

**Good practice in social care: the views of people with severe and complex needs and those who support them**

GRIDLEY, Kate, BROOKS, Jennifer <<http://orcid.org/0000-0001-7735-3718>> and GLENDINNING, Caroline

Available from Sheffield Hallam University Research Archive (SHURA) at:

<http://shura.shu.ac.uk/11486/>

---

This document is the author deposited version. You are advised to consult the publisher's version if you wish to cite from it.

**Published version**

GRIDLEY, Kate, BROOKS, Jennifer and GLENDINNING, Caroline (2014). Good practice in social care: the views of people with severe and complex needs and those who support them. *Health and Social Care in the Community*, 22 (6), 588-597.

---

**Copyright and re-use policy**

See <http://shura.shu.ac.uk/information.html>

# **Good Practice in Social Care: The Views of People with Severe and Complex Needs and Those Who Support Them**

## **Abstract**

This paper reports findings drawn from a study of good practice in English social care for disabled adults and older people with severe and complex needs. People with severe and complex needs are a relatively small proportion of adult social care service users, but they are growing in numbers and have resource-intensive needs. The study involved qualitative research with disabled adults and older people with severe and complex needs, family carers and members of specialist organisations (n=67), focusing on the features of social care services they considered to be good practice. Data were collected between August 2010 and June 2011. The approach to data collection was flexible, to accommodate participants' communication needs and preferences, including face-to-face and telephone interviews, Talking Mats© sessions and a focus group. Data were managed using Framework and analysed thematically. Features of good practice were considered at three levels: 1) everyday support; 2) service organisation; 3) commissioning. Findings relating to the first two of these are presented here. Participants emphasised the importance of person-centred ways of working at all levels. Personalisation, as currently implemented in English social care, aims to shift power from professionals to service users through the allocation of personal budgets. This approach focusses very much on the role of the individual in directing their own support arrangements. However, participants in this study also stressed the importance of on-going professional support, for example, from a specialist key worker or case manager to coordinate diverse services and ensure good practice at an organisational level. The paper argues that, despite the recent move to shift power from professionals to service users, people with the most complex needs still value support from

professionals and appropriate organisational support. Without these, they risk being excluded from the benefits that personalisation, properly supported, could yield.

## **Keywords**

Social care, disabled people, continuity of care, qualitative research, dementia, service delivery and organisation

## **What is known about this topic**

- The English policy approach to meeting the social care needs of people with severe and complex needs is personalisation using direct payments and personal budgets
- Research has begun to identify gaps between the rhetoric of this approach and the reality as experienced by some groups.

## **What this paper adds**

- People with complex needs and their carers value a range of person-centred approaches which include *but are not limited to* direct payments and personal budgets
- Findings highlight the importance of good practice in service organisation, including flexible systems and coordination via case management. Getting it right at this level could be the key to achieving true personalisation for people with severe and complex needs.

## **Introduction**

Developments in English adult social care have been dominated in recent years by a drive for 'personalisation' (HM Government 2007, HM Government 2011) characterised

by the allocation of 'personal budgets' to individual service users (TLAP 2011a, 2011b). This agenda has its origins in campaigns by disabled people and as well as discourses of consumerism (Glendinning 2008) and is underpinned by assertions about the capacity to harness individuals', rather than professionals', expertise; achieve congruence with people's everyday lives and secure better outcomes from public funding (Needham 2011). Cash direct payments, held and managed by users or carers, are the favoured means of receiving a budget (HM Government 2011, p.4); alternatively the budget can be held by the local authority or a third party and used to purchase services on the individual's behalf. The initial policy ambition was for all adults eligible for publicly funded social care to receive a personal budget, preferably as a cash direct payment, by April 2013 (DH 2010); in October 2012 this target was reduced to 70%. England is to a large extent unique among developed welfare states in its emphasis on personalisation, although other countries increasingly aim to promote 'consumer' choice through cash payment alternatives to 'in kind' services (Timonen *et al.* 2006, da Roit and le Bihan 2010).

While few question the desirability of personalising support, questions have been raised about the potential for personal budgets to achieve the expected improvements for all groups of service users (Glendinning 2008, Lloyd 2010) and particularly people with severe and complex needs (Henwood & Hudson 2008). Moreover, the assumption that personal budgets guarantee personalisation - and that their absence necessarily implies an absence of personalisation - has been challenged: '*[B]y confusing the two... we risk excluding those less able or willing to engage with the personal budget process from the personalisation agenda.*' (Wood 2011, p.12). This paper takes forward the debate.

No single definition of 'severe and complex needs' exists (Henwood & Hudson 2008, Rosengard *et al.* 2007). Rankin and Regan (2004) distinguish those who require intensive help from multiple services by the breadth and depth of their support needs. Hereafter we refer to the various groups of disabled adults and older people with these intensive and multiple needs as 'people with complex needs', but recognise that their individual characteristics vary widely.

People with complex needs are a small, but growing, proportion of English social care users. Developments in medicine and surgery mean increasing numbers of people survive catastrophic illnesses or accidents with severe impairments (Glendinning *et al.* 2001, Snell *et al.* 2011) and the numbers of older people with complex needs are estimated to have increased from 551,000 to 631,000 in the last decade (CSCI 2009). These demographic changes present challenges. People with complex needs are likely to require high levels of on-going support from a wide range of health and social care providers. However, current arrangements are too often characterised by a lack of appropriate support, poor coordination between services and poor outcomes (Morris 2004, Rosengard *et al.* 2007, Beresford & Cavet 2008). Additional resources have recently allocated for councils and NHS partners to develop integrated services in response to these demographic changes (LGA/NHS England 2013), but English councils are nevertheless facing spending cuts of 28%, which some fear will impact disproportionately on the most vulnerable (Duffy 2011).

As part of wider research into good practice in social care for people with complex needs, we conducted a qualitative study to explore key characteristics of good support from the perspectives of people with complex needs using services and those close to them.

## Methods

This research was conducted by the Social Policy Research Unit (University of York). The aim of the qualitative study was to identify the features of social care services and support arrangements desired by adults and older people with complex needs. Data were collected for this between August 2010 and June 2011.

The study focussed on three 'exemplar' groups of people with complex needs:

- young adults with complex or life-limiting conditions
- adults with brain or spinal injury and complex needs
- older people with dementia and complex needs.

A report of services for people with learning disability and challenging behaviour had recently been published (Mansell 2007, 2010) so this group was not included.

Social care service responsibilities and boundaries change over time (Means and Smith, 1998, Means *et al.* 2002), but when the term 'social care' is used in the UK context it generally refers to non-medical services that disabled and older people need to live as independently as possible. Services can be provided by local authority, charitable or private sector providers, and include support purchased using personal budgets, as well as National Health Service-funded support meeting social care needs.

This paper reports findings from the first stage of the research: a qualitative study of the views of people with complex needs from the three exemplar groups; family carers of people from these groups; and staff and volunteers from user-led and specialist organisations working with them (hereafter referred to as 'members of specialist organisations'). Other strands of the research included a literature review (Gridley *et al.* 2013) and identification of case examples of services with the desired characteristics

(Gridley *et al.* 2012). The study was approved by the Social Care Research Ethics Committee for England.

### ***Participant recruitment***

Recruitment was purposive (Merriam 2009), targeting individuals who, through personal or professional experience, could describe features of good social care relevant to the exemplar groups. Organisations of and for people with complex needs were approached to identify potential participants, using agreed criteria.

Advice was taken from user groups and experienced practitioners about inclusive approaches to recruitment and communication. Where enhanced communication methods could facilitate the involvement of people with cognitive and/or communication impairment (who had the mental capacity to give informed consent), such provisions were made. People known by recruiting organisations to lack capacity to consent were not approached. Several carers of people who lacked capacity did take part, but these were interviewed in their own right as carers, rather than as proxies for the people they cared for.

Potential participants were sent information about the study and invited to respond. 'Easy read' invitations were developed and, where necessary, organisations directly supported individuals to read and respond to invitations. Further participants were identified through 'snowball' sampling (Biernacki & Waldorf 1981). Written consent was obtained before data collection began.

Following grounded theory principles, recruitment, data collection and analysis were undertaken concurrently; recruitment ceased when saturation was reached; that is,

across the three exemplar groups no new data pertinent to the research questions were found (Glaser & Strauss 1967).

### ***Data collection***

Data collection methods were flexible, to accommodate the preferences of participants (see Table 1):

**Insert Table 1 here**

Separate topic guides for people with complex needs, carers and members of specialist organisations were used. Those for people with complex needs and carers were similar, but those for specialist organisations differed, in light of the different source of these participants' expertise (i.e. primarily professional, not personal, experience) (see Table 2):

**Insert Table 2 here**

Talking Mats®, a low-tech symbols-based communication tool (Murphy *et al.* 2010), was used in interviews with people who had communication and/or cognitive impairment. One focus group was conducted, with an established group of people with dementia, using a topic guide similar to that developed for the interviews.

All data collection sessions were audio-recorded, with participants' written consent. Interview transcripts were returned to interviewees for respondent validation (Lewis & Richie 2007) as were summaries of audio-files from Talking Mats® sessions and the focus group.



### ***Data analysis***

Data were managed using Framework (Ritchie *et al.* 2007) and analysed thematically. Information about the desired features of support were entered into charts, which were subsequently combined so that summarised data about a particular feature of support from each exemplar group and type of participant could be viewed in a single document and common themes could be identified. In order to maximise the robustness of the reported data, the analysis focused on identifying those characteristics of good support where there was agreement across all exemplar groups and types of participants.

A form of member validation (Lewis & Richie 2007) was employed to check and refine the team's interpretation. Three workshops were held: one with social care professionals organised through the Making Research Count collaborative research dissemination initiative; one with members of specialist voluntary sector organisations; and one with an existing consultation group of disabled people, older people and carers. At each, draft features of good support were presented, discussed and refined. None of the workshop participants participated in the study itself.

## **Findings**

### ***Participants***

Sixty-seven people participated in the study (Table 3):

**Insert Table 3 here**

While recruitment of carers and members of specialist organisations was relatively straightforward, it was harder to identify people with complex needs who met study

inclusion criteria and had the capacity to consent to take part. Fifty-one organisations (including branches) were approached to recruit the final sample of 22 people with complex needs. All but one of the carers interviewed was a family member. The exception was a paid, full-time befriender recommended by the service user's family.

All interviews with people with complex needs took place face-to-face, seven with full or intermittent support from a carer or support worker. One focus group was held with people with dementia. Talking Mats© were used in five interviews. Two carers sent written responses and all other participants were interviewed by telephone or face-to-face.

### ***Features of good support***

Table 4 summarises the features of good support identified by participants. Many of these are also valued by other users of services, but the focus here is how and why these are particularly important for people with complex needs. Following Henwood and Hudson (2008), findings are arranged into three levels: 1) delivery of everyday support; 2) arrangement and coordination of support; 3) commissioning:

**Insert Table 4 here**

This paper concentrates on the first two levels: everyday support and service organisation. Participants had less to say about commissioning, and commissioners themselves were not interviewed.

## **Everyday support**

### *Person-centred ways of working*

Participants stressed the importance of individually-tailored responses to their unique combinations of needs. *Time* to get to know individuals was particularly important, as was flexibility to alter arrangements in response to changing needs:

*... rather than putting them all in pigeonholes, "This person's got dementia, we'll do this, this, this and this," so it doesn't always fit that that is going to work for that person....*

[5CD - wife of man with dementia]

*... we wanted somebody who would understand. He had his turban and he had his peculiarities, but... it's about seeing the person, trying to get to know them, find out about them and building relationships with them...*

[12CD – daughter of man with dementia]

While some stressed the value of personal budgets and direct payments in achieving personalisation, most did not have experience of these (see Table 3). Instead, they described personalisation as a way of working that respects and is tailored to the uniqueness of the individual and is particularly important for people with complex needs, whose situations and wishes can differ in many ways. This theme, of uniqueness and the importance of tailoring, recurs throughout the analysis and will be returned to in the discussion.

*Meeting practical, emotional and social needs*

Participants stressed that social care should meet the full range of practical, emotional and social needs. Practical support extends beyond personal care to include help with finances, transport, socialising and occupation. Emotional support includes encouragement to do practical tasks or maintain skills; having someone to share worries with; help to feel included or cared for, and having good company:

*...you can talk to them [his personal assistants]...that's nice sometimes just to get stuff off your chest without, like, not just your mum or whatever... that's helpful. It's just being company sometimes.*

[5UY – young man with complex needs]

Participants valued spending time with other people with similar experiences. Group activities and condition-specific services provided opportunities to meet people who understood their complex needs:

*...we all understand each other because, although we've all got different problems, we've all got the same problem.*

[FGDR5 – woman with dementia, focus group]

Support to maintain friendships, socialise and pursue interests was a priority for all participants. Some wanted to attend group activities, others to be supported to communicate with friends or pursue hobbies. For some, distinctions between paid helpers and friends were blurred and they looked for qualities of friendliness and shared interests in people employed to support them:

*...it's good to come here and everybody's so – well, they respect me and I respect them... Staff and the people who use the service. Everybody's my buddy.*

[6UB – man with brain injury]

For others, there was a clear distinction between friends and care staff but it nevertheless remained important to have good relationships with the people paid to deliver support.

#### *Staff attitudes and approach*

People with complex needs and carers across all exemplar groups stressed the importance of support staff having the right attitudes and approach. This included willingness to spend time with the person and get to know them, being proactive and using common sense. Having things in common and generally 'getting on' was a big part of this:

*... there are two things: the one is that it often requires people to take a bit of initiative ...the second thing is that ... I need to have somebody around that I can relate to on some level or other. Even though it's a working relationship, the boundaries get very blurred between where work starts [and ends] and there needs to be some sort of personal relationship as well.'*

[1UB – man with spinal injury]

The above participant had 24-hour live-in care, but even where staff came in for relatively short slots each week, friendliness was paramount:

*Q...so you said you're not so keen on her?*

*A: I'm not. I'm not.*

*Q: Is there any particular reason?*

*A: Well, she weren't as friendly as the others, do you see?*

[1UD - woman with dementia]

Participants also stressed the importance of a willingness to listen and learn and it was argued by some that the attitude and personality of care staff and personal assistants were more important than training, as training to meet the needs of the individual could be provided on the job. Nevertheless, all felt that staff who *organised and coordinated* services for people with complex needs should have considerable experience and specialist knowledge (see 'Specialist expertise and information' below).

#### *Reliable, well coordinated delivery*

Reliability was particularly important for people who could not easily resolve service delivery problems themselves. Participants explained that, where support was unreliable, the impact on people with complex needs could be catastrophic. The son of one man with severe dementia, for example, felt that the unreliability of the staff supporting his father meant that he was at continual risk:

*...he could be on the floor all night long and they wouldn't even [know]*

*– they don't even carry out their own procedures.*

[6CD – carer of man with dementia]

In contrast, a participant with brain injury felt well supported by her team of carers who organised sickness cover amongst themselves:

*...with my staff, they've all got [each others'] mobile numbers... they're not going to ring me and say, "I can't come in" and I'm, like, [it's] seven o'clock in the morning, "Who am I going to get?" ... They take the responsibility off us, sort it out, and then let me know...*

[2UB - woman with brain injury]

This level of coordination had, however, taken considerable time and help from a social worker, a voluntary sector advocate and a supportive family, to establish. It was also resource-intensive and at risk of being undermined by new restrictions on local authority funding (Gridley 2012).

#### *Continuity in support*

Reliability comes, to some degree, from continuity. Without this, as one carer noted, it is hard to have confidence in a service:

*...it was a bit, you know, nerve-wracking, because you didn't know who was going to come.*

[1CY - mother of young man with complex needs]

Respondents valued having the same worker or small team delivering support over time because this gave them chance to get to know each other and build trust:

*It's kind of stability. You don't have to explain to someone that, "Oh, can you do it this way?" Because [if] they've been there for ages then they already know.*

[5UY – young man with complex needs]

Support workers needed time to develop expertise in meeting the needs of the individuals they worked with. Similarly, people with complex needs and carers did not want to waste time repeating instructions or training a succession of workers. Carers of people with dementia stressed the importance of familiarity, as often the person they cared for would not accept support from someone they didn't know:

*...you just can't start again. By the time you've gone through everything you had to tell them and plus, by then, [husband] was very – if I wasn't here, it needed to be somebody that he knew otherwise he would be ang[ry] – you could see in his face the anxiety.*

[3CD – wife of man with dementia]

#### *Sufficient resources*

Participants emphasised that meeting complex needs could cost considerably more than standard social care because of the necessity for round-the-clock support and workers who could handle difficult situations:

*...with the mental health thing... she kicks, she bites, she's aggressive, she can be verbally abusive, and not everybody can put up with that... We can't go through the agencies because our money – the money's not enough.*

[7CD - daughter of woman with dementia]

Some people with complex needs who were particularly happy with their support had live-in staff or a team of personal assistants working together, but this was expensive and the costs were not always met by local authorities. Moreover, those who did



receive local authority-funded support were concerned that this was at risk, regardless of their needs and even where they received only modest budgets:

*...the social worker came at first, and said that he could go to [day service] and they'd pay for it, and she sorted that. And then one day, about 18 months' later, I got a letter to say that they were stopping his [day service] money and I said, "Like hell you are...This is the only thing that [son] likes and goes [to]..."*

[4CB – mother of man with brain injury]

## **Organising services**

### *Flexibility*

For all groups, flexibility in how services operated and funds could be spent was very important, as was the responsiveness of services to changes in circumstances and the reversibility of decisions. Standardised care pathways are rarely appropriate for these groups:

*Brain injury care pathways that are linear don't work because people don't quite live their lives like that when they have cognitive problems.*

[SB2 - member of brain injury organisation]

*There's no standard pathway for dementia because it affects people so differently*

[SD2 - member of dementia organisation]

Participants instead argued for flexible care pathways, imaginative approaches to assessments, and to be able to alter support arrangements once in place. This is

particularly important because when needs are complex it can be difficult to foresee which arrangements will work best:

*[When support was originally arranged, son] had been in hospital for a year and, obviously, we weren't quite sure what his needs were going to be when he came out. And then, eventually, I just said, "Well, you know, I'd like to have a bit of a life of my own and, can I have some more time?"*

[7CB - mother of son with brain injury]

Facilitating flexibility can be both labour- and time-intensive, but was considered to deliver long-term benefits:

*...the more complex the needs the more unique they are... they do take up a lot of professional time and they need extra planning, but if you get it right it saves so much time...*

[SY5 – member of young people's organisation]

Thus, person-centred ways of working are just as important at this service organisation level as they are at the level of everyday support.

*Timely, proactive approach*

Prompt responses to requests for support were considered essential. In particular, interviewees wanted proactive interventions that anticipated and averted crises:

*If we'd had four visits much more quickly, then probably we'd have been able to keep the situation under control for longer instead of it turning into a crisis, which is what did happen.*

[7CD - daughter of woman with dementia]

A proactive approach was also important where major transitions were anticipated:

*....we had [daughter's] review at college on the 4th of November ... now, we're nearly in March and still we haven't got anything sorted definitely. We don't know what's going to happen when she leaves college.*

[3CY - mother of daughter with complex needs]

#### *Specialist expertise and information*

While attitude and personality were felt to be more important than formal training for everyday care staff and personal assistants, it was stressed that social workers and care-coordinators need considerable expertise to properly support people with complex needs.

This was highlighted by those in the dementia group:

*A. I had the impression that she had a great deal of experience in dementia, a very experienced social worker, yes.*

*Q. Right, right, and did you think that was important to...?*

*A. I think it's very important because she knew where I was coming from...*

[FGDR1 – woman with dementia, focus group]

*...[social worker] was very young and very inexperienced and we were classed as the most complicated case in the area at the time and we*

*had lots of clashes ... I think, probably, they should have put some more input in with ... somebody that knew what they were doing more.*

[5CD - wife of man with dementia]

Interviewees from specialist organisations recognised that it is not always possible for generalist workers such as primary health physicians to have specialist knowledge about complex conditions, but they should be willing to listen and learn, and able to signpost to more specialist services when needed.

Help to access information was of particular importance for people with complex needs, both because information needs cover multiple issues; and because communication and cognitive impairments, pain and fatigue, can make it harder to find and use information. Voluntary sector helplines and documents were highly valued sources of information, as were peers. However, participants did not want peers to be their only sources of information. Specialist workers should provide vital links to information and advice, help people use information, weigh up options and make decisions – in other words, provide support in making the choices upon which personalised support arrangements are presumed to rest.

Those who felt well supported tended to be in touch with a single professional or service that understood their condition and was experienced in helping them navigate the system.

#### *Case management and coordination*

Participants wanted a named individual or team to act as a key worker or case manager:

*A key worker or somebody who coordinates, an advocate for the young person I think is essential, and that's where you see really good practice. Where someone who's got the time to help that young person, get the right people around the table at the various points to look at joint assessment and joint planning, that really works well.*

[SY5 – member of young people's organisation]

Such roles included facilitating access to services; informing other professionals about needs; and bringing together disparate elements of complex service systems.

Advocacy was another important element of the role, extending to mainstream services such as universities and the police. Those who were highly valued also had a 'can do' attitude and were available as and when needed:

*She's like a whirlwind. And you ring her up and you tell her your problem, and [she] will go to the end of the earth to sort the problem out.*

[2UB – woman with brain injury]

*...if I need anything, I can just – I ring them up and they'll put me right.*

[FDGR4 – woman with dementia]

Participants wanted continuity at this level too, rather than a different duty worker each time a need arose:

*...everything's, sort of, going along fine then they stop you, basically ...They close the case ... that's their system and that's what you do. But to reopen it again it seems like it's an awful lot of trouble to get it going, but there's no other choice and you have to, sort of, wait in a queue.*

[6CD – son of man with dementia]

Getting to know individuals and their needs over time was considered to increase key workers' effectiveness in negotiating and advocating with other services. Only interviewees with stable conditions, who required minimal assistance to manage their own support arrangements, did not want this on-going relationship.

People with compensation-funded support following traumatic brain injury often had privately-funded case managers to coordinate their support, and several participants saw this as the 'gold standard' towards which publicly-funded services should aspire.

## **Discussion**

This paper reports qualitative findings from a purposively selected sample of information-rich cases (Merriam 2009). The sample was not representative, but covered a range of situations and had breadth as well as depth. One limitation is that it did not include people without capacity to consent to take part. While carers and members of specialist organisations did discuss the needs of these groups, this was from their own perspectives and the voices of those with the most severe needs were therefore not heard first hand. This leaves a gap in the findings.

Unlike other studies which have highlighted service deficits (Morris 2004, Rosengard *et al.* 2007, Henwood & Hudson 2008, EHRC 2011) this study focussed on elements of support considered to be *good* by people with complex needs, their carers and members of specialist organisations. Many of the features of good support they identified resemble those valued by other social care service users. Reliability, continuity, flexibility and coordination are commonly-cited criteria of service quality

(Francis & Netten 2004, Power 2008). For people with complex needs, these features are arguably critical because of the greater level and reach of their support needs, which permeate most aspects of daily life. Yet good support may also be harder to achieve, because of its intensive, specialist and costly nature and the challenges of recruiting, remunerating and retaining suitable staff. Similarly, while all social care service users may desire high quality, reliable services, the consequences of sub-standard support and unreliability for the safety and quality of life of someone with complex needs could be catastrophic.

Participants stressed that social care for people with complex needs should be holistic, ensuring quality of life in social and emotional, as well as personal care spheres, which could include: support to build and maintain confidence; pursue hobbies; see and communicate with friends; or access and sustain employment. This necessitates considerable staff input, which in turn requires adequate funding. While social and emotional needs should routinely be identified in the course of assessments, it is questionable whether, in times of considerable budget constraints, provision is always made to meet holistic needs.

Many features of good support identified in this study were consistent with the principles underpinning personalisation (Carr 2008) and person-centred care (Kitwood 1993, Brooker 2004). Person-centred ways of working were repeatedly emphasised by participants as central to good practice. However, these did not always equate with the dominant approach to personalisation in English social care. Participants valued individually tailored support from dedicated workers, but this seemed more dependent on the time staff could dedicate, their attitude and expertise and the flexibility of wider systems than whether someone had a personal budget. This echoes Mansell, who found that, while some people with learning disabilities and challenging behaviour

achieved person-centred arrangements through personal budgets, others achieved these in other ways. What was common to all good support arrangements was that services had:

*...overcome organisational barriers (for example between health and social care) to deliver the services the individual needed in a coordinated way.'*

(Mansell, 2010, p.9)

While the focus of personalisation in England has been on changing how everyday support is delivered (through service users controlling budgets and arranging support themselves), this study found, like Mansell, that person-centred working in the organisation and coordination of services is equally important.

In summary, two features of the desired arrangements appear at odds with current approaches to personalisation. First, personalisation, as currently implemented, aims to shift power from professionals to service users, with the latter's expertise playing a greater role in shaping support. However, whilst the recognition of service users' considerable expertise, gained through lived experience, is welcome, people with complex needs continue to value professional expertise and expert knowledge, particularly in the organisation, coordination and purchasing of services.

Second, there were strong arguments for dedicated key workers or case managers to facilitate access to fragmented services and facilities; advocate and liaise with these; and co-ordinate support across boundaries. Currently, personalisation in England pays little attention to cross-sectoral coordination for individuals requiring support from multiple sources; and recent initiatives to bring these together have not met with



success (Moran *et al.* 2011). Moreover, for people with complex needs, the desired approach is not short-term input, but a long-term relationship involving knowledge of the individual and trust; both of which were considered to enhance the effectiveness of staff as advocates and coordinators. Long-term involvement also enables changes to be anticipated and managed proactively. The model widely used to support people with compensation payments could be adapted for other groups with complex needs.

## **Conclusion**

Personalisation, as implemented in England, entails a radical shift in power, from professionals to individual service users and their families. There was some support for this from the participants in this study, but the greater emphasis was on person-centred ways of working at all levels, including dedicated support to organise multiple services.

Current developments risk undermining the quality of support received by people with complex needs. Partly this reflects financial constraints and the consequent pressures on high cost support arrangements, but quality may also be jeopardised by a failure to acknowledge the on-going need for specialist professional expertise and service coordination. When shifting power and control to service users, it remains important that people with complex needs can draw upon appropriate professional and organisational support as and when they need it.

## References

ADASS (2012) Personal Budgets Survey March 2012. Available online:

<http://www.adass.org.uk/images/stories/Policy%20Networks/Resources/Key%20Documents/PersonalBudgetsSurveyMarch2012.pdf> [accessed 12/07/12].

Biernacki, P. and Waldorf, D. (1981) Snowball sampling: problems and techniques of chain referral sampling, *Sociological Methods & Research*, 10, 2, 141-163.

Beresford, B. and Cavet, J. (2008) *Transition to Adult Services of Disabled Young People Leaving 'Out of Authority' Residential Schools*, Social Policy Research Unit (SPRU), University of York, York.

Brooker, D. (2004) What is person-centred care in dementia? Reviews in *Clinical Gerontology*, 13, 215-222.

Carr, S. (2008) *Personalisation: A rough guide*, Social Care Institute for Excellence (SCIE), London.

Commission for Social Care Inspection (2009) *The State of Social Care in England 2007-08*, Commission for Social Care Inspection (CSCI), London.

Da Roit, B. and le Bihan, B. (2010) Similar and yet so different: cash-for-care in six European countries' long-term care policies, *Millbank Quarterly*, 88, 3, 286-309.

Department of Health (2010) *A Vision for Adult Social Care: Capable communities and active citizens*, Department of Health (DH), London.

Duffy, S. (2011) *A Fair Society and the Limits of Personalisation*. A discussion paper from the Centre for Welfare Reform first presented at the Tizard Memorial Lecture, March 2011. <http://www.centreforwelfarereform.org/uploads/attachment/261/a-fair-society-and-the-limits-of-personalisation.pdf>

Equality and Human Rights Commission (2011) *Close to Home: An inquiry into older people and human rights in home care*, Equality and Human Rights Commission (EHRC), London.

Francis, J. and Netten, A. (2004) Raising the quality of home care: a study of service users' views, *Social Policy and Administration*, 38, 3, 290-305.

Glaser, B. and Strauss, A. (1967) *The Discovery of Grounded Theory: Strategies for qualitative research*, Aldine Publishing Company, New York.

Glendinning, C. (2008) Increasing choice and control for older and disabled people: a critical review of new developments in England, *Social Policy and Administration*, 42, 5, 451-469.

Glendinning, C., Kirk, S., Lawton, D. and Guiffrida, A. (2001) Technology-dependent children in the community: definitions, numbers and costs, *Child: Care, Health and Development*, 27, 4, 321-334.

Gridley, K. (2012) A good arrangement - now under threat, in M. Davies *Social Work with Adults: Policy, law, theory, research and practice*, Palgrave Macmillan, London

Gridley, K., Brooks, J. and Glendinning, C. (2012) Good Support for People with Complex Needs: Examples of Potential Good Practice (webpage).

<http://php.york.ac.uk/inst/spru/research/summs/complexCS.php>

Gridley, K., Brooks, J. and Glendinning, C. (2013) Good practice in social care for disabled adults and older people with severe and complex needs: evidence from a scoping review. *Health and Social Care in the Community* (Available online from 27 July 2013 <http://onlinelibrary.wiley.com/doi/10.1111/hsc.12063/abstract> )

Henwood, M. and Hudson, B. (2008) *Getting Personal: Supporting people with multiple and complex needs*, Commission for Social Care Inspection (CSCI), London.

HM Government (2007) *Putting People First: A shared vision and commitment to the transformation of Adult Social Care*, Department of Health (DH), London.

HM Government (2011) *Think Local Act Personal. A sector-wide commitment to moving forward with personalisation and community-based support*, Department of Health (DH), London.

Kitwood, T (1993) Person and process in dementia, *International Journal of Geriatric Psychiatry*. 8, 7, 541-545.

LGA/NHS (2013) *Statement on the health and social care Integration Transformation Fund*. Downloaded from [www.local.gov.uk](http://www.local.gov.uk) 3 September 2013.

Lewis, J. and Richie, J. (2007) Generalising from qualitative research in J. Ritchie and J. Lewis (eds), *Qualitative Research Practice: A guide for social science students and researchers*, Sage, London.

Lloyd, L. (2010) The individual in social care: the ethics of care and the 'personalisation agenda' in services for older people in England, *Ethics and Social Welfare*, 4, 2, 188-200.

Mansell, J. (2007) *Services for People with Learning Disabilities and Challenging Behaviour or Mental Health Needs*, Department of Health (DH), London.

Mansell, J. (2010) *Raising our Sights: Services for adults with profound intellectual and multiple disabilities*, Tizzard Centre, Kent.

Means, R. and Smith, R. (1998). *From poor law to community care: the development of welfare services for elderly people*. Bristol: The Policy Press.

Means, R., Morbey, H. and Smith, R. (2002). *From community care to market care? The development of welfare services for older people*. Bristol: The Policy Press.

Merriam, S. (2009) *Qualitative Research: A guide to design and implementation*, John Wiley & Sons, Chichester.

Moran, N., Glendinning, C. and Stevens, M. *et al.* (2011) Joining up government by integrating funding streams? The experiences of the individual budget pilot projects for older and disabled people in England, *International Journal of Public Administration*, 34, 4, 232-243.

Morris, J. (2004) *One Town for My Body, Another for My Mind. Services for People with Physical Impairments and Mental Health Support Needs*, Joseph Rowntree Foundation (JRF), York.

Murphy, J., Oliver, T. M. & Cox, S. (2010) *Talking Mats and Involvement in Decision Making for People with Dementia and Family Carers*, Joseph Rowntree Foundation, (JRF), York.

Needham, C. (2011) *Personalising Public Services*, The Policy Press, Bristol.

Rankin, J. and Regan, S. (2004) *Meeting Complex Needs: The future of social care*, Turning Point and Institute for Public Policy Research (IPPR), London.

Power, A. (2008) 'It's the system working for the system': carers' experiences of learning disability services in Ireland, *Health and Social Care in the Community*, 17, 1, 92-98.

Rankin, J. and Regan, S. (2004) *Meeting Complex Needs: The future of social care*, Turning Point and Institute for Public Policy Research (IPPR), London.

Ritchie, J., Spencer, L. and O'Connor, W. (2007) Carrying out qualitative analysis, in J. Ritchie and J. Lewis (eds), *Qualitative Research Practice: A guide for social science students and researchers*, Sage, London.

Rosengard, A., Laing, I., Ridley, J. and Hunter, S. (2007) *A Literature Review on Multiple and Complex Needs*, Scottish Government, Edinburgh.

Snell, T., Wittenberg, R., Fernández, J-L., Malley, J., Comas-Herrera, A. and King, D. (2011) *Projections of Demand for Social Care and Disability Benefits for Younger Adults in England*, PSSRU Discussion Paper 2800/3, October, Economics of Health and Social Care Research Unit (ESHCRU), London.

Think Local Act Personal (2011a) *Personal Budgets: Taking stock, moving forward*, downloaded from: [www.thinklocalactpersonal.org.uk](http://www.thinklocalactpersonal.org.uk)

Think Local Act Personal (2011b) *Think Local Act Personal. A sector-wide commitment to moving forward with personalisation and community-based support*, downloaded from: [www.thinklocalactpersonal.org.uk](http://www.thinklocalactpersonal.org.uk)

Timonen, V., Convery, J. and Cahill, S. (2006) Care revolutions in the making? A comparison of cash-for-care programmes in four European countries, *Ageing and Society*, 26, 3, 455-474.

Wood, C. (2011) *Tailor Made*, Demos, downloaded from: <http://www.demos.co.uk/publications/tailormade>

**Table 1 Method of data collection**

	Telephone interviews	Face-to-face interviews	Focus group	Responded in writing	Total number of participants
People with complex needs	0	15	7	0	22
Family Carers	12	9	0	2	23
Members of organisations	20	2	0	0	22
Total participants	32	26	7	2	67



**Table 2 Interview topics by role of participant**

People with complex needs	Family carers	Members of organisations
<ol style="list-style-type: none"> <li>1. About you and your support</li> <li>2. Assessment</li> <li>3. Personal budgets and funding</li> <li>4. Arranging support</li> <li>5. Coordination of support</li> <li>6. Ideal service</li> </ol>	<ol style="list-style-type: none"> <li>1. About the person you support</li> <li>2. Assessment</li> <li>3. Personal budgets and funding</li> <li>4. Arranging support</li> <li>5. Coordination of support</li> <li>6. Ideal service</li> </ol>	<ol style="list-style-type: none"> <li>1. About you and your organisation</li> <li>2. Views on good practice</li> <li>3. Priorities for developing good quality services</li> <li>4. Role of social care</li> <li>5. Personal budgets</li> <li>6. Information and advice</li> <li>7. Examples of good practice</li> </ol>

**Table 3 Type of participant by use of personal budgets or other type of support**

Participant type and exemplar group	Personal budget (for person with complex needs)	No personal budget – other type of support	Total
Young person with complex needs	1	4	5
Person with brain or spinal injury	3	4	7
Person with dementia	2	8	10
Carer of young person with complex needs	4	1	5
Carer of person with brain or spinal injury	2	4	6
Carer of person with dementia	3	9	12
Subtotal	15	30	45
Specialist young people’s organisation			7
Specialist brain or spinal injury organisation			10
Specialist dementia organisation			5
Total			67

**Table 4 Summary features of good social care**

<b>Level</b>	<b>Key features of good support</b>
<b>At the level of everyday support</b>	Person-centred ways of working Meeting practical, emotional and social needs Staff attitudes and approach Reliable, well coordinated delivery Continuity in support Sufficient resources
<b>At the level of service organisation</b>	Flexibility Timely, proactive approach Specialist expertise and information Case management and coordination
<b>Commissioning</b>	Specialist expertise Crossing boundaries Communication