

# Putting People First

Shaping your future, choosing your care

Hampshire County Council Commission of Inquiry to help shape future services for people needing support and care

Briefing Paper 3 : People and carers- summary of submitted evidence



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## Briefing Paper 3 : People and carers- summary of submitted evidence

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We received information from a range of people and organisations in Hampshire, including people who have used social care services, friends, family and carers of people in need, legal and social care professionals, and advocates. This paper summarises points from the responses, focusing on people's experiences and views on the concept of personalisation and highlighting general points on what is needed to ensure that it can make a difference to people in need of support and care, including carers. Some practical ideas on ways forward are highlighted. Comments we have had from people exploring the detail of funding, the care market and shape of service provision, employment issues, standards, quality, risk and regulation relating to personal budgets and tailored services, transport, the workforce and staff culture will be included in more depth in the papers for the second, third and fourth sessions, Partners and Funding, The Care Market and the Local Authority. This paper is intended for quick reference and it is essential to additionally read the submissions in full in order to appreciate people's personal stories.

### ***Personalisation – positive and negative responses to the concept***

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<sup>i</sup>, being treated as an individual<sup>ii</sup>, person-centred planning,<sup>iii</sup> personal/individual budgets<sup>iv</sup> and direct payments.<sup>v</sup>

Most respondents suggested caveats (e.g. Direct payments cannot be universal) and specified requirements needed to counter the potential of personalisation to bring further burdens to people who are often not well equipped to bear them. See 'Key messages on the way forward' below.

One carer, C.S. Drake, felt that the flip-side of rhetoric on enabling more choice and control - the implication that people in need should take more responsibility for determining their own care - is an insult to carers as their responsibility is total, involuntary and comes at great personal cost. However, he offered support for the concept of making support for carers tailored to individual needs.<sup>vi</sup>

One respondent, John Evans, felt that personalisation is an unnecessary exercise that disabled people have not called for.<sup>vii</sup> In contrast, a carer's organisation,

Carers Together, said they were pleased to hear about the current personalisation agenda as they had been talking about it for at least 15 years.<sup>viii</sup>

## ***Developments in transforming current services to put people first in Hampshire***

### **Self-Directed Support**

Hampshire is piloting Self-Directed Support in Basingstoke from 1 May 2008. This will include individual budgets, support planning and brokerage for older people, people with learning disabilities and people with physical disabilities.

Representatives from user-led organisations across the county make up a 'Service User Group' who are involved in shaping the development of Self-Directed Support in Hampshire and all services users and carers in the pilot will be asked for feedback on their experiences and suggestions for improvements. They will also be invited to join this Service User Group. It is hoped that the developments and improvements made to the process and systems during the pilot will enable the development of an approach that can be rolled out across the county.<sup>ix</sup>

### **Personal Assistance Service**

New developments have been made in day care opportunities in Fareham, Gosport and Havant which enable more choice and flexibility to meet the needs of people with physical disabilities in a way that is tailored to the individual. The new 'Personal Assistance Service' is a move away from traditional day care. The service is available from 8.30am to midnight seven days a week and enables people to access venues of universal appeal such as cinemas, concerts and adult education with a personal assistant on a one-to-one basis (where 2 assistants are needed this is also available). It aims to support service users in determining their own goals and outcomes in a sustainable manner, promoting independence and confidence. The service is currently supporting 18 adults who have variously chosen to access their local colleges, swimming pools, snooker club, theatres, shop independently, become involved in community life and regenerate old hobbies and past times. Service users can continue with their existing day care whilst having access to the new service for an agreed period so they can make an informed choice about the future direction of their provision.<sup>x</sup>

### **OPAL**

The Older People's Area Link pilot project is a partnership between the Council, Age Concern Hampshire and Hampshire Voluntary Care Groups Advocacy Service. This service, available on some areas of Hampshire, seeks to help older people to access community services to reduce social isolation and improve their well-being and health.<sup>xi</sup>

### **Community Innovations**

The Community Innovations Project aims to find older people at risk who are not eligible for state funded care and help maintain their independence, prevent need for emergency and other services, and build the capacity of the community

to provide them with support. The project is taking place in 6 areas in Hampshire and is being funded by the Government's 'Invest to save' initiative. The local Councils for Voluntary Services in each of the six localities hold the funds for the project. Around half of each grant is spent on a half time community development worker who forms an active link between the locality innovations teams, the community and the voluntary sector. Nurses, social workers and occupational therapists identify needs for support that cannot currently be met by agencies in the community and it is then the job of the community development worker to devise a solution with local voluntary organisations to meet these needs. Each scheme aims to become self sustaining and so able to continue after the project has finished. The project is monitored by assessing the well-being of older people supported by the scheme before they start and after three months on the project in order to note any changes. The County Council and partners are looking at the pattern of use of emergency and other services within the localities to see if there are any changes. The figures for each locality will be compared with other areas that act as controls. The aim is to ensure the project is self sustaining. The outcomes for individuals will be reviewed and the best schemes developed by the local councils for voluntary service will be replicated in other localities.<sup>xii</sup>

### **Direct Payments**

A recent review of Direct Payments in Hampshire was undertaken in the light of the national direction to implement personalisation and self-directed support. In 1981, following initiatives by services users, Hampshire was the first council to adopt the 'Self Operated Care Scheme', from which the model for Direct Payments developed. The county gained national recognition for valuing independent living as a result. By the time of the review CSCI identified increased uptake of Direct Payments as an area for improvement for Adult Services. A consultation took place as part of the review and this resulted in agreement to develop self-assessment of finances and needs prior to professional assessment; develop a support assessment tool on what users need to help them manage the money effectively, keep them safe and reduce time spent by the authority unnecessarily checking the bank details of some service users; pilot self-reviewing; and make care plans, reviews and monitoring outcomes-based rather than service-based.<sup>xiii</sup>

### **Telecare**

Hampshire has invested in contracts with organisations in district council areas across the county to raise awareness of Telecare and make it available to more older people. The older person only has to pay a small monitoring charge.<sup>xiv</sup>

### ***Experiences of a lack of personalisation in current services***

- Rita Kinsey's son, who has substantial learning disabilities and autism, lives in a 5 bedded residential home. He has had no say or choice in who he lives with and the staff that support him, even though these matters seriously affect his day to day life. Other residents are much older and have different communication skills to him. He is often unable to do daily activities he has chosen to do because of staff shortages. Rita told us some providers still seem to want to do it 'their way', rather than doing what the individual wants. She was concerned that

vulnerable people in residential care with complex needs like her son should not be left behind and miss out on personalisation and its opportunities for more choice e.g. choosing staff who you have shared interests with.<sup>xv</sup>

- James Rose, a service user who has Direct Payments, told us *“I’ve never felt more out-of-control of my life than I do now”*. He has experienced professionals in Hampshire prescribing what they think service users need rather than listening to him with regards to his needs. He felt that he is not being looked at as an individual, and as a result he has not been given appropriate services or equipment. For example, he was given specialist equipment at University which he did not need because the occupational therapist based her decisions on generalisations and minimising risk to meet legislation rather than considering his individual capability. He felt he needs a 24 rolling rota of care from two different people but he has been given funding for a 'live-in' package of one assistant. When reassessed, he was told that he would no longer receive funding for hours of assistance that have been allowing him to socialise with friends. The struggle to try to obtain the packages he wants has been detrimental to his mental health.<sup>xvi</sup>
- A disabled service user with Kingsley Organisation told us:  
*“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.”<sup>xvii</sup>*
- Carers Together told us that people are often treated as a medical condition, disability or carer rather than as people with aspirations and lives outside the role with which they have been labelled:  
*“It is assumed that they will do what they are told, follow what the professional has ‘advised’ (instructed), be grateful for help and support (even the wrong help). They are expected to fit the box prepared for them whether or not it is disguised as person-centred care or care and support or is service or building driven.”<sup>xviii</sup>*
- Woodford, primary carer for person with long-term disabilities, told us that since the home care service was reorganised to focus on reablement, care for long-term clients has badly deteriorated. Care is given by whomsoever is available, meaning that the staff have no knowledge of the client or the details of the actual care needed, nor whether there is a change in his or her condition. Not only is the service less personalised, having to explain and demonstrate what is needed means that the primary carer is not really being helped. Irregular arrival times have caused additional stress and the situation is worsened when the primary carer's own health breaks down and it is more difficult to obtain the additional support needed.<sup>xix</sup>
- Kingsley Organisation told us parents and carers said:  
*“Confusing systems also make their lives difficult, instead of a contact with someone who they can relate to. Care Managers and social workers moving frequently means that there is a lack of trust and consistency with the carers and/or parents concerned.”<sup>xx</sup>*

## **Key messages on the way forward**

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## Transformation may be hard to achieve under the current system of funding social care

- Greater resources are needed:

*"...Every person is an individual, with different needs, finance, experiences/capacity, and family support and the present provision for their support is driven by finance firstly and needs secondly... at this time people are not automatically linked to Adult Services, some are missed completely until a crisis occurs, and those who are assessed do not automatically receive a service, either because their assessed need is lower than the arbitrary Eligibility Criteria, there is inadequate provision of the service needed, or for other reasons including 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." (C.S. Drake, Carer)<sup>xxi</sup>*

*"...why is it that many of those people who should benefit most from the proposed changes are most suspicious and least enthusiastic about the latest proposals and about the process of consultation? One reason is that previous experience has given them many initiatives that have started out well, usually well funded initially and become less positive over time e.g. Self Operated Care Scheme (SOCS) where Hampshire was ahead of the rest was a welcome and much appreciated resource – then it became Direct Payments and has become less popular and more restricted and controlled. Much of the change was finance driven and has left people living in dread of assessment, reassessment and the financial assessment – not because they are doing anything wrong but because it almost always and inevitably leads to a reduction in care and resources. One recent case highlighted was a man with complex needs having to fight to get acknowledgement for his wife's personal and caring contribution of 80% to his care - whilst being provided with only sufficient resources for 20% of his care, which is proposed to reduce. He is neither workshy or able to go out to work, his needs could be met in a nursing home – but he wants to stay at home with his wife – if she left and he moved into a nursing home the cost to the authorities would be enormous – so why not a little more support, empathy and understanding now?" (Carers Together)<sup>xxii</sup>*

- The funding system is unfair and must be changed:

*"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. (What's happened to the Wanless report?)... And when it comes to applying for N.H.S 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.." (George H. Hollobone, Carer)<sup>xxiii</sup>*

## Grounding transformation in co-production and research on people's needs

- *"There will never be enough money to meet every ones needs, but as carers and people using services we can help the local authority to commission cost*

*effect responsive services and to cut out red tape, make service more individual and person centred but we need to be treated as equal partners and hopefully "personalisation" will help towards this." (Janet Chierchia, Carer)<sup>xxiv</sup>*

- *"The leadership and ownership has to come as a partnership with disabled people and their organisations first and foremost" (John Evans)<sup>xxv</sup>*
- *"Desirable changes come only from a firm foundation of a knowledge of a client's needs. Adult Social Care fails when it ignores the market approach and uses 'Top Down' solutions... Vulnerable care users are far from a homogenous group. A further problem is that many lack capacity and are unable to give a full account of themselves. It follows that proven research methodologies are needed and consultations should be undertaken by appropriately trained researchers." (Terence and R..E.. Lister, Care user and Carer)<sup>xxvi</sup>*
- In contrast, one respondent, Jane Hunt, felt money should be spend on support for disabled and older people using notes from previous consultations and the Office for Disability Issues Independent Living Strategy, not on more consultation.<sup>xxvii</sup>

### **Features of transformation and personalisation that people want**

- *"[I'd like] more choice over where I spend respite, I'd like to sort my own plans out. Perhaps stay at home with a carer, while my family go away, or book a holiday of my choice." (Service user, c/o Kingsley Organisation)<sup>xxviii</sup>*
- *"More choice about what I do and where I go in the daytime." (Service user, c/o Kingsley Organisation)<sup>xxix</sup>*
- *"Living at home with parents it can be hard to make our own choices. Parents can tend to take over. Sometimes it would be good to see our Care Manager without our parents or carers." (Service users, c/o Kingsley Organisation)<sup>xxx</sup>*
- *"Hopefully under personalisation "Carers" will have a choice, be able to work if they wish, as affordable alternate care will be available or there will be flexible, individual services for the people we care for to enable us to have regular breaks and have choices as how we wish to spend our retirement. We need quality services so that we can trust the service to deliver the same quality of care that we give to our "loved" ones" (Janet Chierchia, Carer)<sup>xxxi</sup>*
- *"A named Social Worker always available when we need them. Someone who knows us and we get to know them." (Service users, c/o Kingsley Organisation)<sup>xxxii</sup>*
- *"Our parents do a lot for us and we need to have a break from each other sometimes." (Service users, c/o Kingsley Organisation)<sup>xxxiii</sup>*
- *"Doing our own care assessments would be a good idea." (Service users, c/o Kingsley Organisation)<sup>xxxiv</sup>*

- *“Having our own budget to pick our own services and support would be good.” (Service users, c/o Kingsley Organisation)<sup>xxxv</sup>*
- *“We may need help with understanding our money and looking after it. (Service users, c/o Kingsley Organisation)<sup>xxxvi</sup>*
- *“We need help to enable us deal with this awful illness and we need access to professional help that I can turn to for guidance and advice as the illness develops.” (George Hollobone, Carer whose wife has Alzheimer’s)<sup>xxxvii</sup>*
- *“We may need help with understanding our choices.” (Service users, c/o Kingsley Organisation)<sup>xxxviii</sup>*
- *“We need good advocates and independent brokerage services to help us.” (Service users, c/o Kingsley Organisation)<sup>xxxix</sup>*
- *“Any new process or procedure should provide:*
  - *Simpler access for people and their family carers – preferably self assessed and looking at the whole person*
  - *Clear information about what is available from all sources and how it can be accessed*
  - *Support to encourage and enable all individuals to achieve and maintain independence and prevent crises rather than wait for emergencies and respond to crises e.g. Emergency Planning for Carers*
  - *Transparent provision of services, resources and funding so it is clear what the taxpayer pays for and what the individual is expected to pay and why*
  - *Available and flexible care services and resources which are outcomes based to meet the individual needs of people, families and carers.” (Carers Together)<sup>xl</sup>*
- *“As a matter of good practice local government should provide their tax and rate payers with:*
  - *A simple statement identifying what a citizens should expect by way of a service.*
  - *Ensure the ready availability, well resourced and independent advocacy service available to act with any citizen on his or her individual complaint, dissatisfaction...*

*What do we want? ...The local authority to ensure the ready availability of expert social care related advice, information and recommendation to the public; and for people who identify themselves as care dependent to identify and confirm needs and Institute the means of meeting these needs.” (HCIL- Hampshire Centre for Independent Living)<sup>xli</sup>*
- There needs to be a system in place to ensure that people are supported if things go wrong:

*“Parents often express their concerns about their young people needing extra support...There is also some concern for how their young people will be supported when things go wrong, and whether the system will pick them up again, if they have been involved with individualized budgets, or direct payments.” (Parents/Carers c/o Kingsley Organisation)<sup>xliii</sup>*

- Prevention services:

*“Receiving low levels of the right support over a prolonged period can prevent a crisis.” ( Advocacy members and self-advocacy group members of Speakeasy Advocacy)<sup>xliiii</sup>*

*“The absence of a managed Home Help service leaves many people struggling to obtain help.” (C.S. Drake, Carer)<sup>xliv</sup>*

### **How mechanisms to maximise opportunities and minimise risks might look**

Mechanisms to ensure that vulnerable people get the support they need to make informed choices and benefit from the flexibility of personal budgets include assessment, support-advice-information, and regulation.

#### **Assessment**

- *“People may not necessarily say what they want, or know what they need. For example many older people will say that they want someone to do something for them when they really want to be able to do it for themselves. Or they might know what transformation they wish in their lives but not the best way of achieving it. This is why it is vitally important that there be a comprehensive assessment of their needs, verification of wishes and discussion of what is possible by way of outcome and prognosis. This highlights the importance of the therapeutic counselling role of social workers. Without this involvement the application of Direct Payments and Personalised Budgets could reinforce dependency and accelerate decline – perpetuating the “minding” service rather than returning to a “mending” service. ” (Chris Perry, Age Concern Hampshire)<sup>xlv</sup>*
- *“We need a national Person Centred assessment process that can stand up to scrutiny and audit. A regular (annual) update process should be included in the needs assessment process. There must also be a simple appeal and arbitration system, capable of delivering a verdict that is considered binding in a short time (max 3 months). ” (Chris Munns, Turning Point)<sup>xlvi</sup>*
- *“Social care provision is generally a risk averse activity. The requirement to complete risk assessments inadvertently supports risk aversion. This problem is likely to be more severe where a small number of carers are providing support to an individual. Without management oversight it will be a natural default position to consider activities that may pose a challenge to carers as too risky and frame the risk assessment accordingly. This tendency needs to be guarded*

*against – one way of doing this is to ensure that every time risk assessment is completed, the risk of **not** doing the activity is also considered.” (Chris Munns, Turning Point)<sup>xlvii</sup>*

### **Advice, support, information**

- *“Only about 5.4% of those eligible for direct payments actually use them, despite their seemingly numerous advantages and the fact that they have been available for at least 5 years... There needs to be a concerted (preferably national) information campaign that highlights the potential benefits of personalisation and the mechanisms that are available to achieve it. This campaign should be a joint effort between commissioners and providers and needs to provide answers to some of the questions that follow – any information campaign that poses further questions will be counter productive.” (Chris Munns, Turning Point)<sup>xlviii</sup>*
- *“Professional managers in residential services are paid and trained to manage their resources effectively and economically. This includes making contingency plans to cover unexpected staff absence, sickness, administration of leave, performance management etc. This is a demanding task that will need to be conducted by the individual being supported or their family/friend – perhaps without any specific training ...What about those people who don't have close families or friends to help them organise their personalised services? ‘Standard’ services support a significant number of people that unfortunately do not have real friends and who are not close to family members. Nonetheless, these people need the support of such close associates to make the most of opportunities that personalisation offers. They should have the same choices as those who do have family/friends to support them. There is therefore a question of who will help them obtain personalised services. Unless a practical answer can be found for such people, we risk developing a disadvantaged group who will be effectively restricted in choice to residential services..... Without a universally available backup advocacy/support network capable of stepping in when family/friend support is no longer available or overstretched, there is a high risk that support arrangements could collapse and individuals revert to a lower standard of care than they had been used to.... It will be very difficult for most people to navigate the various inputs to the funding process, make best use of staff recruitment techniques, write role profiles etc., and ensure that they are getting best Value for Money.*

*Impartial ‘One Stop shop’ advice needs to be available to provide advice on all of these aspects of getting involved in personalisation. Neither local authorities nor current providers are truly impartial in this respect. There is therefore a need for a new body to provide such advice. Organisations such as the Citizen’s Advice Bureau (with its considerable ‘reach’ and good accessibility) and similar independent charities could provide this advice.” (Chris Munns, Turning Point)<sup>xlix</sup>*

- *“...the following things are key to personalisation: access to advocacy so that they have the necessary time and support to speak up and take part in decision*

making processes; making information accessible, and providing support and time so that people can understand as much as possible; ...Understanding that some people may be difficult to engage with or uncooperative for many reasons (previous negative experiences, lack of understanding or because of their disability for example), but this can usually be overcome with support, good communication and a positive attitude." (Advocacy members and self-advocacy group members of Speakeasy Advocacy)

- Provision must be made for those who lack capacity to make choices:

*"A high proportion of elderly and mentally handicapped people are unable to make suitable choices and manage their affairs and they need the support of knowledgeable close family or skilled advocates to continually advise and monitor the changing level of support required". (C.S. Drake, Carer)<sup>i</sup>*
- *"Any scheme should allow Attorneys to act on behalf of someone. It is perverse that a system designed to help people with their finances excludes such help at the very time they need it most."* (Fiona Heald, Solicitor)<sup>ii</sup>
- Information and support is needed to mitigate risk with regards to the legal obligations involved in employing one's own carer:

*"a. Provide concise high quality information on the process of recruitment, short listing, interviewing and making an offer, including example documents required for each of them.*  
*b. Provide a quality contract of employment toolkit, ideally drawn up by an employment lawyer.*  
*c. Provide concise quality information that will enable a DP/SDS user to respond appropriately to employment events.*  
*d. Provide concise quality information to enable DP/SDS employers to manage all types of dismissal.*  
*e. Provide human hands-on support to DP/SDS employers where they have not been able to resolve problems having accessed the written information provided."* (Tony Holland)<sup>iii</sup>

## **Regulation**

*"If a staff member in a 'standard' service is unexpectedly absent, there is usually enough capacity to ensure that the people supported by the service are kept safe whilst a manager arranges additional cover at short notice. When an individual is managing their own support package, this responsibility transfers to them or their families causing additional stress. How does an 11 year such as Laura cope with arranging emergency agency cover when one of her mother's carer's fails to turn up to work? In 'standard' provider services, staff are provided with induction and continuation training and this is subject to external monitoring through CSCI etc. This ensures that staff are kept up to date with regulatory and professional developments. In a situation where DPs or IBs are used to support someone with learning disabilities, who ensures that the support team are briefed on the implications of the Mental Capacity Act? Who ensures that medication procedures are properly conducted? Staff recruited by 'standard' providers are*

subject to certain recruiting procedures such as CRB checks, reference checks, nationality and health checks. They are subject to legislation on employment, equal opportunities, equality and diversity and the national minimum wage; salaries are made visible to HMR&C etc. The risk of these steps being by-passed are greater in a market place that is difficult to monitor and regulate. This poses risks for the staff involved and the individuals that are supported by them.

In order to minimise the risk of staffing problems, a form of staff regulation is needed. This can take the form of

- 'Licensing' staff to provide reassurance of their competence/eligibility to work with, for instance, vulnerable people. The licence would need to be subject to audit by a regulatory body. There would be a cost associated with administering a regulatory body.
- Accredited Agencies or other providers from whom staff can be 'hired' by individuals for their support packages. The Agency would no doubt charge a fee over and above the cost of the labour provided that would have to be borne on the individuals' budgets.
- A form of 'policing' of staff (through inspections) may be required to avoid unqualified individuals being hired or exploitation of staff. " (Chris Munns, Turning Point)<sup>iv</sup>

### **Making personalisation universal: issues in scaling-up transformation and replacing traditional services rather than having 'bolt-ons'; service provision and the care market- gaps, availability, flexibility and the nature of provision**

- "It is possible for the community to make a big difference by willingly including people with problems but this needs education and there is a limit e.g. if the patient is disruptive or is incontinent. The idea that health or adult Services can take the responsibility for taking patients to community groups which happen to be of personal interest to a patient seems impractical and effort intensive, and is likely to involve only a small proportion of the total. There is a real danger of making the personalisation case rest upon a few good examples which cannot be applied universally and use a higher than equitable share of scarce resources .. I believe that while the joint NHS/Adult service teams set up under the Innovations project are the best way forward, they are necessarily labour intensive and cannot remove the need for existing and expanded provision of Sitting Services, Day Centres, Day Care, Respite breaks. The idea of choice is a luxury that can only exist when existing demand is satisfied, and this is far from the case. " (C.S. Drake, Carer)<sup>v</sup>
- "Hampshire County Council...embraced new ideas and concepts without changing its basic structure, culture or ethos. In consequence many of these developments like, for example, the 'Innovations Project' were bolt-ons rather than becoming embodied in the department as new ways of working and cultural change." (Age Concern Hampshire)<sup>vi</sup>
- "The problem for statutory organisations is that traditionally everything provided has been provided against a background of buildings and services and disabilities. Investment in buildings, block contracts, staff employed and fixed

*packages of care are the norm and can be excellent ways to provide some care and support. They can also be limiting, restrictive, inflexible and unresponsive to the needs of individuals - with many services offering what they are prepared to do or give rather than responding to what people need as a whole person." (Carers Together)<sup>vii</sup>*

- Direct Payments cannot be universal:

*"Whilst I applaud the idea of choice I am not sure that Direct Payments are a great idea. How many people in need of care themselves truly understand that they are employers and therefore have duties to Revenue and Customs. " (Fiona Heald, Solicitor)<sup>viii</sup>*

Re: older people with dementia: *"In the majority of cases individuals are being cared for by their elderly spouse, with limited support from family. It is enough for these people to take on the role of carer without having to worry about additional paper work (a requirement if receiving Direct Payments) and certainly without having to worry about managing and organising the care package. This is not my personal opinion, this is evidence from 23 years working in a rural area with it's limited resources and the majority of my clients telling me time and time again they do not want Direct Payments, they want to be able to pass over the worry of organisation and management to someone else. (Linda Batchelor, Care manager and Social worker)<sup>ix</sup>*

*"Many parents are elderly, and do not want, or cannot cope with taking responsibility for the paperwork, and agreements needed to employ carers." (Parents/carers c/o Kingsley Organisation)<sup>x</sup>*

- There is a lack of awareness, apparent from some responses to the Commission, that personal/individual budgets will not have to be taken as Direct Payments but can be managed by a professional instead. This needs to be made clearer to the public.
- Traditional day care may need to be retained for older people:

*"Those authorities that support most people in their own homes and have the lowest number in residential and nursing home care tend to do it from a day care base - and it would be a mistake to transfer theories of "normalisation" which have rightly been applied in respect of people with learning difficulties, people with mental health problems and people with a permanent physical disability (in respect of normal day time activity and real work for real pay under sheltered placement) to the highly dependent older person at the expense of structured day care. Day Care gets the very dependent person out from their four walls, provides social interaction and by adopting a person centred approach can improve motivation and functioning and, most importantly, by involving them in planning events way into the future gives them things to look forward to in anticipation. This is now established through research by the London School of Hygiene and Tropical Medicine, "Successful Ageing and Social Interaction - A Policy Brief" - November 2007" (Age Concern Hampshire)<sup>xi</sup>*

- 2 respondents felt it is debatable whether personalised provision for older people with mental health problems is achievable and a practical replacement for day care in reality:

*“Day Care Services are limited - mainly provided by day care centres, an out of date provision, but what is the alternative going to be for people with dementia? Day centres enable the individual to be cared for in a safe and secure environment with appropriate activities, enabling the carer to have some valuable respite, alone in their own home. How will a personal budget benefit these people?” (Linda Batcheldor, Social Worker and Care Manager)<sup>xii</sup>*

*“Mental and Physical Stimulation is essential for the patient and is the most neglected service available except for Day Centres, but then only for those people who do not require personal care. Many problems can be reduced if the patient is stimulated and content. This is an area where the Private Sector does offer a limited number of Day Centre places in Care Homes as an alternative to Adult Services funded Day Centres but these are expensive... It is possible for the community to make a big difference by willingly including people with problems but this needs education and there is a limit e.g. if the patient is disruptive or is incontinent. The idea that health or adult Services can take the responsibility for taking patients to community groups which happen to be of personal interest to a patient seems impractical and effort intensive, and is likely to involve only a small proportion of the total. “(C.S. Drake, Carer)<sup>xiii</sup>*

- Lack of provision for self funders, people who are not eligible for state-funded care, carers and certain groups who fall between gaps in services needs to be addressed. Many respondents mentioned the lack of support and advice for self-funders and people who are not eligible for state-funded care, and inadequate or non-existent provision of specific services needed, such as services for people with brain injury, autism, carers, Asperger's syndrome, people in the early stages of dementia for whom there is no system to ensure they are reminded to take their medication, and visually impaired people who wish to be retained or retrained for employment:<sup>lxiv</sup>
  - *“I got no support from Social Services as I have my own money. They didn't provide any advice or information once they decided they weren't going to fund any support” (Service user, c/o Kingsley Organisation)<sup>xv</sup>*
  - *“There is concern that people who are deemed “self funders” are sometimes denied this and their carers “waved away” to make their own provision... We would be concerned that under “direct payments” and “personalised budgets” that people deemed to be “self funders” should not be denied a service.” (Age Concern Hampshire)<sup>xvi</sup>*
  - *“Its is very frustrating that there are people who fall between help. Someone with a brain injury who is neither elderly nor with learning*

*difficulties is clearly vulnerable but no one seems to wish to help once they have recovered as much as they will ever do. These people are open to abuse of all types and a befriending service would be a great idea. Such a service would work for others as well who are vulnerable but able to cope most of the time on their own." (Fiona Heald, Solicitor)<sup>xvii</sup>*

- *"People don't always fit neatly into categories or existing service provision – for example people with learning disabilities sometimes have mental or physical health issues as well, people with autism and Asperger's syndrome often fall between gaps in learning disability and mental health services, people with mild learning disabilities may not be eligible for any services but are still vulnerable and need help and support." (Advocacy members and self-advocacy group members of Speakeasy Advocacy)<sup>xviii</sup>*
  - *"At the end of the day, I and my family am willing to support my parents but would wish to ensure that they could also rely on Social Service to support and maintain my parents dignity" (Anonymous carer whose father has Alzheimer's and has refused traditional support)<sup>xix</sup>*
  - *"There is certainly a need for formal training of carers to enable them to look after their own health, and for them to be given the opportunity for respite breaks. In so far as both could be tailored for personal needs then Personalisation would make sense, but at this time neither service is adequate, not universal so that extra resources would need to be found." (C.S. Drake, Carer)<sup>xx</sup>*
  - *"We know Hampshire is considered a "rich" shire county and gets less allocation from Central Government, but please, please monitor the "UN MET" of carers and people who require a service, even those who do not meet the substantial or critical so that "we the people" of Hampshire have statistical evidence to lobby for more resources." (Janet Chierchia, Carer)<sup>xxi</sup>*
- There are insufficient numbers of paid carers available to provide flexible care at times tailored to individuals:

*"Client's who have embraced Direct Payments have not found the care service to be more flexible. The services that Care Agencies provide are limited, they are restricted by the number of carers available and willing to work unsocial hours/weekends." (Linda Batcheldor, Social worker and Care manager)<sup>xxii</sup>*

*"Personal Care is time consuming and physically exhausting. All these services can be provided at a cost from Adult Services or Agencies but because of high demand and limited resources then they are frequently not able to meet the need for regular timekeeping and quality service. This is challenging for the Carer and inefficient. Night-time and weekend services are particularly difficult.*

*The prospect of finding and funding an alternative Care Service from a private person is likely under only exceptional circumstances. " (C.S. Drake, Carer)<sup>xxiii</sup>*

- There needs to be more collaboration between social care and non social care agencies, e.g. Transport, to ensure that provision is not patchy.<sup>lxxiv</sup>

*"I understand OpenSight (Hampshire Association for the Blind) has just started up the Insight courses again for people within Hampshire. These are accessible only if you live near their HQ. Travelling as a VIP is not easy within the county." (Dennis Haig, Care broker and visually impaired person)<sup>xxv</sup>*

*"A further barrier to Day Centres is that unless the Centres are close to the users then a lot of time is taken by collecting and returning clients, and the benefit to the carer is reduced by the shorter free time and uncertain timing." (C.S. Drake, Carer)<sup>xxvi</sup>*

- Staff recruitment and culture needs to change:

*"One young man we know who receives a DP package likes to cycle around the roads near to his house. His support staff need to be able respond without delay when he says he wants to go cycling and to cycle with him. He also likes to be driven round in his car when he chooses. He requires 2 to 1 support and all of his support staff therefore need to be able to drive and cycle; there is no scope for 'pooling' skills among staff as there might be in a residential service. He is only able to do this because his family provide dedicated, proactive management of his support package. Providing a standard of support that is able to respond to needs such as this is very difficult. Many 'standard' services with perhaps a dozen or more staff have difficulty in recruiting even a few drivers, let alone cyclists who are able to keep up with a young man. For personalised services to be a genuine advance on what is available in a 'standard' home, significant extra effort (and possibly expense) is needed to recruit staff that are capable of offering the required options. " (Chris Munns, Turning Point)<sup>xxvii</sup>*

*"The problem is not at the top where the incentive and commitment to change is given – it is turning around staff at the point of access who need retraining and support to change the traditions of years. Some staff are excellent and recognise the need to change the system and provide different support to enable independence and there has been a considerable shift in recent years towards individual support. However the impetus will have a major effect on numbers and skills needed in future....Many people who are professionals start from the premise that they are giving resources or services to someone and that they need to create a series of checks and balances to make sure the gift is used correctly. No one is denying that public finance has to be spent wisely and economically – but the nitty gritty of financial restraints should not detract from the individual freedom to choose for themselves how they wish to live their lives... I recognise that the shift in provision will need careful managing and retraining of statutory organisation staff who are used to being the gatekeepers*

and the providers." (Anne Meader, Carers Together)<sup>lxviii</sup>

*"I would say it requires better trained, better paid staff (raise their profile); more flexibility and ingenuity by providers. Also, make full use of people already trained in Person-Centred Planning, to help people with a plan, and also check rigorously that organisations work in a person-centred way." (Rita Kinsey, Carer)<sup>lxix</sup>*

- The structure and role of the Local Authority could be changed:

HCIL argue that in order to achieve radical change to meet people's rights of self-determination a change in the law would be required to alter the power relationship between the client and the local authority, but recognise that local authorities have a role in providing expert advice and practical support to meet people's needs:

*"...ask whether or not the resources already attributed could not be more effectively used by the 'clients'? We should ask, what do social services do that people cannot do for themselves or find out for themselves? Today's Social Care professional expertise lies in two areas: 1- providing unbiased expert social care related advice, information and recommendation; 2 - quantifying and ensuring appropriate practical support to those identifying themselves with 'needs'. Both areas build on existing expertise at the service of the individual. Both areas can and should be 'freely available'. Do we need today's local authority infrastructure? By and large once the individual's care needs are identified, agreed and costed the financial means to meet those needs, (including purchasing services from peer organisations, individual care broker, et cetera) will be agreed and made available, thereafter the individual will be left alone unless and until he/she identifies differently. We accept that this scenario will prove challenging to some in society. Some people will want continuing practical support in the process of meeting their needs. This too should be available and costed built into 'the means to meet needs' and again outsourced by 'client' selection. Do we need an adult social care department? We anticipate that adult social care departments would be pruned to a minimum and that in most instances their roles outsourced. We suggest that in future the role of adult social care will be to identify and confirm needs and Institute the means of meeting these needs, a sign post. 'Get off our backs and leave us to get on with life.'" (HCIL)<sup>lxxx</sup>*

*"HCC might consider that "flatter" structure for central Adult Social Care management is needed so that decisions about care could be taken closer to the care user...no office holder should be allowed to make decisions affecting care users without having worked as a hands-on care worker for two weeks in current years. This practice will provide an opportunity for them to consult, to collect ideas and to work towards Dame Denise [Platt]'s objectives. This policy should precede and assist the introduction of Personalisation." (Terence Lister and R..E.. Lister, Care user and Carer)<sup>lxxxi</sup>*

## ***Conclusion***

Responses from people and organisations in Hampshire run the gamut from people who feel confident and wish to have much more control in determining their lives to those who fear that people who lack capacity or need a lot of support will be left more vulnerable; from people who want a totally different approach to care to people who are unable to get any help at all under the present system. The challenge now is to find ways forward to make the transformation meet the needs of the diverse situations of people in Hampshire and achieve a system that can truly respond to the needs of individuals yet be sustainable.

Rachel Dittrich 08.04.2008

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- i See Rita Kinsey, [My concerns about whether Personalisation can really work for a person with complex needs and living in Residential Care](#), Janet Chierchia, [Commission response](#), [Kingsley Organisation's response to the Commission](#), and Fiona Heald, [People who fall between services, people who forget to take medication, Direct Payments and attorneys](#).
  - ii See [Carers Together's response to the Commission](#), Janet Chierchia, [Commission response](#), and [Speakeasy Advocacy's response to the Commission](#).
  - iii See Janet Chierchia, [Commission response](#), [Carers Together's response to the Commission](#) and [Turning Point's response to the Commission](#).
  - iv See [Carers Together's response to the Commission](#), [Hampshire Autistic Society's response to the Commission](#), [Kingsley Organisation's response to the Commission](#) and [Turning Point's response to the Commission](#).
  - v John Evans, [Personalisation Commission response](#) and [Turning Point's response to the Commission](#)
  - vi C.S.Drake, [Personalisation of Care](#)
  - vii John Evans, [Personalisation Commission response](#)
  - viii [Carers Together's response to the Commission](#)
  - ix Caroline Harrop, [Self Directed Support in Hampshire](#)
  - x Miriam Smith, [Hampshire day care opportunities are being personalised](#)
  - xi Nicky Capell, [Treasured OPAL workers will help even more Hampshire residents](#) and [Age Concern Hampshire's response to the Commission](#)
  - xii Executive Member of Adult Social Care, [Community Innovations Project: Invest to save fund](#)
  - xiii Director of Adult Services, [Direct Payments Review Report](#)
  - xiv Nicky Capell, [Calls for independence are answered](#)
  - xv Rita Kinsey, [My concerns about whether Personalisation can really work for a person with complex needs and living in Residential Care](#)
  - xvi James Rose, [Commission response](#)
  - xvii [Kingsley Organisation's response to the Commission](#)
  - xviii [Carers Together's response to the Commission](#)
  - xixA. Woodford, [Commission response](#)
  - xx [Kingsley Organisation's response to the Commission](#)
  - xxiC.S.Drake, [Personalisation of Care](#)
  - xxii [Carers Together's response to the Commission](#)

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- xxiii [George Hollobone, Commission response](#)
  - xxiv [Janet Chierchia, Commission response](#)
  - xxv [John Evans, Personalisation Commission response](#)
  - xxvi [Terence Lister and R.E.Lister, "Personalisation" -a change for the better?](#)
  - xxvii [Jane Hunt, Commission response](#)
  - xxviii [Kingsley Organisation's response to the Commission](#)
  - xxix [Kingsley Organisation's response to the Commission](#)
  - xxx [Kingsley Organisation's response to the Commission](#)
  - xxxi [Janet Chierchia, Commission response](#)
  - xxxii [Kingsley Organisation's response to the Commission](#)
  - xxxiii [Kingsley Organisation's response to the Commission](#)
  - xxxiv [Kingsley Organisation's response to the Commission](#)
  - xxxv [Kingsley Organisation's response to the Commission](#)
  - xxxvi [Kingsley Organisation's response to the Commission](#)
  - xxxvii [George Hollobone, Commission response](#)
  - xxxviii [Kingsley Organisation's response to the Commission](#)
  - xxxix [Kingsley Organisation's response to the Commission](#)
  - xl [Carers Together's response to the Commission](#)
  - xli [Hampshire Centre for Independent Living's response to the Commission](#)
  - xlii [Kingsley Organisation's response to the Commission](#)
  - xliii [Speakeasy Advocacy's response to the Commission](#)
  - xliv [C.S.Drake, Personalisation of Care](#)
  - xlv [Age Concern Hampshire's response to the Commission](#)
  - xlvi [Turning Point's response to the Commission](#)
  - xlvii [Turning Point's response to the Commission](#)
  - xlviii [Turning Point's response to the Commission](#)
  - xlix [Turning Point's response to the Commission](#)
  - l [Speakeasy Advocacy's response to the Commission](#)
  - li [C.S.Drake, Personalisation of Care](#)
  - lii [Fiona Heald, People who fall between services, people who forget to take medication, Direct Payments and attorneys](#)
  - liii [Tony Holland, Exploring Employer Issues Relating to Direct Payments /Self-Directed Support Users Employing their own Carers.](#) These issues will be explored with more depth in Session 3: The Care Market.
  - liv [Turning Point's response to the Commission.](#) For more on regulation see [Hampshire Autistic Society's response to the Commission](#) and briefing papers for Session 3 (not yet published).
  - lv [C.S.Drake, Personalisation of Care](#)
  - lvi [Age Concern Hampshire's response to the Commission](#)
  - lvii [Carers Together's response to the Commission](#)
  - lviii [Fiona Heald, People who fall between services, people who forget to take medication, Direct Payments and attorneys](#)
  - lix [Linda Batcheldor, Commission response](#)
  - lx [Kingsley Organisation's response to the Commission](#)
  - lxi [Age Concern Hampshire's response to the Commission](#)
  - lxii [Linda Batcheldor, Commission response](#)
  - lxiii [C.S.Drake, Personalisation of Care](#)

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- lxiv See [Age Concern Hampshire's response to the Commission](#), C.S.Drake, [Personalisation of Care](#), [Speakeasy Advocacy's response to the Commission](#), Dennis Haig, [Services for visually impaired people](#), Janet Chierchia, [Commission response](#) and Fiona Heald, [People who fall between services, people who forget to take medication, Direct Payments and attorneys](#).
- lxv [Kingsley Organisation's response to the Commission](#)
- lxvi [Age Concern Hampshire's response to the Commission](#)
- lxvii Fiona Heald, [People who fall between services, people who forget to take medication, Direct Payments and attorneys](#)
- lxviii [Speakeasy Advocacy's response to the Commission](#)
- lxix Anonymous carer, [My dad has Alzheimer's](#)
- lxx C.S.Drake, [Personalisation of Care](#)
- lxxi Janet Chierchia, [Commission response](#)
- lxxii Linda Batcheldor, [Commission response](#)
- lxxiii C.S.Drake, [Personalisation of Care](#)
- lxxiv See also J.Fuge, [Putting People First](#)
- lxxv Dennis Haig, [Services for visually impaired people](#)
- lxxvi C.S.Drake, [Personalisation of Care](#)
- lxxvii [Turning Point's response to the Commission](#)
- lxxviii [Carers Together's response to the Commission](#)
- lxxix Rita Kinsey, [My concerns about whether Personalisation can really work for a person with complex needs and living in Residential Care](#)
- lxxx [Hampshire Centre for Independent Living's response to the Commission](#)
- lxxxi Terence Lister and R.E.Lister, ["Personalisation" -a change for the better?](#)