

# 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 2 : People and carers- summary of pre-existing evidence from experts and research

# Putting People First - Shaping your future, choosing your care

## Briefing Paper 2 : People and carers- summary of pre-existing evidence from experts and research<sup>i</sup>

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### Personalisation meets people's vision for social care in the future

When asked what social care services should be like in a country-wide 2005 survey of 112 service users, respondents said:

- *"Assistance to lead your life in the way that you choose" (Service user)<sup>ii</sup>*
- *"Social care should transcend disability and include education, training and support...[People's] aspirations are greater than services" (Service user)<sup>iii</sup>*
- *"Choice and control" (Service user)<sup>iv</sup>*
- *"Care statements need to look at people's whole lives" (Service user)<sup>v</sup>*
- *"More flexible services, for example, more help for older people with decorating and cleaning so that they can stay in their own homes and be independent" (Service user)<sup>vi</sup>*
- *"Social workers should be able to fine-tune each care package to that person's needs" (Service user)<sup>vii</sup>*
- *"Social care does need to engage with the issue of resources, but balance that against a sense of autonomy for the service user: care workers need to be person-centred" (Service user)<sup>viii</sup>*
- *"You need to look at desires as well as basic needs- more pleasure as well as care" (Service user)<sup>ix</sup>*

In a new study of people who do not yet receive care, commissioned by Counsel and Care, 56% of respondents stated a preference for receiving a cash sum direct from their social services department, enabling them to arrange their own social care (i.e. Direct Payments).<sup>x</sup>

It has been mooted that eligibility criteria currently favour those who 'shout loudest', while disadvantaged groups include young people in transition and older

people, against whom institutional and cultural ageism is likely to lead to poorer packages of support. Some people who have been excluded from council arranged care because they do not pass the threshold of eligibility hope and expect that personalisation (through direct payments and individual budgets) will be helpful in making implicit and explicit discriminatory practices in administering eligibility criteria more transparent and open to challenge.<sup>xi</sup>

## Positive experiences of aspects of personalisation in current services

### Bespoke commissioning and specialist services

**In Hampshire** a groundbreaking transition project is helping four 21-year old people with moderate to severe learning disabilities live semi-independently, and preparing them for further independence in the future:

*“Now, they all work at the local Pizza Hut, pay their own bills, cook, eat together and clean - with a lot of encouragement and some practical help from the team of eight support workers provided by Tact, a domiciliary support agency. They do their shopping and banking, and enjoy nights out to the pub, bowling, and bingo. They even go on holiday together this year they went to Mallorca for a week. They have their own support worker, and one of the team stays overnight, so there is 24-hour assistance if necessary. The scheme costs adult social services £214 a week for each woman - far cheaper than a residential home place. The women are also funded by Independent Living Funds and Supporting People. [Vanessa] Eales says: “There’s all this buzz about individually commissioned services and bespoke services - well, this is a bespoke service, we know that it works, and it’s cheap. We try to get best value for money but above all it’s the clients’ own choice...” [Karen] Peet [mother of one of the girls] says: “The scheme is fantastic. I never thought Jade would get a job. She does it with support but they are starting to stand back. Jade now has a life.” When you speak to Samantha, the most gregarious of the four, she clearly enjoys her time. She says: “I’m happy, I love it here. I feel proud of myself.” ”<sup>xii</sup>*

It is predicted that the ethnic minority elderly population will increase ten-fold in the next twenty years to two million as migrants who came in the 1950s age. Research shows that minority older people are increasingly seeking social care from public sources as it is becoming less likely that their family will care for them due to different patterns of employment, people moving away and smaller houses.<sup>xiii</sup> Specialist tailor-made social care services can be very beneficial to members of minority populations:

- *“We had a big person who was now like 30 years in the hospital, for 30 years he never tasted Indian food and he was Indian and he was asking nobody knows what he wants. And he came out he couldn't speak and when he came here he was lively, he was eating his food and we - it was shocked.” (Jyoti Raja, committee member for a day centre in North London run by the Asian People’s Disability Alliance)<sup>xiv</sup>*
- *“People are getting more dementia. In the Asian background if there’s somebody speaking their own language then they can respond better, better than in other mainstream centre. I’ve got one dementia client here, he’s so happier in this environment. When he started he didn’t want to stay here but*

*now he wants to come here, he doesn't want to go away. Now when they come to collect him he doesn't want to go. So that makes a difference of all the environment - cultural environment not language environment - the food he likes, it makes the completely different life." (Myash Armin, Coordinator at the day centre)<sup>xv</sup>*

Some councils have begun to move away from traditional institutional respite care for people with dementia to more creative models that might be more acceptable to people who had previously turned services down and improve quality of life for the carer and the person with dementia. Dundee City Council provides day care activities that are determined by the needs of service users. After consultation with users and their carers it was agreed that service development would enable people to continue doing what they had done before the onset of dementia e.g.: going to the pub; going out for something to eat; going for a walk; going to the bookies; going for an ice cream.<sup>xvi</sup>

### **Person-centred planning**

Person-centred planning is a process designed to assist someone to make plans for their future. It is used to enable individuals to increase their personal self-determination and improve their independence. It has been Government policy for people with learning disabilities since 2001 through the 'Valuing People' White Paper. Personalisation means that methods of person-centred planning will be extended to all vulnerable people. Research by Lancaster University has shown that people with learning disabilities who had a person-centred plan experienced:

- a 52% increase in the size of their social networks;
- 2.4 times more contact with family;
- 40% increased contact with friends;
- 35% increase in activities;
- 2.8 times greater chance of having more choice.<sup>xvii</sup>

### **Self-directed support and personal budgets**

Pilots of self-directed support- where people are allocated personal budgets so they can shape, with the advice of professionals, the support and services they need- have been a successful means of delivering a more personalised approach. Evaluation of the 17 pilots has shown that most people who are self-directing the support they get believe it makes a positive difference to many aspects of their lives. Of the 196 participants,

- 47% reported improvements in their health and well-being since starting self-directed support;
- 55% were able to spend more time with people they liked;
- 77% said their quality of life had improved;
- 72% said they had more choice and control over their lives;
- 59% said their lives had more dignity.<sup>xviii</sup>

Only a small minority, about 5% felt their lives had got worse in any regard.

A previous evaluation by Lancaster University of self-directed support in six local authorities found that, once people took charge of their individual budgets and support, their satisfaction with the level of control in their lives rose from 42% to 97%. Satisfaction with their support rose from 48% to 100% even though, in some cases, costs were reduced. Savings ranged from 12% in one local authority to 33% in another.<sup>xix</sup>

**In Hampshire** in 2006/2007, working with the In Control national programme for self-directed support, we piloted the 'Dynamite Project': self-directed support with 6 young people with disabilities and their families. We found that self-directed support had significant benefits for carers as well as service users such as 'Laura', a young lady with severe learning disabilities:

*"Prior to embarking on the pilot, Laura attended her local in-house day service, but although she found some of the sessions enjoyable, many she did not. The service was not tailored around her, and she had to fit in with the system. This meant that Laura often got bored and so did not want to go to the day service at all. This had a significant impact on Laura's parents who were not able to work, whilst caring for Laura when she stayed at home.*

*Due to her involvement on the pilot, Laura has successfully been supported to develop a comprehensive support plan, which is costed and linked to identified care providers. The plan is very person-centred and provides a holistic package of care, which meets the needs of both Laura and her family. Laura's support plan starts by illustrating who she is, what is important to her and it provides a description of her dreams and the realistic steps needed to achieve them. This involves aspects of Laura's life that she wishes to change, and also aspects that need to be maintained, in order for her to remain happy. The plan also meets the needs of Laura's parents by providing support for her during working hours, so they are enabled to work. This was developed using a model called, 'My ideal week', which involves outlining the things that need to happen for a week to go well, as well as identifying things that need to be avoided.*

*It was not possible to include an anonymous copy of Laura's support plan in this report, since there is so much of 'Laura' in it, that to remove all the information that identifies her would make the resulting document meaningless...*

*Laura's father was adamant that developing this support package would not have been possible, were it not for the family's involvement in the Dynamite Pilot. He described self-directed support as "A radical change for the better that puts the person in control".<sup>xx</sup>*

When Demos undertook 40 interviews with services users in 12 authorities they found that having the power to design one's own plan enables people to think more creatively about the services they want and what they want to achieve in life:

- *"Gavin, for example, who was diagnosed with multiple sclerosis four years ago knew he did not want a traditional service at a day care centre. Instead Gavin uses his personal budget to pay Norma, who visits him to help out with ironing*

*and cleaning. Norma's support fees up Gavin's wife Karen who looks after Gavin's personal and intimate care- dressing, bathing and washing- something he doesn't want anyone else to do.... Simon, a personal-budget holder from Essex, has become less depressed and isolated because he can use his personal budget to pay a friend a few pounds to take him to the cinema, something that was virtually impossible under his local authority care plan.*"<sup>xxi</sup>

- *"Brenda ... is elderly, confined to a motorised wheelchair, frail, and almost entirely dependent upon her husband for her personal care. Yet the way she has reorganised her care, using a personal budget and a self-directed support plan, provides a model not just for the reform of social care but for many other public services. Brenda was not enamoured with her local authority respite services, so when Oldham council gave her the opportunity to take a personal budget she jumped at the chance. She quickly employed two market traders she knew as personal assistants and bought a car that could carry her wheelchair. Now, when she wants her husband to have some respite, her carers drive her to a market, often with one of her friends, and they go shopping. When Brenda wanted a longer break, she bought very cheap flights to Tenerife and booked herself and her carer into a hotel designed for people with disabilities. The trip was cheaper than going to Oldham's specially designed respite care centre, and she gets personalised services at a lower cost than a standard care plan devised by social workers."*<sup>xxii</sup>

The Guardian recently interviewed people who have experienced personal budgets and self-directed support:

- *Christopher Bott, 26, Newport, Shropshire has complex physical and mental disabilities and is unable to speak or move unaided. He lives with his mother near Newport, Shropshire. She says: "Before Christopher was given an individual budget in June 2007, he was going to a day centre for 15 hours a week and we were very unhappy with the arrangement. There were people with all sorts of different needs and Christopher seemed to spend a lot of time sitting in his wheelchair. He needs quiet, personal attention to develop, and now we are able to give him that thanks to the budget. I heard of personal budgets at a carers' meeting and thought, 'that's it'. I had to write a very detailed account of the support Christopher needed and we were given funding of £113.46 a week to provide 15 hours' care. I had to set up personal liability insurance, a bank account where the allowance is paid fortnightly, and make tax arrangements - but that was easy. We do PAYE online. Christopher now has a structured day, has undivided attention from a personal assistant, is spending less time in the wheelchair and is becoming more mobile. After a lot of difficult years with health and social services, it's good to be able to endorse an arrangement wholeheartedly."*
- *David Adderley, 54, a mental health service user, lives near Barnsley and has had an individual budget for a month. His annual budget is £5,180, which covers 26 sessions at a day centre and five hours a week from a support worker. Adderley says: "Someone from social services came and told me about individual budgets and I liked the idea of being asked what I wanted, and*

*being able to spend part of the money on going out. I want to go to Bridlington, Leeds and Bradford. I like the idea of choice, but would find it too stressful to handle the administration, so my social worker does that for me. But I know how much is in the budget and how much I have left. And I was able to say I wanted an extra hour from my support worker. We go out shopping together and we're working at improving my diet and getting me back to doing more walking. I was pleased to be asked what support I wanted and what was important to me."*

- *Sean Dunn, 20, has been receiving an individual budget for 18 months. He has a learning disability and previously lived in a children's home. He now lives in supported housing and works four days a week in a recycling social enterprise. He hopes to get a job at a fencing company. Dunn says: "Before I started on the individual budget scheme I was quite angry and frustrated and my life wasn't really going anywhere. I was easily led and got into trouble. But gradually I have developed confidence and shown I can be trusted to do things on my own. I like the fact that the support is flexible and can be varied according to what I feel I need. I go to work alone, taking a taxi and I am working towards getting a paid job. I think I should be ready for that in 12 months. At the beginning, my support workers asked what was important to me and I said a nice home, nice things, good friends and independence. My life now is certainly much better. I've made good friends and walk the dog for one of my neighbours every day. I share my house with two others and have become very house-proud. I'm also part of a service users' group. I set goals with my support workers and I work towards them. I'm learning new skills and my confidence has grown enormously. I can see a future now."*
- *Tony Bennett, 53, says he knew nothing about individual budgets last year when he moved, with his wife Caroline and two children, to his father's home in Friskney, Lincolnshire, to look after him. Dennis Bennett, 81, has Alzheimer's. Tony Bennett says: "My mother was already in a care home, and the services my father was getting at home just weren't working. They would come and give him breakfast and lunch, but they were too rushed to talk to him so didn't know if he ever ate it. The microwave meals were piling up and he was living on crisps and biscuits. He was deteriorating and becoming isolated. So I rang social services and said: 'We are caring for him but need some support. What can you offer us?' Eventually they told me about individual budgets. We wrote a very detailed support plan and were awarded a budget of £4,168, to which we had to contribute £234. This was great because it provided for respite care to enable us to go on looking after my father. He used to go to my mother's care home for six hours a week, plus some overnights.... Someone like my mother would not have been able to cope with the administration, but it wasn't complicated, and the money came through very quickly. My father improved physically and used to come out for walks with the family. It was a huge improvement on the previous situation.... Moving to user-driven services may involve a lot of heartache, but from my experience there were no negatives to personal budgets."*
- *Jacky Korner, a retired senior manager with Barnsley council, was diagnosed with Alzheimer's in 2005, aged 54. She remained in her own home with 24 hours-a-*

*week care from social services, but when she started wandering at night she had to be admitted to a residential home for eight weeks in March last year. Then her best friend of 40 years, Hilary Tucker, a retired college principal, who held an enduring power of attorney, was offered an individual budget. This allowed Korner to be cared for in her own home until her death in November. Tucker says: "I was very dubious at first, fearing the arrangements might be complicated and difficult to oversee from Cheshire, where I live. But it was marvellous and made a great difference to Jacky's life. She became a ghost of her former self in the residential home and said she didn't like being surrounded by people she didn't know. Barnsley did a financial assessment and Jacky received £500 a week from social services and contributed £250 a week herself for a carer who lived in. I set up a bank account and found a wonderful Polish carer through an agency recommended by Barnsley social services. The agency charged £85 a week, but they trained the staff and helped find holiday cover. The carer received £420 a week, which I paid, plus her keep. A kind neighbour ordered the food online and liaised with the carer. The carer stayed for the rest of Jacky's life and provided superb support. Since Jacky was back in her own home, she became much more cheerful and friends started to visit again. "She had always loved her independence and this way she was able to maintain some of it. It was also economical. A specialist nursing home would have cost about £1,400 a week - and she would not have liked that situation."*<sup>xxiii</sup>

Individual budgets can provide greater flexibility to meet the needs of people who might have refused conventional services in the past:

*"Mr G had previously refused meals on wheels, but now employs someone to fetch a meal from his local pub."*<sup>xxiv</sup>

## **Direct Payments**

Direct Payments are one way that people might receive their personal budget. People who do not want Direct Payments or cannot manage them safely will know of their nominal budget but the local authority will administer it and pay providers. Others will have a combination of the two. From those who have Direct Payments, views have mainly been positive.

*"It's given me my life back. Now I control who's helping me and when they come in. It's also given me a social life and I can do things that I want to do."*  
(Service user)<sup>xxv</sup>

Findings from a consultation by Sense on deafblind peoples' experiences of Direct Payments include:

- 65% of respondents who currently receive them felt that they had changed things for the better;
- 45% felt they had more control over the services they received through direct payments.<sup>xxvi</sup>

**In Hampshire**, responses to a 2007 consultation in Direct Payments include:

- *"The Direct Payment scheme has been an absolute godsend."* (Hampshire resident)<sup>xxvii</sup>

- *“Direct Payments gave my son opportunity to have his say in what he wanted to do and how and when he wanted to do this. It has been BRILLIANT.” (Hampshire resident)<sup>xxviii</sup>*
- *“Direct payment is fantastic, I live in my own home independently. I could not possibly do this without direct payments. Thank you so much.” (Hampshire resident)<sup>xxix</sup>*
- *“Direct Payment Scheme has given me back my independence.” (Hampshire resident)<sup>xxx</sup>*
- *“The Direct Payment Scheme has worked out perfectly for us.” (Hampshire resident)<sup>xxxi</sup>*
- *“Being fortunate, I have been able to find a carer who is known to me, who is able to attend when required which I’m quite sure wouldn’t be available through Social Services. Therefore am very grateful for direct payments with which to pay her.” (Hampshire resident)<sup>xxxii</sup>*

## Telecare

*“Sara lives with, and cares for her 76 year old mother Alice, who has dementia. Sara enjoys her job, but she found her work was suffering because she constantly worried about her mum as she had left the house on a number of occasions and had been brought back home by the police as she had become lost. Other risks were causing great concern, and Sara was considering giving up her job to care for her mum full time. Alice had a tendency to leave the gas cooker on unlit whilst trying to make a cup of tea. Sara was concerned that a serious gas leak may start as a result and so introduced an electric kettle, however Alice had tried to use this on the gas cooker. In addition, Alice had fallen several times whilst going to the bathroom in the night as she found it difficult to remember to turn the lights on. This was affecting Sara’s sleep as she was so worried about her mother falling. The local authority introduced a range of telecare sensors to her care package including:*

- *Property exit sensor – this alerted the 24 hr response centre when Alice opened the door and went outside, raising an alarm. The operator was able to speak to Alice and reassure her by encouraging her to come back indoors. This was followed up by a visit by the Response Team to check that Alice was back indoors and no one had entered the property.*
- *Gas detector and shut off valve – this ensures that if Alice leaves the gas on, it is automatically switched off. An alert is also sent to the response centre who informs Sara of the situation.*
- *Bed sensor linked to an automatic light system – has also been installed in Alice’s bedroom so that if she wakes up in the night and gets out of bed, the lights automatically come on gradually. If she doesn’t return to bed within a certain time, the sensor alerts Sara.*
- *Sara is thrilled with the new arrangements. She says: “Since the*

*telecare equipment has been installed I have been able to continue working, reassured that Mum will be OK. The lights are fantastic – I don't need to worry now at night when Mum gets up. The equipment really gives me peace of mind.* " xxxiii

## **The paradox of personalisation**

A paradox exists in that some service users, specifically some older people, want to *be able to choose* to opt out of obtaining certain aspects of choice and control over their services as they feel having this choice and control will give them more stress.

*"The downside of this is empowering people with something they don't want. Some people may find this totally against their wishes because they have never been put in this position. Are they being expected to do far more than they feel is right for them?" (Service manager) xxxiv*

In particular, some people do not want to have Direct Payments:

*"As a social worker having tried to encourage Direct Payments which gives greater control [I found it] was not received well by many elderly people, but also often by their relatives who found it to complicated and too much work to deal with that!" xxxv ('V', Social worker)*

**In Hampshire**, responses to the 2007 consultation on Direct Payments included:

- *"I don't have Direct Payments because I've always felt that I couldn't take on any more responsibility i.e. paperwork/book-keeping/being an employer/dealing with tax, payroll etc. Life is hard enough. Please try to make this as easy for us as possible - I can't keep on top of everything now as it is. Thank you for listening." (Hampshire resident) xxxvi*
- *"...difficult to find someone to work for me - lucky to get carers - need someone trained to do things - would be more pressure to deal with this - as old person dealing with physical changes - don't need extra worry - do all other things self like bills, don't want extra - no one to help with this - like idea of self-directed support, choose what not manage for self." (Hampshire resident) xxxvii*
- *"As a family member who has to totally organise my mothers' life, I think I could find Direct Payments quite difficult to cope with. I also have my own life - a family, job etc. It is hard and stressful finding the time and dealing with all the complications." (Hampshire resident) xxxviii*

**However, it is important to note that with a personal (or 'individual') budget, the money people are allocated to spend on any reasonable means of enhancing their wellbeing does not have to be taken in cash as a Direct Payment. It may be administered by the local authority instead, or partly by the individual and partly by the authority. This means that personal budgets can work for those for whom direct payments are too risky, complex or stressful.**

When 60 people with learning disabilities piloted self-directed support in 2003, all chose to move out of residential care.<sup>xxxix</sup> However, many older people who piloted individual budgets in 8 local authorities in 2006/07 adopted a 'mix and match' approach, combining conventionally commissioned care services with a small direct payment to purchase additional services or equipment:

*"Mrs L uses most of her allocation for traditional home care, but keeps a small amount each week as cash for holidays and emergencies."*<sup>xi</sup>

Some people will want to stay entirely with traditional services that they are familiar with (e.g. day centres) rather than becoming an independent commissioner of services. This may be difficult to provide if the majority of service users choose other options.

- *"From an older person's perspective, is it worth the bother? They will say 'I don't want to be a fuss; I'll just have the care provider'. It's those kinds of things with older people."* (Service manager)<sup>xii</sup>
- *"A lot of the elderly don't want the choice. They are of the age where you used to go to social services and say 'I have got a problem' and social services provided the answer. And now they are being asked 'what do you want?' Well they don't particularly know what they want."* (Service provider)<sup>xiii</sup>
- *"Closure and consolidation of local authority services is almost inevitable. Yet some local authority provision will be necessary for a minority who still need and want it."*<sup>xliii</sup> (Charles Leadbeater, Demos)

Some feel that personalisation is the state 'opting out' of social care and 'washing its hands of responsibility':

- *"Society has a responsibility to those who, through age or infirmity cannot manage their own affairs.... The elderly, who may be able to manage at basic levels, often cannot locate, call and coordinate present system. This is not giving more choice, it is abnegating responsibility for the weakest in society."*<sup>xliv</sup> (Jay Morgan, Member of the public)

## **Experiences of a lack of personalisation in current services, and barriers to personalisation**

Factors that prevent personalisation include financial issues, risk adversity, ideological issues, lack of information to help make choices, lack of creativity and flexibility in service provision, a 'one-size fits all approach', and a lack of alternatives to statutory support. A recurring theme is that social care fails to offer choice and can at best meet only critical personal care needs, not social 'wants' due to financial restrictions. Inadequate staffing, for example, can mean that care is so depersonalised it affronts personal dignity and offers not even the most basic choices.

### **Risk adversity**

Risk adversity can inhibit choice and personalisation.

- *“A resident had been sitting at the table talking with the inspector. At 7.10pm the inspector left the dining room. The inspector next saw this resident in bed at 7.20pm. The resident said that she had not asked and did not want to be in bed. The care plan said that the bedtime was 9pm. When staff were questioned about this they said that this resident had to be put in bed for their safety. They were at risk if left in the lounge in the chair.” (Inspection report)<sup>xlv</sup>*
- *“The people in the home said ‘we can’t let you go out as we can’t take the risk that you might get run over.’ (Care home resident)<sup>xlvi</sup>*
- In order to reduce risk and ensure quality, other countries have used lists of approved personal assistants, set up voluntary organisations offering registered personal assistants from a pool, or organised their employment and payment through statutory agencies. These schemes have on occasion given rise to angry protests by some care users, who see them as an attempt to recolonise services.<sup>xlvii</sup>

Personalisation and self-directed support encourage people to design their own care packages, which might include creative ways of approaching meetings needs involving potential risks. Research suggests that this is what most people want.

- Comments from older people in a 2006 research report on choice and risk include:
  - *I recall my mother saying, when she first faced a raft of assessments, that the professionals [unintentionally] treated her as if she had just arrived on the planet as a problem older person, rather than as a woman who had already managed some 86 years without the involvement of services.”<sup>xlviii</sup>*
  - *“You should be able to make your own decisions, depending on what level you feel safe at. You spend your whole life making decisions about things- your work, your relationships, your children. You don’t want to suddenly give up that responsibility because you’re older.”<sup>xlix</sup>*
- In Control say:

*“Managing risks – visiting a swimming pool, crossing a road, going for a walk in a park – is an important part of everyday life, which young and non-disabled people take for granted. In Control shows that even people with severe learning and physical disabilities and frail elderly people want more scope to manage the risks associated with their care. As one personal budget-holder told us:*

*“You feel like a baby with direct services, like an adolescent with direct payments, and like an adult with a personal budget. Because it means being allowed to take a risk which most people take for granted, but which is a big deal for me.”<sup>l</sup>*

However, although the majority of research suggests that self-directed ‘consumer-led’ schemes are safe, vulnerable people who have more freedom and choice can be at risk from abuses and incompetence of all kinds.<sup>li</sup> Last year, in

*Community Care*, a social worker in a London borough spoke about a client who was taken advantage of:

*"She came across one elderly man whose agency domiciliary care worker was sacked but on his wishes continued to visit him. Her mother, a convicted thief, was also on the scene. He used direct payments and gave them his PIN so they could do his shopping.*

*"By the time I went to see him he was in debt and living in squalor. I had to remove him there and then. I got the police involved but no action was taken because it was one person's word against the other."* <sup>lii</sup>

Moving to personal budgets does not mean that local authorities do not have a role in risk management. They retain a duty of care and will administer personal budgets in full or in part for a client where a direct payment might be too risky. A local authority has the responsibility to approve an individual's plan and it can intervene where it believes there is an undue risk. It is essential that people are given enough support they need to minimise risks and that monitoring is in place.<sup>liii</sup>

### **Lack of sufficient support**

Nearly half of the respondents to the Sense consultation on Direct Payments felt there was not enough support provided for managing the Payments.<sup>liv</sup>

### **Lack of information to enable choice**

The exercise of choice and informed decision-making depends on up-to-date, accurate, accessible information about available service options.

- When CSCI undertook a 'mystery shopping' exercise to see what information 150 councils would give about social care services at the first point of contact, they found room for improvement:
  - In 15% of cases the mystery shoppers had to telephone three or more times before getting an answer;<sup>lv</sup>
  - 5 calls were abandoned completely after the shopper was unable to get through to someone after six attempts;<sup>lvi</sup>
  - Some mystery shoppers felt that they were being pushed towards the private sector;<sup>lvii</sup>
  - Of those councils that said they would send written information, 11% failed to materialise;<sup>lviii</sup>
  - *"One said point blank we don't have any leaflets to give out. Your elderly relative can pop around to the library and pick stuff up. So I said 'we live 200 miles apart' to which she replied 'Well the next time you are visiting you can go down to the library for her;'"* <sup>lix</sup>
  - Nearly 40% of the information packs received also contained commercial information. The expert panel thought there should be more from the voluntary sector included. A brochure for frozen ready-meals appeared in a number of packs and there was no explanation as to why these councils appeared to be endorsing that particular

- company over meals services provided by the main supermarkets or any other local companies that do deliveries;<sup>lx</sup>
  - 25% of the packs were either poor or very poor when it came to accessibility;<sup>lxi</sup>
  - A third of councils said they did not have information for someone with poor sight.<sup>lxii</sup>
- Findings from the consultation on Direct Payments by Sense include:
  - 75% respondents were not given appropriate information on Direct Payments;
  - Over half felt that the local authority had not promoted Direct Payments enough;
  - Only a third had first heard about Direct Payments from their local authority, despite the fact that local authorities have a duty to tell individuals who are eligible about Direct Payments;<sup>lxiii</sup>
  - 5 respondents felt they were not given an alternative of receiving a service from the council instead of receiving Direct Payments. This is contrary to the Department of Health guidance on Direct Payments, which states that the council must make it clear that people do not have to accept Direct Payments and the council will arrange services in the normal way if they do not accept them.<sup>lxiv</sup>
- A recent review of research found that carers are ill-informed about services, individual providers and what they can offer. Instead, they often rely on family and friends for information about what services are available, which can further undermine their capacity to make choices as the preferences of people they care for often conflict with the needs and wants of the carer.<sup>lxv</sup>

### **One size fits all, institutionalisation**

- *"I am one of the lucky ones. I have survived a crazy system that crushes your spirit and stigmatises you... I am now on the road to recovery. People need to be treated as individuals, not packed in a box, which is just convenient for mental health services." (Lucy, Service user)<sup>lxvi</sup>*
- *"The one-size-fits-all approach to the trip to Worthing (it was always bloomin' Worthing because 'it would be good for us') was not what several of us wanted. Why the heck couldn't we go somewhere else? We would have liked something different (and cheaper) like a trip to some woods to see the bluebells. There was a rather unimaginative, institutional approach which could have been avoided if we had only been asked." ('John Cobbett', Care home resident)<sup>lxvii</sup>*
- *"There is a lot of expertise among the residents but the skills that they have developed in their lives are completely wasted here. There are several residents who have been first-class cooks and gardeners who could input into the home. There are a lot of things that we could share if given an opportunity but the running of the place is not shared with us, which is a shame. Things just get settled." ('Alex Thompson' Care home resident)<sup>lxviii</sup>*

- *"I have never yet met a parent whose child is going through transition who says 'I want them to go to that day centre for the next forty years and have the same key worker and the same friends doing the same thing every day' And I have not yet met an older person who says 'I want to go and stagnate'." (Senior manager)<sup>lxxix</sup>*

### **Lack of flexibility**

- *"The council took a very rigid view of Direct Payments. It was 'if we give you money for half an hour of personal care between 8 and 8.30 that's what you have to spend your direct payment on'. Well what's the bonus? Why should anyone take on the responsibility?" (Carer)<sup>lxxx</sup>*
- According to Department of Health guidance, local authorities should make sure that Direct Payments are sufficient to enable the recipient to secure a service of a standard that the council considers is reasonable to fulfil the needs for the service. There is no limit on the maximum or minimum amount for a Direct Payment. However, some deafblind people have not been given a high enough hourly rate to recruit staff with the specialist skills to meet their needs.<sup>lxxxi</sup>
- In a recent national survey of carers of working age undertaken by the University of Leeds almost half of the 1909 respondents said the use of services by themselves or the person they are caring for is limited by the fact that services are not flexible enough. 43% also said that services are not sensitive enough to their needs.<sup>lxxxii</sup>
- *"Social care's lack of priority means it is financed through non ring-fenced budgets resulting in permanent insecurity and an uncreative approach to service delivery." (Service user)<sup>lxxxiii</sup>*
- In Australia, it was noticed that some recipients of individual budgets who belonged to ethnic minority groups found the flexibility of the schemes enabled them to access culturally appropriate services, while others found the barriers to accessing the schemes even higher for them than for other service users.<sup>lxxxiv</sup>

### **Critical needs, not wants, lack of staff, and financial restrictions on choice and control**

- *"You have to say 'I need...' to get anything, not 'I would like...' or else you end up getting nothing." (Service user)<sup>lxxxv</sup>*
- *"I've got to fight to be able to go to church." (Service user)<sup>lxxxvi</sup>*
- *"In a job which requires ten people, they have three people to do it." (Service user)<sup>lxxxvii</sup>*
- *"Mrs H was kept waiting up to three hours before being taken to the toilet. The staff only take them to the toilet after lunch and tea. All residents have pads on. Matron said: 'They go to the toilet when I say so; the pads hold three litres of fluid'. Her attitude is that it doesn't matter if they wet themselves. Mrs H said: 'My mum is compos mentis, and knows when she wants to go to the toilet'. Matron said: 'I can't take your mother to the toilet six times a day.'" (Complaints data)<sup>lxxxviii</sup>*
- When Gill Bailey of Helen Sanderson Associates did some person-centred work to find out what mattered to people and how they wanted staff to support

them in a care home near Manchester it helped the staff to see Florrie, a 98 year old lady, as a person rather than a mouth to feed. Without this special project this would not have happened:

*"I was really upset that after working at Tree Lodge for 9 years, I didn't even know that Florrie had led such an interesting life or worked as a housekeeper. We never get chance to talk because we would get in trouble if the chores don't get done."* (Staff member)<sup>lxxix</sup>

- *"The most fundamental factor in undermining the impact of person-centred planning is the lack of responsiveness of human services and other service systems to the kinds of lives people want. Nothing undermines the efficacy of a person-centred approach more; families and individuals are encouraged to have the courage to say what they want, often after years of feeling ignored, only to find barriers in the way of what they want to achieve, which are usually summarised in three words: lack of resources."* (Steve Coulson, Person-centred planning facilitator, trainer, author, Edinburgh Development Group)<sup>lxxx</sup>
- When Wiltshire Council cut Direct Payments for 'leisure opportunities' in 2006 it meant that the former recipients were no longer able to undertake some of the activities that other people take for granted:

*"I think it's disgraceful," says Vivien Cantrell, who has written to prime minister Tony Blair about the council's conduct. Cantrell, who has been registered as disabled since 1992, has fibromyalgia, a chronic condition that causes intense musculoskeletal pain, and also suffers from ankylosing spondylitis, which she was diagnosed with in her late teens. Now she fears her mental health will suffer because of the inevitable reduction in her social life. She has had to stop using her personal assistant of two years, Colin Biggs, meaning she will find it difficult to make her way around college and travel anywhere (although she can drive herself, she needs his help to get in and out of her wheelchair). She'll also lose a companion with whom she has clearly struck up a close relationship. It won't be so bad in the summer, she says, because at least she can sit in the back garden of her house in Corsham, four miles from Chippenham, where the temperature is nudging 30 degrees centigrade when I visit her. But she fears for her health in the winter when she will be stuck in the house."*<sup>lxxxii</sup>

- [On self-directed support] *"It's a very good concept to enable people to have choice and control but because of the financial restrictions you can't help thinking there is a lot of rhetoric."* (Commissioning manager)<sup>lxxxiii</sup>
- *"The government is driving hard on its personalisation agenda, setting an ambition that all service users have control over the support they need. But the good intentions of a policy that currently is just a coating of values without the commitment of cash gives way, when scratched, to hidden rationing and restrictions, with choice and opportunity being overwhelmed by a declining quality of life and more stress...it carries the dangers of just passing on to disabled people the requirement and responsibility to be the restrictors of their own ambitions and the rationers of their own quality of life. At worst, personalisation could be a charade for keeping service users excluded and disadvantaged, still at the margins, and then blaming them and holding them to account for how they fail to manage their lives and aspirations with the little*

money that is made available." (Peter Beresford, Service user and Professor of Social Policy at Brunel University)<sup>lxxxiii</sup>

- "If you don't qualify for personal care, you don't get home care- and I think that is very wrong. I think personal care is one of the last things you want to give up and yet you can't have some help in the home if you won't accept personal care and I think that is very wrong. Because providing somebody could do the housework it could keep that person in their own home, whereas if their house goes to pot social services walk in and say you can't live like this and away you go to a care home" (Person ineligible for council-arranged care).<sup>lxxxiv</sup>

- The tightening of eligibility criteria and personalisation are, arguably, diametrically opposed. CSCI recently commissioned research on people who are not eligible for council-arranged care in order to inform 'The State of Social Care in England 2006-07'. The research, which took place in 6 councils, found that whereas people who received council-arranged care were obtaining better outcomes as services become more personalised, the majority of those ineligible were receiving less help than they needed and experienced a poor quality of life.<sup>lxxxv</sup> One carer- who was acutely ill herself- had repeatedly tried to get day care for her husband who had dementia, but with little success:

*"The social worker, she did suggest respite care... but she had this thing about respite care, when you are on the bottom we will take him away... where you are saying 'why should I have to be on the bottom, crying on the phone? Why can't we just set something up once a week?' To stop getting into that state."*<sup>lxxxvi</sup>

- A recent study found that, though self-funders might be thought to have the greatest choice and control of all as they can use their money as they please, in practice they are often the most disadvantaged and isolated in the whole system:

*"Rather than making active choices, many appear to end up in their situations as a matter of chance."*<sup>lxxxvii</sup>

- Research evidence shows that 'informal' carers experience a marked lack of choice and control: they may find it difficult to accept respite breaks due to feelings of obligation and duty to the person they care for; their opportunities can be restricted by the explicit objections of the care recipient. When carers do make a choice, those choices are 'least worst' rather than positive (e.g. choosing to carry on caring or ask for the recipient to go into residential care). Their opportunities for choice and control are further compounded by the limited budgets of statutory services and eligibility criteria. Carers have very little opportunity to combine paid work with their caring role. Studies show that they refuse or stop services because they (or the person they are supporting) cannot afford them.<sup>lxxxviii</sup>

*"Most people I know who have responsibility for people with Alzheimer's have guilt going most of the time, some level of guilt somewhere inside themselves. For a start a lot of people who've got Alzheimer's behave in such a difficult and distressing way and they're not often like the person who you once knew, so there's a kind of rage at this person that you're confronted with - how dare you take away my mum, how dare you take away my dad and you're making me*

*feel really upset and really nervous and really tired. A great cocktail of guilts, I think, swirls round most of us. And one of the frustrations to me about this whole issue is the fact that we don't talk about it enough and all over England there are people carrying this huge sack of guilt about with them, thinking that they're really lousy people when all they really need to know is that virtually everybody else who looks after someone with Alzheimer's feels exactly the same way as they do...*

*...if you foster a kid what are you going to get- around about 350 quid a week. If you are in charge of looking after the care of an elderly person you get 48 quid a week. And if you earn more than 100 quid a week, apart from that, then they're going to take it back from your pension. What a big thank you that is for sacrificing your life in order to look after an elderly person." (Tony Robinson, Carer)<sup>xxxix</sup>*

Personalisation will only transform social care if there is sufficient money to enable all people who need care, and their carers, to benefit from it, rather than just those people who are judged according to eligibility criteria to be in 'critical' need. If there is not enough money for people with substantial, moderate and low needs to receive any kind of social care, personalisation will be meaningless to them and their carers and prevention will not be possible. As Counsel and Care have stated, the responsibilities of families are continually increased by ever-tightening eligibility criteria for social care that mean many of them have to take on a greater caring role, often to the detriment of their own health.<sup>xc</sup> When 'informal' care breaks down, due to the carer's own health failing, or because they do not want to carry on the caring role through lack of support, this then leads to emergency intervention when the person being cared for reaches crisis point. There are almost 6 million unpaid carers of adults in the UK saving the economy £87 billion per year. Without them, the social care system would collapse.<sup>xcii</sup>

### **Lack of alternatives to statutory support**

Some people who receive Direct Payments have had problems in recruiting suitable staff to employ themselves. 70% of respondents to the Sense survey who receive Direct Payments said it is hard to find qualified or experienced staff.<sup>xciii</sup>

People in need who do not meet eligibility requirements for council-directed care are usually signposted to other sources of help and support. Recent research in 6 authorities found that signposting typically left people having to take the initiative of finding any help, and at times people ran into a dead end with no offer of help and no idea of where else to turn:

*"She gave me a list of where I could contact different sorts of people and I contacted [voluntary organisation]... they said they would be in touch with me... I waited five weeks.. I had a letter and it was to say that at this moment there was not any likelihood of me getting any help" (Person who does not qualify for council-arranged care)*

*"They gave me [a voluntary organisation] to contact, and [they] said they don't know if they can help us or not because they have got so many people on the books" (Person who does not qualify for council-arranged care)<sup>xciii</sup>*

## How it can be paid for

It has been argued that personal budgets may provide direct cost savings to the social care budget of around 10% when compared to traditional services.<sup>xciiv</sup> It has also been suggested that there may also be longer-term and indirect savings to the public sector as a whole:

*“Julia... has a serious respiratory problem, which used to keep her in hospital for three months a year. Julia knew her problems would be eased if she had air conditioning installed in her house but neither traditional services nor direct payments could pay for that. When she went on a personal budget she immediately invested in an air conditioning system and has not been back since. Julia is not only consuming fewer resources from the social care budget but fewer from the health budget too.”<sup>xciv</sup>*

However, it has also been suggested that a transformed system may actually be more costly due to moving from large scale institutional services to one-off customised support packages and the imperative to provide the support infrastructure people will need to enable them to manage personal budgets.<sup>xcivi</sup>

It is thus essential to make sure that people have enough money to support their independence, rather than being limited by ever-increasing funding constraints as demand for care rises.

During 2007 the Caring Choices coalition of 15 organisations across the long-term care system obtained views on how care should be funded in the future from over 700 older people, carers and other people with experience of the care system at events and via a website. It was found that:

- There was almost no support for the current funding system;<sup>xciivii</sup>
- Almost all participants in the study believed more money needs to be spent on long-term care regardless of where that money comes from;<sup>xciiviii</sup>
- Just under three-quarters of all participants believed that the costs of long-term care should be shared between the government and the individual;<sup>xciix</sup>
- *“Many older people would be happy to pay a contribution, so that they feel they are not a burden” (Caring Choices participant, Leeds)<sup>c</sup>*
- *“It means you are buying a service and can act as consumer rather than as a passive recipient of a state service” (Caring Choices participant, Birmingham)<sup>ci</sup>*
- There were many calls for a wider range of care needs beyond those narrowly defined as ‘personal care’ (help with washing and dressing etc.) such as shopping or help with gardening, to be better supported;<sup>ciii</sup>
- Participants wanted a system that gave a much clearer sense of entitlement to some level of state support but there were many calls for older people and their

families to have control over the service they obtain with the help of this support;<sup>ciii</sup>

- There was an unresolved debate about whether and to what extent existing general and non-means tested disability benefits, such as Attendance Allowance, should be brought in to any reform of long-term care funding;<sup>civ</sup>
- Most participants were in favour of the idea that the state should support schemes, such as equity release, that help unlock private resources or encourage private contributions towards the cost of care. Participants felt that a variety of options should be encouraged rather than a single 'solution';<sup>cv</sup>
- There was an overwhelming view that the current level of support for unpaid carers, financial or otherwise, is totally inadequate and any settlement will fail if it neglects carers' needs. <sup>cvi</sup>

A survey of 2000 adults commissioned by the Resolution Foundation had similar results:

- Survey respondents were strongly in favour of reform of the care system. Only 4% of respondents believed the way we pay for care should stay the same. 73% of respondents said they viewed elderly care as equal to or more important than improving hospitals;<sup>cvii</sup>
- 71% said they would be willing to pay an extra 1p in the pound in income tax in order to raise funds to improve the quality and provision of elderly care. This rose to 75% among those respondents who were low earners;<sup>cviii</sup>
- 46% of total respondents, and low earners in particular, supported the idea of a compulsory savings scheme to enable individuals to prepare for their future care costs. 15% of low earners favoured a private insurance scheme option. Only 6% supported an equity release method, but support slightly increased in line with degreasing age of the respondent- suggesting opinions regarding use of property equity in later life may be becoming more favourable.<sup>cix</sup>

In contrast, however, two thirds of people not yet receiving care who responded to a survey commissioned by Help the Aged, Counsel and Care and Carers UK said they have no plans to put any money aside to fund their social care in older age.<sup>cx</sup>

## Conclusion

Personalisation meets the aspirations of people and carers and can provide many benefits to them. Personalised services can be more flexible and innovative than traditional services in order to meet the needs of individuals. However, personalisation cannot provide better outcomes to all unless there is sufficient money to ensure that those who need help can receive it.

Rachel Dittrich 21.02.2008

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