of equity release schemes - which deters people from using such schemes. The majority of respondents who expressed a view on selling one's home to pay for care felt vehemently that no one should have to sell their home. By contrast, there were a small number of respondents who made it evident that they felt that it was a reasonable way to pay for care. The two respondents who mentioned Disability Living Allowance said it should not be taken away to pay for care.

Notably, two respondents suggested that the funding crisis could, in part, be alleviated if euthanasia was made a legal option for the elderly sick and recommended that this option be at least debated.

Partnership and co-production

Partnership with stakeholders is arguably the best mechanism through which to address many of the issues that pose a barrier towards achieving personalisation and transformation that respondents raised. Respondents suggested the need for a closer relationship between providers and the workforce to ensure that services can

respond to people as individuals. Moreover, several respondents stressed the importance of partnership or co-production between local authority departments and the people who need care and support (or organisations who represent them) in determining the future of services, their design and their delivery in order to make them more accessible and more responsive to individual needs. It was suggested, for example, that disabled people's organisations could help local authorities to ensure that all of their services are made inclusive to disabled people.

Some respondents had been concerned that the 'Commission of Inquiry' approach itself was contrary to the ideal of co-production inherent to *Putting People First*. They called for greater effort to work with people needing support and care as partners to determine the way forward, and commitment was made to re-address this both during the life of the Commission and through actions arising from the inquiry:

The leadership and ownership has to come as a partnership with disabled people and their organisations first and foremost. (Disabled Service User)

The evidence highlighting the importance of partnership with service users and carers correlates with key findings from the first report of the *Standards We Expect* project, which looked at stakeholder views on ways to tackle barriers to achieving person-centred support in 2006 (Glynn & Beresford, 2008).

Conclusions

The evidence submitted to Hampshire's Commission demonstrates the plethora of issues that need to be tackled to ensure that personalisation is an opportunity rather than a threat to the future of people in need of care and support. Some issues are familiar. For example, the apparent paucity of information and advice for self-funders

echoes findings from research undertaken in other local authorities (see Arksey & Glendinning, 2007; Henwood & Hudson, 2008). The suggestion of an intrinsic link between the success of personalisation and obtaining sufficient funds for social care mirrors concerns aired by Age Concern (2008), amongst others. Significantly, this study shows that, though we must tackle major challenges in securing sufficient funding for social care to achieve personalisation, we must not forget that personalisation is fundamentally about respecting people and we must bear in mind the difference that small and easily achievable actions, like changing the wording on a form, can make towards maintaining dignity. Finally, the key message to local authorities from this study is that engagement and partnership with users and other stakeholders is needed right from the outset of the transformation process if personalisation is to meaningfully enhance dignity, choice and control.

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References

- Age Concern (2008) *The Age Agenda 2008: Public Policy and Older People*, accessed 24/9/08 at http://www.ageconcern.org.uk/AgeConcern/Documents/Age_Agenda_2008.pdf.
- Arksey, H. & Glendinning, C. (2007) 'Choice in the context of informal care giving', *Health and Social Care in the Community*, **15** (2), pp.165-75.
- Boyatzis, R.E. (1998) *Transforming Qualitative Information: Thematic Analysis and Code Development*, London: Sage.
- Community Care (2008) *Social Workers Split over Personalisation Impact*, accessed 24/9/08 at <http://www.communitycare.co.uk/Articles/2008/05/27/108358/social-workers-split-over-personalisation-impact.html>.
- CSIP (2007) *Older People's Services and Individual Budgets: Good Practice Examples and Ideas*, accessed 10/9/08 at <http://www.learningdisabilitiesuk.org.uk/docs/OlderPeople'sServicesIndividualBudgets.pdf>.
- Department of Health (2006) *Our Health, Our Care, Our Say*, accessed 24/9/08 at http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyandGuidance/DH_4127453?IdcService=GET_FILE&dID=456&Rendition=Web.
- Department of Health (2008a) *Putting People First – Working to Make it Happen. Adult Social Care Workforce Strategy – Interim Statement*, accessed 20/8/08 at http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_085642.
- Department of Health (2008b) *LAC (DH) (2008)1: Transforming Social Care*, accessed 28/8/08 at http://www.dh.gov.uk/en/DH_081934.

- Dittrich, R. (2008a) *Putting People First - Shaping Your Future, Choosing Your Care. Briefing Paper 2: People and Carers - Summary of Pre-existing Evidence from Experts and Research*, accessed 24/9/08 at http://www3.hants.gov.uk/briefing_paper_2.pdf.
- Dittrich, R. (2008b) *Putting People First - Shaping Your Future, Choosing Your Care. Briefing Paper 5: Partners and Funding - Summary of Pre-existing Evidence from Experts and Research*, accessed 24/9/08 at http://www3.hants.gov.uk/briefing_paper_2.pdf.
- Dittrich, R. (2008c) *Putting People First - Shaping Your Future, Choosing Your Care. Briefing Paper 7: The Care Market - Summary of Pre-existing Evidence from Experts and Research*, accessed 24/9/08 at http://www3.hants.gov.uk/briefing_paper_2.pdf.
- Dittrich, R. (2008d) *Putting People First - Shaping Your Future, Choosing Your Care. Briefing Paper 9: The Local Authority - Summary of Pre-existing Evidence from Experts and Research*, accessed 24/9/08 at http://www3.hants.gov.uk/briefing_paper_2.pdf.
- Glynn, M. & Beresford, P. (2008) *Person-centred Support: What Service Users and Practitioners Say*, accessed 24/9/08 at <http://www.jrf.org.uk/bookshop/eBooks/2173-person-centred-support.pdf>.
- Goldingham, J. (2007) 'Interim report on implementation of individual budgets in West Sussex', cited in Duffy, S. (2008) 'Care management and self-directed support', *Journal of Integrated Care*, **15**(5), pp.3-14.
- Henwood, M. & Hudson, B. (2008) *Lost to the System? The Impact of Fair Access to Care*, accessed 24/9/08 at http://www.csci.org.uk/pdf/20080128_Lost_in_the_system.pdf.
- IFF Research (2008) *Employment Aspects and Workforce Implications of Direct Payments*, accessed 24/9/08 at [http://www.topssengland.net/files/Employment%20Aspects%20of%20Direct%20Payments%20Report_v9%20FINALwith%20foreword\(1\).pdf](http://www.topssengland.net/files/Employment%20Aspects%20of%20Direct%20Payments%20Report_v9%20FINALwith%20foreword(1).pdf).
- Jones, R. (2008) 'Self-directed support: watching out for the pitfalls', *Journal of Integrated Care*, **16**(1), pp.44-7.
- Leadbeater, C., Bartlett, J. & Gallagher, N. (2008) *Making it Personal*, accessed 10/9/08 at <http://www.demos.co.uk/publications/makingitpersonal>.
- Lombard, D. (2008) *Reforms Could Leave Vulnerable Adults in Danger*, *CSCI Chief Says*, accessed 24/9/08 at <http://www.communitycare.co.uk/Articles/2008/04/25/108006/personalisation-cscisnell-sounds-abuse-alert.html>.
- Ministers, local government, NHS, social care, professional and regulatory organisations (2007) *Putting People First: A Shared Vision and Commitment to the Transformation of Adult Social Care*, accessed 29/8/08 at http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_081118.
- SCIE (2007) *Choice, Control and Individual Budgets: Emerging Themes*, accessed 24/9/08 at <http://www.scie.org.uk/publications/briefings/files/scare20.pdf>.
- Stephenson, P. (2008) *Personalisation Pilots Face a Cultural Ethos Challenge*, accessed 20/8/08 at <http://www.communitycare.co.uk/Articles/2008/05/07/108125/personalisation-pilots-face-a-cultural-ethos-challenge.html>.

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