



UNIVERSITY OF
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BRIEFING

Independent paid care - boon or risk?

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SUMMARY

We interviewed a small group of independent carers as well as older people who were purchasing care from independent carers. By independent and unregulated care, we mean care given by paid carers who work alone or in small groups rather than for traditional care providers (such as, home care agencies). They are not subject to inspection or registration of their services and are self-employed although it is evident that some independent carers are paid for their services 'under the radar'.

Both older people and independent carers in our study believed there were significant advantages to care purchased from independent carers when compared to care provided by registered agencies. Independent carers highlighted the freedom they gained by not working for large, for profit, care businesses. They felt able to offer more flexible and personalised care, earning a better rate of pay whilst charging lower hourly rates. Older people valued having regular and consistent care from one or two familiar carers who usually lived locally and with whom they built up trusted and valued relationships.

However, there were also challenges and risks for independent carers and older people. Independent carers had little or no access to training, supervision and support. They could feel a high level of responsibility for older people for whom they were providing care, sometimes leading them to provide extra care without additional pay. Employing an independent carer is potentially risky for older people who may not be aware of what they should routinely ask about when employing a carer, such as whether the carers have appropriate liability insurance and are capable of providing the care being asked of them. There was not an obvious route for older people to take if they wanted to complain about an independent carer or if they were worried about the care they were getting.

Independent carers managed additional responsibilities when compared to home care agency workers. For example, they needed to manage their own billing, accounts and tax, ensure their insurance was up-to-date, arrange cover if they could not fulfil agreed care arrangements and take responsibility for their own professional development. It was evident from our research that some of these responsibilities proved challenging, for example, accessing suitable training and finding cover.

INTRODUCTION

This briefing draws on research findings from the Ethical Issues in Self-funded Social Care: Co-producing knowledge with older people project. Conducted over 3 years and funded by the Wellcome Trust, this participatory research project explored how older people experience the process of finding and paying for personal care from their own resources in three local authority areas in England. For the full research report and further information about the project please visit <http://www.olderpeopleselffundingcare.com/>

BENEFITS OF INDEPENDENT CARE

The independent carers in our study had opted out of working for 'traditional' home care agencies because of the pressures this placed on them personally and experiences of giving what they judged to be poor quality care. They referred to having to manage large care 'rounds', particularly in rural areas, where they were often geographically dispersed and care could not be fitted into the time allocated. A late finish with one client had a knock-on effect on remaining clients that day and they might be called at short notice to pick up unfamiliar rounds and clients because of staff shortages. This caused dissatisfaction amongst their clients and high levels of anxiety for them personally. In contrast, independent carers felt that working on their own or in small teams of independent carers enabled them to manage their workloads better. This improved the quality of care for their clients and increased their own job satisfaction. Independent carers often worked locally and acquired new work from older people and family carers by local recommendation or word of mouth:

'We found out about one particular woman who was visiting a few of the residents. And so, I think it was actually, my sister approached her originally, and said, "Would you just come and meet my mum?" And so she came round, and that worked fine because they're all Catholic, this woman was Catholic, her kids had gone to the same schools, they'd got very same experience. So she sat down and talked to my mum, and it sort of got over that, here's this stranger. She said, "I don't want a stranger coming in", and this wasn't a stranger then. It was somebody with a very similar background, obviously younger and more capable, very similar background.'

Victoria, family carer

Independent carers were able to charge lower rates than care agencies as they had minimal overheads and were not driven by the need to achieve a profit:

'Well, for the patients, the clients' point of view, I think they probably get a better service ...because ... you're paying us directly or we're being paid directly as in the case of Brokerage Agency, but they know there's no big business behind us that needs to make a profit.'

Independent Carer 1

Older people generally paid less whilst independent carers still earned more than they did working for a care agency. One independent carer we interviewed explained that in the agency she worked for, older people were charged £19.00 an hour for a 'standard' visit. She earned the minimum wage and received no travel expenses. As an independent carer, she charged £13.00, giving her clients the benefit of cheaper care while increasing her own hourly rate by several pounds. This enabled independent carers to work with fewer clients but to earn the same or more than when working more hours for an agency. Cheaper care meant that older people's financial resources may last longer or they could afford more care should it be needed. Independent carers had more control over their workload and could offer continuity of care which allowed them to develop closer relationships with the older people they cared for:

'Because that old lady, old man, doesn't want anybody else coming in, they want Fred that they've known for ages or Sophie or whatever. Because you get to be part of the family, you get a very close relationship with the family as well.'

Independent Carer 3

Older participants and carers identified that independent carers were often able to offer flexibility as they were not tied to large care rounds:

'I say to her "could you do a sleepover for me because I need to be away?" and she says "yes". "Or could you come, could you stay a bit later to make sure Steve gets whatever he needs?" and she says "yes". So we've got that kind of...flexibility'

Jo, family carer

Both independent carers and older participants who employed independent carers felt that care arrangements were less tied to 'time and task' care arrangements and instead, tried to respond to the needs of the person on the day:

'She is very very good, she does all the major cleaning, hoovering, she does my shopping for me she helps me write my letters because I still write a large number of letters, always have done, to all my family and my family is growing ..whatever I need she does'

Bernard, older participant self-funding their care

'I went over there and she had this long list of jobs for me...it was like...when you go and see your mum or someone like that...a light bulb needs fixing, a little bit of weeding...can I take the dog for a walk...her TV wouldn't work...I measured her curtains and I ordered some bras on the internet for her because she'd lost a lot of weight and nothing fitted....I spent...about five hours with her that day just doing stuff like that really and she was really happy about that...I've said to her at the moment I'm quite flexible so if she wants me, in fact I got an email from her last night asking me if I'd drive her to S because she's got a friend there...and then ..spend a couple of hours there and then drive her back'

Independent Carer 3

Independent carers believed that greater autonomy in their day-to-day decision making gave them flexibility to respond to social and emotional needs, rather than being preoccupied with practical tasks:

'I've sat and chatted to my lady, you know, when I can sense that she's feeling a bit lonely and she wants a chat. And she says, 'Oh clock's ticking, you're over your time' and I say, 'Oh that's alright, it's my choice', you know. Because I don't mind, if I've got the time. If I can't, I can't.'

Independent Carer 1

CHALLENGES OF INDEPENDENT CARE

Independent carers sometimes faced ethical dilemmas when a client's care needs exceeded the amount of care it was agreed they would provide. Although this tension also arose when working for an agency, independent carers had to take responsibility for deciding whether to ask for extra payment or to provide the additional care for free. Some independent carers we spoke to worked extra time without pay or even lowered their rates because they were aware that the older person could not really afford the care they needed:

'The team leader.... has got clients who only have her.... And could do with having her for two or three hours but only pay for an hour and she invariably ends up going longer because she's soft. I keep telling her she's not going to make a fortune like that, but that's not why she's in it. Yeah, you get people who say, 'I can only afford to have you for an hour or so' and they're self-funded.'

Independent Carer 1

Another disadvantage for independent carers was the lack of access to affordable training, making it difficult for them to keep their skills up-to-date or learn new or specialist aspects of care delivery. They tended to rely on their previous experience and qualifications, continued learning on the job and, where possible, collaborating with other professionals.

'I don't really in all fairness, I don't [keep up to date with training], but what I do is I work alongside other health professionals, [...] and myself do what they've asked us to do, but you're right, I do really need to look at that because some of my stuff does need updating... but the basics of it is very much the same anyway, if there's anything I don't think is right or I'm not sure of, I don't do it or I'll get in touch with somebody, I'll try and find out, yeah.'

Independent Carer 2

Independent carers could be asked by older people or their families to provide care which exceeded their capabilities. This required them to understand and be honest about the sorts of care that fell within their skill set:

'Obviously I have to abide by my liability insurance because there's certain things, like for example Warfarin I wouldn't touch with a bargepole and stuff like that because you just wouldn't because controlled drugs are different, if they're prescribed that's fine, but yeah, so you have to be a little bit careful about that as well.'

Independent Carer 3

Independent carers also tended to fare worse in accessing supervision and support than carers employed in an agency who, at the very least, had access to support from colleagues. Some independent carers sought support from collaborations with other independent carers or chose to work in a small team.

Knowing how and when to respond to concerns about safeguarding and abuse was a worry for some independent carers working alone. They were also vulnerable to being the subject of accusations of malpractice or abuse which would have a negative, potentially disastrous, impact on their reputation. This was keenly felt by participants whose work and reputation depended on 'word of mouth' in their local neighbourhood.

'...and I also get worried about oh I wonder if Mrs so-and-so thinks I'm doing something you know, I have that, especially in a place where it's warden controlled as well, you think you know, you have to be careful because you only have to do one little thing wrong, maybe I'm being a bit paranoid about this...'

Independent Carer 1

Independent carers had different views about whether they should be regulated in some way. Some felt that a 'light touch' registration would lead to better recognition of their role in providing personalised care as well as giving greater accountability and other potential benefits, such as improved access to professional support and training:

'I think registered in as much as just to say, 'hello, I'm a carer' that sort of thing.....you don't have to be qualified. In fact, some of the best carers aren't, they're instinctive. But I think it would be good to have them registered somewhere so that they were on the radar.'

Independent Carer 1

There was a feeling that there would still be people who provided care 'under the wire' via informal cash arrangements who would resist any attempt to formalise the role:

'It definitely needs to be (registered).....definitely, but then you will always have people that will not be a part of that, like they won't do it, because you always have people out there that do things that they shouldn't be doing.'

Independent Carer 4

The potential disadvantage of independent care cited by older participants focused on concern that carers who they had come to rely upon might decide to leave. This would potentially leave them bereft of an important relationship and without care. Although the same could be true of care provided by an agency, older people employing independent carers were more likely to rely on a single carer or a very small, consistent care team.

'I don't think anything is going to change very much, unless Mary (sole independent carer) leaves me and I would cry my eyes out.'

Bernard, older participant self-funding their care

PERSPECTIVES ON THE DIFFICULTIES AND RISKS OF SELF-FUNDING

Independent carers recognised how difficult it often is for older people to find care. Independent carers usually got work via personal recommendation or by advertising locally in shop windows, community Facebook or parish magazines. Older people who employed independent carers confirmed that they found care via local connections and word of mouth:

'...we got to know them (carers) through the disabled shop. There's a lady that works in the disabled shops. Millie had been talking to her about something else, and she said well there were these three girls, as we call them, had got together and they were looking for jobs and the sort of thing that I needed ... and I think they're pretty well kept busy all the time.'

Adele, older participant self-funding their care

They acknowledged the challenge this presented to older people and their families needing to be assured that they were securing capable and trustworthy carers. Some older people did not ask independent carers for references, Disclosure Barring Service (DBS) checks or attempt to assess their capability to do the job.

'..when I went there she asked me to bring my driving licence and a utility bill and my DBS and a reference, and I thought, you know, that's good because she is...savvy enough to ask for that. Whereas the other lady didn't....I just went there...I took it and made her look at it but she just trusted me the minute I walked through....I know I'm trustworthy but there's other people that aren't.....'

Independent Carer 3

Older people and unpaid carers may not know what they should check when employing someone. If, as was often the case in our study, the independent carer was local or recommended by friends and neighbours, older people and family carers may feel embarrassed about asking to see references or evidence of a DBS check, or they may decide it is not necessary.

'I suppose in a way we were lucky, very lucky. We didn't do DBS checks... But they said, "I've been DBS, I've been checked, I'll show you my certificate", and we accepted that, so they all had done that.... it's like a network, and we knew about them. Now, if something, nothing did go wrong, nothing went missing, if something had gone missing, I think we'd have known pretty quickly because we were around...'

Victoria, family carer

The independent carers we spoke to felt that self-funders should have easier access to assessment of their needs and the use of brokerage systems or an up-to-date, vetted advertisement service:

'I think it's very much just putting out feelers and finding out. I mean if they're tech-savvy and can use the internet then there's a lot of pointers. I tell you who is a good source, Bell Flower(brokerage). They've got a ... great set-up, again you have to pay for it but they can provide and therefore vet people, I presume, to come and help and you have to pay but at least you know it's come from a reliable source if it's someone you don't know. They try and find somebody locally'

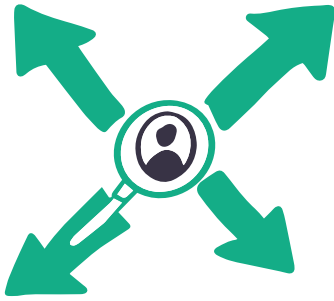
Independent Carer 1

Independent carers saw the key risk for older self-funders as being that of purchasing care from unreliable or untrustworthy people. 'Rogue' independent carers were viewed as potentially very dangerous to older, vulnerable people as well as to the reputation of independent carers in general:

'I also see the fact that it [unregulated care] could be very much abused.... because some of my clients will say oh you know (offering money) like that right, if you want to give me a treat at Christmas that's fine but I am not prepared to..... It is open to abuse...'

Independent Carer 2

POLICY & PRACTICE IMPLICATIONS



Independent carers could benefit from 'light touch' registration of their services, possibly via existing brokerage services, especially if it provided them with access to affordable training and the ability to advertise their services. This would also give some security to older people and their families who are purchasing care from independent carers.



Local Authorities should make more efforts to make older people aware of their right to an assessment of need which could support them to explore various care options, including what to consider if they are employing independent carers. Information should be publicly available about safe practice when employing an independent carer and how to access support if there are safeguarding or other concerns.



There should be greater support for small micro-enterprises as they can find it easier than large organisations to deliver more flexible, person-centred care.



There is a need for more research on the role of independent carers, their impact on the care market for self-funders and older people's experiences of this form of care.

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