

Home care

Stories from service users



Healthwatch Islington

Healthwatch Islington is an independent organisation led by volunteers from the local community. It is part of a national network of Healthwatch organisations that involve people of all ages and all sections of the community.

Healthwatch Islington gathers local people's views on the health and social care services that they use. We make sure those views are taken into account when decisions are taken on how services will look in the future, and how they can be improved.

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Introduction

Over the last few years the local community has suggested that Healthwatch Islington look into home care services due to the negative publicity attracted by these services. We carried out some initial interviews with service users in 2013. As services were re-commissioned by Islington Council in 2014, we decided to look again at this area. In the re-commissioning process, we welcomed the council's requirement that potential contractors pay the London Living Wage, make some contribution towards travel time as well as sign up to the Unison Ethical Care Charter.

This year, Healthwatch worked with two of the three local agencies to contact residents receiving council funded (at least in part) home care services. The user stories collected here offer a snapshot of what it is like for users receiving care and support, told in their own words.

Methodology

Healthwatch worked with two of the three local agencies to contact residents receiving council funded (at least in part) home care services.

Before the interviews we contacted the council's contract monitoring team to see if there were any areas on which we should particularly probe respondents. We wanted the interviews to be led by participants, so that they could tell us what was important to them. Whilst hearing their story we prompted them on particular points pertinent to the preliminary discussion with the council. These prompts focussed on:

- ▶ Whether paid carers came on time and stayed for the full amount of time,
- ▶ Whether respondents felt safe or knew what to do if they did not feel safe,
- ▶ Whether respondents knew about the complaints process.

The user stories offer a snapshot of what it is like for users receiving care and support, told in their own words. Care agencies circulated information about the survey to their users and those who were interested sent us their contact details so we could give them a call. As such, users were self-selecting.

Below, we outline the user's experiences. There was a sense from service user responses that whilst service users and their family carers were grateful for services, services need to be more personalised. There were small numbers of responses, so we do not want to suggest that all recipients of care are facing these difficulties. However, some of the issues raised clearly had a big impact on those receiving care and their families.

There was frustration from both users and family carers and in some cases a feeling of helplessness about how to resolve problems, with the power all being in the hands of providers. There was also praise for particular carers. Where services were delivered well this clearly had a very positive impact on those receiving care.

User stories

'I've been [making breakfast] myself because I get up at 5.00am and don't want to wait till 10.00am when the carers come in.'

Mrs A is a visually impaired older person. She receives visits from carers on a daily basis to help her prepare breakfast. 'Lately I've been doing this myself because I get up at 5.00am and don't want to wait till 10.00am when the carers come in.'

What she likes for breakfast is a 'simple English breakfast' - by this she means two slices of toast and marmalade, porridge and sometimes poached eggs.

Although she has stated this to the company that provides the care, and to the carers themselves - this is not always provided. She has often had carers reluctant to make porridge (to the point that Mrs A has stopped asking them to do it) and carers providing her with blackcurrant jam (instead of marmalade). On one occasion she was given two very soggy pieces of toast that she was unable to eat - she thinks the carer put the slice of bread with butter in the toaster and then toasted it.

However, on another occasion she had a carer who was able to make lovely poached eggs for breakfast, even though she had never cooked these before. The carer was able to follow the instructions that Mrs A provided.

Mrs A was also concerned about carers' lack of Health and Safety awareness in the kitchen - there have been some instances where sharp instruments have been left protruding upwards, which posed the danger 'of poking them in your eye as you are about the kitchen'.

Another issue in relation to her care is that she has been billed for care she has not received and for her she understood was free. This included charges for providing daily personal care to Mrs A, though these are not required and she does not receive this service.

Mrs A was unaware of who co-ordinated her care. She had been unhappy with her social worker and at the time we spoke to her, she had not been allocated a new worker. However, she mentioned that her psychologist was brilliant - she had given her a DVD that was very useful to help her keep a positive frame of mind - and 'not having negative thoughts'.

‘She makes me feel good. She talks to me and makes me laugh.’

Mr B is Black British, in his 70s and has dementia. He has home care visits twice a day. He only needs the support of one carer. He was not sure whether it was Allied Healthcare or London Care providing his support. It was difficult for him to recall details of the visits.

‘I have home care, come at breakfast, and baths me. Does it well. Doesn’t do everything I need, don’t get everything on the list [from our flyer]. I’ve not told the agency, don’t complain about it. She comes on time and she makes me feel pleasant. Even if she is late sometimes. She apologises. I don’t mind, I’m not in a hurry, I’m a sick person. The woman who comes, she’s usually the same person. Nothing to complain about, she makes me feel good. She talks to me and makes me laugh. Not sure how long she spends with me. If I wanted to complain I would phone you, Healthwatch [we advised him to phone the agency in case we are shut] but I don’t like reporting people, I don’t want to be spiteful, what if they sacked her?’

‘I’m happy with it. She comes everyday apart from Sunday and a different carer comes on Sunday but I’m happy with her too. She’s gentle with me and I’m happy.’

- ▶ Healthwatch Islington always advises service users on how to complain and reassures them that it is safe to do so.

‘There’s no malice in it but they don’t think, and it doesn’t help that they keep changing.’

Mr C is White British, in his 70s and has reduced mobility. Allied Healthcare provide his care.

‘They come between 9.00 and 9.30[am]. It’s all right but I get lots of different ones, they don’t know what I need. I don’t want to complain, they work hard, but I live and sleep in my chair, there’s no movement – I’m hoping my regular carer gets well – need someone regular. The problem is I am stuck in my chair. Everything I need needs to be in reach. But, for example, some of them leave my walking stick on the bed. There’s no malice in it but they don’t think, and it doesn’t help that they keep changing. Some are fine. Sometimes they have a tendency to take over. They ignore my wishes and do things off their own back.

‘There was a new girl this morning. There’s another guy, but he thinks he knows best, he decides when I’ll change my trousers even if I say no. It makes me angry. He said I smell. It’s my legs that don’t work but I’ve got my mind. I’ve got good friends, neighbours keep an eye on me, I’m sick of being in the chair. Another friend took me out to the supermarket.

‘I live in the living room. I miss my regular carer terribly. They think they know what’s best for me. The regular carer took me out each day to a diner or to do shopping. I’ve not been out for ages, no idea what’s in the fridge. Can’t get out of my chair to look.

‘This other guy over-rides my wishes. The regular carer always acted on my wishes. I feel irritated but I don’t want to complain, [Regular carer had gone away and apparently not come back, though we could not ascertain why]. I want him to come back for Christmas, I don’t want to be alone.

‘They come at 5.00[pm] to make me an evening meal. Usually a sausage roll and a cup of tea. I used to go out for a full meal [with the regular carer] But they don’t take me out, I haven’t had a full meal in ages, they say they don’t have permission from the boss. He was supposed to come last week but he didn’t, but he said he is coming today’ (though he hadn’t at 2:00pm, the time of the call).

- ▶ When asked if he knew how to complain the respondent stated that he was expecting that visit this afternoon and would try and talk to the boss and see what he thinks.
- ▶ When asked if he felt safe he replied: ‘I feel fine, safe and have wonderful neighbours. I’m surrounded by nice people but I miss my regular carer.’

'It's making the company happier than it makes us... The care company calls the shots.'

Ms D is a family carer whose father is receiving home care for a range of needs. Sevacare provide his care after the family switched from another provider.

'There aren't enough hours. Sometimes they get the same carers. The night person is pretty regular. Nice but mostly they sleep. Hesitant to ask for a different carer (already had several) just give her some cash from time to time to keep her sweet. In the day time it's more varied. It's hard to know how many carers come. They send different people.

'Dad likes to out to the Mosque but they send someone different and they don't know where the mosque is. We'd prefer it if they didn't send people in wet weather as my parents can't go out then so the carers just sit there. We've said it would be more useful on a Saturday but they say they don't offer that. It's not when we want. It's making the company happier than it makes us. We can't re-arrange things. They say they don't have people at the times that we need them. Like going to a hair salon and they can't do your hair on the day but they still take the money.

'They are often not on time, they come later. For example, they say they will come at 8:00 and then they come at 8:15 but then they come for half an hour not an hour. They say they can, that they are allowed to come 15 minutes later but that's difficult for me to manage.

'I've asked them to phone me because I don't trust them. They don't come for the full time or write anything down. The government tightens the purse strings and the care companies are benefitting - they get the money but there are no services. There's no monitoring. There was some respite care for me, but when I was away, mum fell. The carers aren't trained properly. I can't even get a break. Then they come and they say things like "We don't this" because they saw me using wet wipes on my mum after she went to the toilet.

'I got pushed to taking a Direct Payment for them (one has dementia and the other has Alzheimer's, I'm on a break recovering from a back problem. I was told "it gives you more freedom" but it created problems if they [the carer] is ill and it costs a lot to pay the accounts company, it's not straightforward I'm chasing up more people.'

- ▶ Complaining: 'I've sent so many letters so many times, it's demoralising me. I end up shouting every time I'm on the phone to them. I had respect, I had a job. I've gone in to this thing [caring for parents] and I'm treated like a dossier they treat me like that.'
- ▶ Safeguarding: 'I feel they are as safe as it's possible for them to be. I've put things in place. I find bruises, maybe they've held her too tightly or not tightly enough. It's hard to know.'

'The care company calls the shots. We changed (from another provider) but they're the same, they are driving me crazy.'

'We used the complaints process but it didn't resolve anything. They can always find other clients.'

Ms E was contacting us on behalf of a relative and keen to maintain anonymity.

No one reads the care plan. They're supposed to give her breakfast but there's no food in the house so they stored food at the sister's house next door. They say they have given her orange juice and toast and tea but how can they have done when they haven't been to the sister's house next door to pick it up?

There's no food in the home because of her dementia. One day they gave her some dry cornflakes and a cup of water. No one reads the care plan. There's notes on everything in the house to help memory. We photographed the empty fridge to show them. The problems went on and on. They weren't washing her. I walked in and thought 'what's that smell?' they didn't wash her and her nappy was full of faeces. I talked to the carer about it but she just said that x had only wanted her back washed. She doesn't have capacity. They say, that x sent them away, but she's got dementia.

They don't read the care plan. It's obvious she has got dementia, even after a couple of minutes with her. I've made a report about it. My mother's carer could back me up, she keeps an eye on it and checks on the carers. At the weekend they didn't make her bed. They put a dry clean mattress protector over a wet sheet, a stinking wet sheet. It was between two wet sheets, it won't dry like that. She's incontinent. She had an accident and they just threw her nightie in the bin without even washing it.

She doesn't have a phone because of her dementia and she was dialling all sorts of numbers. So they don't log in and out. But other people are sometimes around when the carer claims to have been there and they've not been.

Their response to our complaint was a pack of lies. I've said I want to take it further. We used the complaints process but it didn't resolve anything. They can always find other clients. We're worried about old people without family around. They get away with this, with this lack of care. They cancelled the care plan due to our complaint and we had no support for her and so had to run around to find another provider. All different carers as a result of that [with London Care].

Islington Council are using agencies that the Care Quality Commission don't give a good rating. No-one is keeping an eye on the finances. On some occasions they paid the agency but they've not turned up. [the relative pays monthly to towards the fees]. It's not right to charge for the service and then not turn up.

‘There’s no chance I’ll get any more support.’

Mr F is a White British man in his 80s with reduced mobility. His care is provided by Allied Healthcare.

‘I have a carer who comes in every morning to change my pressure stockings as my wife is unable to get down and do them for me. My wife does everything else, she washes me, does all the cooking, hoovering and shopping, she should get support as my carer... I’m wasting my time, there’s no chance I’ll get any more support, though I’m 81 and my wife can’t do it all.

‘My carer is fine, does the job weekdays and weekends, comes in puts on my pressure socks, you see with several hip replacements and my back and arthritis I’ve no chance of getting down there and my wife well she can’t get on her knees so it’s no good.

‘Yes, they get me to sign forms for clocking in and out, that sort of thing. I get different carers and they show me their identification, no flies on me I won’t let anyone I don’t know into my home. I’ve had the same care company for it must be 2 years now.

‘They have this electrical appointment thing and one day it wasn’t working so instead of my carer coming at 9:15, this must have been Christmas/ New Year time, they turned up at 10:15am. I called the manager up and he told me that it was due to the electrical appointment thing not working properly.

‘I’ve got big sons but I’m still stronger than them put together, I won’t have any trouble, I know how to look after myself and so I have no worries about my safety.’

- ▶ The service user knew what to do if they were worried about their safety or wanted to complain.

'I have some good regular carers... The office should tell us of a change of carer as I find it hard to read things.'

Mr G is a White British in his 70s who is partially-sighted. His care is provided by Allied Healthcare.

I've been with Allied for a couple of years and I have some good regular carers. My regular carer is great she does the shopping, hovering and gives me some freedom as with my bad eyesight I need some help with some things. I get on well with my carer.

I do have a regular problem which keeps messing things up for me. You see my carer takes me out shopping. She always arrives at 10am and I book a taxi to come and pick us up at 10:15 I'm lucky you see 'cause I've got one of those Com Card taxi things. But no one tells me if she's off sick, say so I book a taxi and then no one turns up at 10:00 and I can't then have a taxi waiting and then not go out. If my carer is being covered then the carer can turn up at anytime and that's then a problem. Why can't they send a replacement carer for 10:00?

The office should tell us of a change of carer as I find it hard to read things what with my sight so if someone knocks on my door and they say they're from Allied, how do I know that?

My carer has a great system, she just rings the office via the phone and the phone then responds by calling her back with two rings. That then means that she is logged in and she logs out the same way.

I've got no concerns with my safety and would call the office at Allied if I was worried. They do however need to sort out their way of dealing with me when my regular carer is off sick or on holiday!

‘It’s not right is it that they are more late than on time?’

Mrs H is a White British woman in her 50s. She has Physical and Learning Disabilities. Her care is provided by Allied Healthcare.

‘I have already spoken to my support worker about this as it keeps on happening and its wrong. My carer helps me to have a shower, helps with the cleaning and the shopping. This is my first experience of carers as I’ve been with Allied for a few months but it’s not right is it that they are more late than on time?’

‘See they should come before lunchtime, but they often turn up at lunchtime which messes with my day. They have this timesheet which I then sign to say what they’ve done and the times they’ve been in at.’

‘I have regular carers but you know what, if I was say got dementia or some other problem I might let [in] anyone I don’t know thinking they’re my carer. I’m streetwise enough to asked for their badge but others might not be. They should phone us telling us we’re seeing a different carer and what their name is so we’re prepared.’

‘Other than that my carer is good and I have no worries about them. If I have something to say then I call my support worker and they get onto it for me. I know also to speak with Allied, but I’ve got learning difficulties you see.’

'Its great to know my uncle is in safe hands.'

Mrs I is a white British woman in her 60s. She talks about the care provided to her uncle, who is also present. His care is provided by Allied Healthcare.

'We wanted to say how fantastic my uncle's carer Gloria is. She is superb, she does the shopping, cleaning, gets him up, gives him breakfast, washes him and gives him dinner, cup of tea and biscuits at teatime. I never see his fruit bowl empty she always makes sure its full for him. The care was awful before we changed to Allied.

'At weekends it's slightly different, he gets men carers. I'm not so keen, you know I think a woman's touch is best as they notice little things. Like, you see they don't put him in his pyjamas and I think this is odd, it might be that he says that he's fine but you would try and insist wouldn't you. You see my uncle doesn't like to be any trouble. They all log in and log out.

'We're really lucky because with Gloria we don't need to complain, she's marvellous but I'm sure if there was a problem then firstly my uncle would let Gloria know first then us second! No seriously its great to know my uncle is in safe hands. But if we ever had any concerns then we would contact firstly Allied.

'We do however need some help over a couple of things, firstly my uncle likes his Chinese food, you know something a bit different from the usual food he eats. We would like to know how he could get that sometimes as a dinner option. We also would like to know if it's possible to get him a narrower wheelchair so that he can get by himself into the kitchen area or to the toilet when he's on his own. You know just a little bit more independence.'

‘Everything is about timings... This all can work well until there is a problem and the office don’t always answer the phone ... There needs to be emergency care’

Mrs J is a White British woman in her 60s with cerebral palsy. Her care is provided by London Care.

‘I am helpless without carers in so many ways as I have various needs. Everything is about timings. I have help with my shopping, cleaning and going to the toilet as I need a hoist. I have overnight care too. My days are the following:

‘Mondays- I am got up at 8am and have my breakfast and a toilet break, then my next visit from a carer for my toilet break is anytime from 12pm onwards. On Tuesdays and Thursdays I get up and ready at 8am then get a toilet break at 11:45am then the next break is between 2.30 and 3.30pm and I am then given a toilet break at 5pm and 8pm.

‘On Wednesdays I get my hair done and my carer meets me at the hairdressers and they take me shopping between 1.30 and 3.15pm and then I have my dinner. On Fridays is housework day and that is between 12 and 3.15pm. On Saturdays I get up 7am and my next toilet break is when the carer arrives anytime between 12 and 1 pm then at 3pm. On Sundays I go to church so I don’t need my carer after I get up at 7am until 3pm.

‘This all can work well until there is a problem and the office don’t always answer the phone and this is on ordinary days not just public holidays. The communication is dreadful and I am helpless.

‘Now let me just look in my little book. You see for example the other Sunday my wheelchair’s motor broke so I couldn’t get to church. If I don’t get to Church then I don’t have anyone to help me to the toilet and I know on a Sunday I can have a toilet stop at 10am. So I rang the office and got [one of the staff]. [The staff member] said that she couldn’t organise a carer for me to go to the toilet as the computer was down and that she would ring back. She never did, which meant I had to just sip water until the carer turned up at quarter past four! That meant I hadn’t got to go to the toilet from 7am to 4:15pm!

‘Now [the staff member] said that if the computers are down then so are those other things they carry around with them, those electronic things. Yet another carer said that they weren’t connected so the office could still get in touch with the carers from their pads if the office computers are down. So who isn’t telling me the truth?

‘What they need is something there that if things aren’t right they can still care for us. There needs to be emergency care. They need to be able to communicate better, tell me what’s happening, phone me back when they say they are going to. Tell me if there is a different carer so I know who to expect, otherwise its frightening having a stranger at your door, make sure they turn up on time and have emergency carers when I need help.

‘My carers don’t regularly turn up on time, it’s a sliding scale of times, they do log in and out. Oh I can’t remember how long I’ve been with them. I’ve spoken to my social worker about the problems. I’m more worried for other people’s safety as these carers when not the regular ones could be anyone.’

My carer makes me feel safe.'

Mr K is White British and in his 60s. He wasn't sure which agency provides his care. He has mobility issues following a hip replacement and heart problems. The respondent had a hospital appointment that they needed to attend, and so the conversation was cut short.

'I have a support worker and a carer. The carer visits me every day and logs in and out via the phone. They visit me on a Monday morning, Tuesday morning, Wednesday morning and then get me ready for bed in the evening, Thursday morning, Friday morning and evening and then Saturday and Sunday morning and evening.

'You see last week I had a fall, I fell off the bus, that platform thing came down and I went to get off it when my foot wouldn't do what I wanted it to do. I fell you see, it was bad, real bad, it took all my skin off my shin and then it got infected, I'm now on antibiotics, it did bleed you know, really bleed. I got this nice lady and she took me to the surgery, she comes every Monday and takes me to the surgery and then we go shopping.

'They log in and log out via the telephone and they keep to their timings. I've had this company caring for me since last autumn so it's not been for very long. I find them good.

'My carer makes me feel safe, she goes down and picks my money up, she helps with my shopping and gets to carry my bags so I don't fall over like I did from the bus the other day. It got infected you know, its really bad, I'm on antibiotics. I spoke to the doctor last week as I need one of those chairs that make it easier to get out of it. I need help with the stairs, my walking. I had a fall you know, my walking ability isn't what it used to be when I was young.'

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Copyright © Healthwatch Islington 2016
200a Pentonville Road, London N1 9JP
020 7832 5814
info@healthwatchislington.co.uk
www.healthwatchislington.co.uk
 [@hwislington](https://twitter.com/hwislington)