

The Care and Support Alliance careandsupportalliance.com

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Introduction: about this summary report



The Care and Support Alliance¹ and Community Care² magazine ran an online survey on Community Care's website between 12 April and 9 June 2017.

The survey was aimed at social workers and other professionals who undertake care assessments. It asked a series of questions about what it is like for them doing their jobs today, particularly asking about any reductions they have had to make to people's care provision over the last year.

This report is the Care and Support Alliance's commentary and interpretation of the findings, using the data supplied to us by Community Care.

Sometimes people's needs do reduce – for example, if they begin to regain their strength and capacity after a spell in hospital – meaning that it makes sense to scale back the social care support they are receiving. To do so in these circumstances is not only a responsible use of public resources, it should also reduce the risks of people becoming dependent on help they don't need, which in turn can undermine their capacity to live a full life on their own terms.

However, we had also heard stories about social workers feeling compelled to reduce people's care provision in response to funding cuts and not because a person's needs had actually reduced. So one of the aims of this survey was to explore this area and provide social workers with an opportunity to describe the state of care today, as they see it in their day to day jobs.

¹ The Care and Support Alliance (CSA) is a coalition of more than 80 of the country's leading charities who are calling for a properly funded care system. We include Age UK, Scope, Royal British Legion, Alzheimer's Society, Mind and many more. See http://careandsupportalliance.com/membership/ for a full list of members.

² Community Care is an online magazine for social workers and social care professionals.

About social care

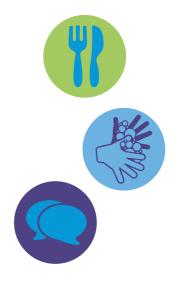
Social care support is essential in meeting the needs of disabled and older people and their families to lead healthy and fulfilling lives. It would not be overstating the case to describe social care as 'life support'.

As well as relying on care and support for help with everyday tasks, like washing, dressing and eating, social care plays a vital role in supporting recipients and their carers to move into, or stay in, employment, and in preventing avoidable expenditure particularly on health services.

However, currently at least 1.2 million older people and disabled people do not receive the care they need³, a 48% increase since 2010. When people don't get the basic care they need, they are more likely to fall into crisis and need more expensive medical attention.

Meanwhile, families are being expected to do more. Carers currently provide care worth £132bn, the equivalent to the UK's total health care annual spend⁴ and over 2 million people have already given up work to care.

A social worker's role is to assess what support someone needs to keep them safe and able to live independently. They are required by law to follow a set criteria and guidance on the level of care to which people are entitled. The main legislation that governs social care today is the Care Act 2014.



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³ Age UK analysis, November 2016, http://www.ageuk.org.uk/latest-news/12m-older-people-dont-get-the-social-care-they-need/.

⁴ Carers UK, The Case For Care Leave, December 2013.

What the survey found

469 social workers and other professionals who undertake care assessments and reviews responded to the survey, from every region of England.

This is a sizeable number but there is no way of knowing how representative their experiences are of social workers more broadly. For this reason we view the quantitative results from the survey as no more than indicative.

However, the qualitative element of the responses given – the quotes and stories from individual social workers – were striking. Whether or not they are representative really isn't the point: some of the situations described were simply unacceptable, morally and sometimes legally too. The fact that such things are happening anywhere in our country is cause for alarm, in our view.

The four key themes that emerged are set out below and over the following pages.

1.The intense pressure on some social workers to ration social care

- 3. The law is being breached, in some places it seems as a matter of policy
- 2. The devastating impact on some vulnerable people of cuts in the support they receive
- 4. The original intention behind personal budgets is often no longer being fulfilled

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What the survey found:

The intense pressure on some social workers to ration social care

Some of the social workers' comments revealed the incredibly difficult position they can find themselves in as they strive to support people in desperate need without enough cash in the system. For example:

"[There is] strong pressure from my line manager and commissioners to reduce costs as a main priority."

"Colleagues constantly battle to keep packages at an adequate level...to keep [our clients] safe."

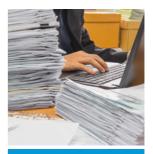
"Care packages are not getting agreed by the funding panel. I am having to submit reduced care packages to the panel in the hope that some support will get funded, as opposed to none."

"I cannot get new packages of care agreed or increases agreed when needs have increased."

"We are being encouraged to use voluntary services despite there not being enough resources to cover the gap."

"Management said they [care packages] needed to be stepped down but, in reality, it was based upon monetary reasons and no other reason."

"Funding not agreed at panel meetings (weekly limit currently set at 300)."



"I cannot get new packages of care agreed or increases agreed when needs have increased." These comments need to be seen against a context in which nearly 7 in 10 (68%) respondents to the survey said they felt expected by their managers to reduce the help on offer to people in need of social care; more than 1 in 3 (37%) said they believed they couldn't get people the care they needed; and, chillingly, more than 1 in 4 (28%) were not confident that the reduced care packages they had to administer were 'fair and safe'.

In addition, 4 in 5 respondents (81%) said family and friends are being expected to provide more support to 'fill in' where care has been reduced – sometimes in circumstances where it is not clear that this assistance is actually available.

In the survey the reason given most often by social workers for having reduced a person's care package was because their needs had changed (130 responses)⁵. However, far more worryingly this was followed by budget pressures (95 responses) and because local authority support is now more restricted (over 60 responses).



7 in 10 (68%) respondents to the survey said they felt expected by their managers to reduce the help on offer to people in need of social care



4 in 5 (81%) respondents said family and friends are being expected to provide more support to 'fill in' where care has been reduced

⁵ This question was a free-text box and the answers grouped by the CSA.



What the survey found:

The devastating impact on some vulnerable people of cuts in the support they receive

The examples some respondents then gave describing the impact of restricting or removing social care from older people and disabled adults, because of lack of resources were often profoundly concerning:

"I worked with a woman who could strip wash but who couldn't reach her back and intimate parts of her body so had carers for years as part of her personal budget to help her... however it was cut as she was physically able enough to strip wash. This was devastating for her."

"A person with hoarding issues and a tendency to eat rotten food had their shopping and housework call cut, resulting in an admission to hospital with food poisoning."

"After one service user was told her care package was being reduced she seriously self-harmed and had to be detained in hospital."

"I had to reduce the care package for three brothers who live together. Each has a mental health problem, physical or learning disability. They had a substantial care package for 15 years. It kept them safe from financial abuse and enabled them to live in the community. After reducing the care package two of them went into residential care and died. The other was admitted to hospital with dehydration and hypothermia."



"After one service user was told her care package was being reduced she seriously self-harmed and had to be detained in hospital."

"In my local authority I work for managers who will not approve time for a carer to visit an older person and prepare a hot meal. I am told to record telling the individual about hot meal deliveries as a reasonable way to meet this need. Meals on wheels are self-funded within the authority and can cost a minimum of £42 per week. Lots of my service users worry about spending money and so go without a hot meal."

"[Reducing care packages] has led to individuals becoming more isolated, engaging in risky behaviour and being exploited."

"The person requires support with walking to the bathroom but due to the cost he is now required to contribute towards it he has decided he would rather have the risk of falling than an evening call."

"There has been pressure on an elderly husband due to a reduction in assistance to his wife, causing the breakdown of the relationship. He ended up in hospital and she was placed in residential care."

"The client was left with so little support he was unable to leave his flat as he was afraid of going out alone and afraid of using his microwave."

"People are not having regular calls throughout the day as a result of the review and are having to wait longer periods to use the toilet, impacting on them physically."



"[Reducing care packages] has led to individuals becoming more isolated, engaging in risky behaviour and being exploited."

"I suspect that now I have taken away a welfare call, one of my cases will stop getting out of bed."

"[I have seen] several admissions to inpatient psychiatric care."

"[I have seen] relationship breakdown and families in turmoil."

"People are ending up in hospital following falls as they are trying to carry out tasks themselves unsafely due to not having adequate care calls in my opinion."

Overall, the survey found that support to get out and take part in social and leisure activities was the type of help which was most commonly being reduced (72%), followed by help with domestic tasks (67%).

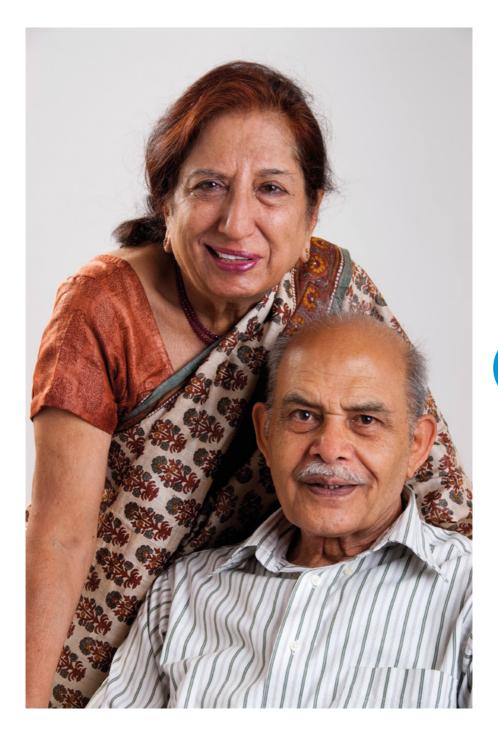
In addition, more than 4 in 5 respondents (83%) did not think there was enough variety and quality of social care provision in their area for people to exercise genuine choice and control over the care they received.



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4 in 5 (83%) didn't think there was enough variety and quality of social care provision in their area





What the survey found:

The law is being breached, in some places it seems as a matter of policy

The Care Act 2014 requires local authorities to assess people who are in need of social care by reference to set criteria and come to an objective judgement based on what they then find. They have some discretion over 'how' to meet the needs which have become evident through this process. However, they should not reduce a person's care package unless their needs have also diminished and/ or they can demonstrate that there are other less expensive ways in which those needs can still be met. The Care Act also places high priority on meeting people's need for 'wellbeing' through the provision of social care. This means that it is vital to look at the support needed to manage household chores, to engage socially with others and to take part in normal leisure activities like other members of the community. as well as personal care needs.

However, some of the comments made by respondents to the survey suggest that in their local authority this objective, needs-based approach that also takes a person's wellbeing into account is not always being followed. In some cases very vulnerable people are being denied their rights.

"The view within the council is that only 20% of all those assessed should be receiving formalised care packages from the local authority and that 80% should only receive information and advice."



The Care Act 2014 requires local authorities to assess people who are in need of social care by reference to set criteria and come to an objective judgement based on what they then find

"I was moved off a case because the cost of a home package was too high (care and wellbeing principle ignored) and I refused to put the client in a care home against his (prior) wishes. The case was removed from me while I was on leave. He was incapacitated but his wife fought. The next case worker did exactly the same and he went home. There were no support services for his wife who provided most of the care and was frail emotionally because it was 'her choice' to have her husband at home. His wife and all professionals were unhappy I had been removed from the case and I was not allowed to say the truth. I left not long after."

"[There has been a] reduction in calls from 45 to 30 minutes - call is now rushed and the basic needs are met but it's not very personal and not enough time to check how the person is emotionally - managers need to remember that wellbeing is not just about meeting basic needs it's about the whole person! They are not just bodies they are people."

"Reducing support for someone with mental health difficulties is very unhelpful. In essence, it usually has a negative impact on any progression that individual might achieve in terms of their wellbeing and personal development, hence producing a revolving door syndrome which I have personally seen in practice. There really is no such thing any more as a person-centred approach."



"I was moved off a case because the cost of a home package was too high and I refused to put the client in a care home against his (prior) wishes." "Funding for quality of life activities, such as to promote wellbeing and social inclusion, is seen as a luxury we can no longer afford. Higher cost providers who will focus on quality skills development are shunned in favour of a need to fund just enough to pay the cheapest provider to ensure people are washed and fed, with little else to ensure a decent, dignified life with hope."

"We are being encouraged to write care plans that do not include any form of social interaction."

"Social support needs are most likely to be rejected by funding panels."

The Care Act 2014 is widely respected as a progressive and humane piece of legislation. It was enacted by the Coalition Government led by David Cameron. Now it seems it is sometimes being observed 'more in the breach' as a result of budget cuts.



"We are being encouraged to write care plans that do not include any form of social interaction."





What the survey found:

The original intention behind personal budgets is often no longer being fulfilled

In recent years, there has been a marked trend within social work theory and practice towards 'personalisation'. This is the idea that rather than expecting people to fit into pre-determined boxes of provision, they should have 'choice and control' over the help they receive and should help to design or co-produce it. This aims to be empowering and recognises the enormous diversity of human needs and aspirations. Moreover, part of the reasoning behind this approach is that it tends to produce better outcomes for those who receive services, which is good for them and for the taxpayer too.

'Personal budgets' are a practical manifestation of this idea: rather than compelling people in need of social care to take a particular service they are allocated a sum of public money, depending on their needs, and can make their own decisions about the kind of support they require. This personal budget is administered for some people by a social worker whereas others can opt to receive the money in the form of a 'direct payment', to spend themselves and/ or with the support of family or friends. It has been suggested that personal budgets tend to save public money, since in practice people's aspirations are often guite modest and the improved outcomes may mean less money is needed in the long run.



Personal budgets are sums of allocated public money that enable those who need care to make their own decisions about the kind of support they require

The often quoted, archetype example of the benefits of personal budgets is of a young man with complex disabilities who when provided with a personal budget chose to spend it on a caravan by the sea. He and his parents used it at the weekends and at holiday time, reducing their stress levels and enabling them to keep caring for him at home in a situation in which they might otherwise not have coped. For all of them this was far preferable to having lots of professional carers coming in and out, and ultimately it saved money too, as well as improving the young man's outcomes.

However, comments from many respondents to the survey suggest that the freedom that personal budgets are supposed to bring is rapidly disappearing, as local authorities clamp down on how this money can be spent, increasingly requiring it to be used only for 'personal care' in the strictest sense.



The survey suggests that the freedom that personal budgets are supposed to bring is rapidly disappearing

Numerous examples were given of local authorities prohibiting people from spending their personal budgets on:

- Transport
- Social activities
- Shopping
- Housework/cleaning
- Washing and ironing
- Gardening
- Gambling (so no bingo)
- Cooking apart from microwaving
- Food and drink
- Equipment, including wheelchairs and crutches
- Day trips or holidays
- Carers' breaks
- Legal advice about your rights
- Communication aids
- A laptop or iPad (to shop online and make social contact)

- University courses
- Live-in care
- Horse riding
- Entrance fees for attractions
- Meals for carers
- Haircuts
- Overnight support
- Gym membership/exercise classes
- Paying for administration of the personal budget i.e. payroll and HR services (highly relevant for people in receipt of direct payments)
- And last but not least, caravans!

Social workers' comments also included the following:

"There are too many exclusions to list. There is no longer any choice exercised."

"There is an emphasis on traditional care services, any leisure activities or more bespoke arrangements are heavily scrutinised and unlikely to be agreed, except in exceptional circumstances."

"There is a constriction on choice, creativity and recognising the diversity of people's needs and priorities."

"The local authority sets a limit on how much they are prepared to spend for care which is far lower than what most care and support providers are charging. This means that service users have to pay 'top ups' which most can't afford. Service users therefore have no choice but to use the standard contracted care agencies, which provide a terrible service."

"Tasks done for the person outside the home, rather than with the person, are now excluded, e.g. taking the dog for a walk."

"Using the budget for a shave rather than the support worker doing it is excluded."

"It has become so much more stringent lately.

Everything has to be itemised and decided upon in advance. It removes the spontaneity of choice and that in itself is restrictive."



"There are too many exclusions to list. There is no longer any choice exercised." "The personal assistant is not funded to wash and style a person's hair after they have had a shower. This should be a privately funded arrangement with a hairdresser. The personal assistant is also not funded to feed the dog or let it out."

"The money cannot be used to pay for a personal assistant's lunch when they are supporting them out to lunch, so the service user has to eat alone or the personal assistant pays out of their own money."

"All leisure activities that don't have employment outcomes are now excluded. Spiritual needs to worship in a community are not funded (e.g. transport to church)."

"Direct payments can be used for the care a service user needs during an activity but not for an entrance fee for the support worker, nor bus fares or other expenses incurred by the support worker that are not related to personal care. This leads to individuals having to pay these additional costs for the support worker in order to have the support."



"All leisure activities that don't have employment outcomes are now excluded. Spiritual needs to worship in a community are not funded."

Conclusion



The overall picture painted from this survey is of a system of care and support for disabled and older people that is buckling under the strain of too few resources and rising demand.

Things do appear to be better in some places than others: some social workers who responded to the survey felt mainly positive about moving to a 'strengths-based approach' to assessing people's needs and some examples were given by them of cases in which provision had been reduced to the betterment of the person concerned. However, there were plenty of other respondents who said there were negative as well as positive examples in their local authority, as well as a significant number who expressed grave concern about the disastrous impact of withdrawing or reducing care from some of their clients.

These social workers' comments stand out as the most worrying feedback to the survey that we received and their quotes make it clear that some people have been put at risk of serious harm and many more subjected to acute anxiety and distress. The knock on adverse effects on families and the NHS are also laid bare.

It is also clear that in some places the law is being at best 'bent', at worst systematically breached, as local authorities scrabble to fulfil their legal duties with grossly insufficient resources. The spirit of the Care Act, with its laudable emphasis on promoting the wellbeing of people, seems at grave risk of fizzling out at a time when there is sometimes not enough



A significant number expressed grave concern about the disastrous impact of withdrawing or reducing care funds or people to provide even the most basic personal care, let alone pay attention to wider needs. This is incredibly sad for all those involved, especially perhaps for younger disabled people who may not now get the educational and training opportunities they need – something that is likely to have a lifelong impact by scuppering their chances of fulfilling their potential.

It must also be very disturbing for social workers to be able to see what adults with mental health problems, disabled adults or older people need, but be wholly unable to provide it. The responses to the survey point to the need for a debate within the profession about how to navigate the grey area between 'empowering' people by requiring them to take more responsibility for themselves on the one hand, and hurting people by taking away more support than is humane and they can cope with, on the other. However, this discussion is frankly eclipsed by the spectre of so many professionals and managers in the social care system seemingly struggling against the odds to keep some semblance of decent care and support going for the population in their areas

Some who have seen the statistics about the underfunding of social care will probably have wondered about their impact in the real world. Now they know: this report shows that the end results include officials in some local areas coming up with ever more creative and sometimes frankly absurd ways of restricting the ways in which precious social care funding can be spent by individuals in need of support. As a result, older people are being repeatedly admitted to hospital when this might easily have



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been avoided through the provision of more social care. Those with mental health problems are not getting the right support to get well and disabled adults are being prevented from accessing the help they need to find and sustain work

We can surely do better than this as a society. Nothing could better demonstrate the need for this Government to live up to its pledge to bring forward proposals for placing social care on a sustainable basis than the awful stories submitted by some of the social workers who responded to this survey. They are a compelling call to action and the Care and Support Alliance urges Government to respond.



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