



Home Care Users Feedback Report September-November 2013

March 2014

Executive summary

Every week in Reading, 14,000 home visits are made by care workers to people who need help with daily tasks such as getting out of bed.

Healthwatch Reading and Reading Borough Council (RBC) have been working together to collect feedback from service users about this care. We carried out our latest interviews during September-December 2013, building on initial research we reported on last summer.

Service users told us that they value home care visits for helping them to remain independent and alleviate loneliness. However, sometimes care workers do not turn up on time, or do not communicate properly. Home care users also experience a variable level of joined-up care for their wider needs. Many people also told of mistakes with equipment.

We make four new recommendations, set out below. The new findings, and previous report, will inform a refreshed set of quality standards being introduced by RBC in 2014-2015 for home care agencies.

Recommendations

1. Ensure home care service users can benefit from local pilots testing out multidisciplinary team working, so they are assigned a case coordinator as a single point of contact to call about ongoing health and social care needs and to prevent future unplanned hospital admissions.
2. Ensure the new frail elderly pathway in development, considers how to secure effective equipment provision, in terms of prompt delivery, prompt help to transfer large items when service users move homes, correct size/specification of equipment or supplies, considerate storage of items in service users' homes, and collection of items no longer needed.
3. Ensure the new frail elderly pathway considers how to meet the needs of people who do not have English as a first language or who have other communication challenges, to ensure equity of access to support.
4. Ensure health and social care professionals share information about sensitive issues such as end-of-life care.

Introduction

This report contains findings from home care service user interviews conducted during September-November 2013. During 2012 Healthwatch Reading began collecting feedback from people who receive home care, resulting in a report based on 57 interviews¹. Capturing the experiences of people who receive home care continues to be an important part of the work of Healthwatch Reading and Reading Borough Council (RBC). Further feedback continues to be fed into ongoing monitoring of the service and into the development of new frameworks and systems to drive up quality.

Background

RBC commissions around 14,000 home care calls per week from agencies to carry out support tasks. Visits range from around 15 minutes to more than an hour.

RBC introduced formal standards for these services in 2010 via an approved list of providers - known as the Domiciliary Care Accreditation Select List (DASL) - which home care agencies can only join once they have satisfied certain requirements. Concerns about the quality of home care in 2012 drove an agreement between Healthwatch Reading and RBC to work together to gather more in-depth accounts of service users' experiences.

A summary project report, published in summer, 2013 and based on in-depth interviews of 57 service users, found that home care was a valuable service for vulnerable people, but that improvements were needed in six areas: timeliness of visits, having enough time for needs to be met, consistency of care workers, care workers' approach to tasks, support from the care agency office and training for care workers. RBC agreed to use the findings to inform 'DASL 2', an updated list of approved providers, due to be introduced in 2014-2015.

Project Aims

This project aimed to build on previous findings with a focus on the quality of home care, and also to question home care users more deeply about social isolation, and whether they felt their various health and social care needs were delivered in a joined up way. These questions were prompted by local changes to day care provision and a new integration project, known as 'Berkshire West 10', which aims to get GPs, district nurses, social workers, and hospitals to work more closely together to better meet the needs of people, starting with the frail elderly.

¹Home Care Users Research Project can be found at: <http://www.reading.gov.uk/council/consultations/this-year-s-closed-consultations/home-care-users-research-project/>

Methodology

Interviews were carried out in service users' homes, jointly by an RBC officer and Healthwatch Reading officer. Service users could have a friend or relative sit in. A script was developed to frame semi-structured questions, but with considerable scope to include further information.

Key Findings

- The majority of home care users interviewed (6), were in their 80s or 90s; lived on their own (5) and had long term and/or multiple physical health conditions. Just over half (4) had started receiving home care following a hospital stay.
- Home care workers provide a largely consistent and good service. The 'best' home care workers give extra social support in the form of friendly chats, showing a genuine interest in clients' lives, and even some informal coordination of care needs. These findings echo the experience of service users interviewed for the 2012 report.
- Frail health prevents many service users leaving their homes, making them dependent on family, home care workers, or voluntary services for social contact. Falls can also knock service users' confidence to venture outside. Even physically able service users often prefer to stay in and receive visitors at home rather than attend other venues, such as day centres. Many wanted more frequent assistance to get out of their house into their back garden.
- Formal coordination of service users' care needs before and after hospital stays is variable.
- Service users reported frustrating delays or mistakes relating to the supply of equipment.

Interview findings in detail

Quality of home care

All seven home care users praised the overall quality of home care workers, describing them as "lovely", "very good", "terrific" and "special".

Service users said the best home care workers stood out by showing a caring attitude, "having a laugh" with the service user, maintaining the service user's dignity, showing an interest in the service user, and checking if anything else needed to be done before they left. One relative of a service user described her gratitude at the way a home care worker eased her mother's embarrassment in relation to personal care issues.

“It probably took about 15 minutes for them to complete the tasks they had to, but they would often stay 30 or 45 minutes if [service user] was able to chat or needed more help to get comfortable.”

“You feel they’re taking an interest in you and they’re not just doing it as a job.”

“They would chat and laugh with her - treated her like someone still alive rather than someone on the brink of death.”

All service users reported that agencies phoned ahead about any delays to home care workers’ arrival times. Service users accepted delays might happen because of traffic, or overrunning on previous calls, but one service user said it was unacceptable for the first call of the day to be late.

“I am put by hoist on this bed just before 10pm and I have to wait until 7am to be ‘rescued’. Imagine what it’s like for a person with arthritis, nine hours not being able to move position. I can understand punctuality goes during the day but there is no excuse for the first visit of the morning not being on time.”

Most service users reported a consistency of home care staff. Changes to regular workers could also offer a fresh pair of eyes - in one case, resulting in a new personal care need being identified and the service user’s care plan being changed accordingly.

One service user with hearing problems said some home care workers had ignored care plan instructions on staying in her line of sight and pronouncing clearly, to aid lip reading and one worker had even shouted in her ear.

Integration of care

Home care service users raised a number of issues about integrated care - or lack thereof - covering hospital discharge, home risk assessments, equipment and aids, initial diagnosis, and communication and coordination.

a) Hospital discharge

Four of the service users started receiving home care after a hospital stay. One of the service users had fallen and broken her hip on a ward at the Royal Berkshire Hospital while being helped by two staff to the bathroom, following an operation, which otherwise would not have required her to receive home care visits post-discharge.

Two of the service users were able to recall - and praised - the reablement package put in place after they came out of hospital. Home care workers came from the very first day out of hospital. However one service user was unimpressed with the suggestions raised during a risk assessment of her home, soon after discharge from hospital.

b) delays to diagnosis and/or care and treatment

“There was the wonderful suggestion that this [nursing] bed could go in the front room. But it’s like an oven in there, as it’s south facing and the foot of the bed would be in the doorway. Then they said the wall could be taken down between the hall and the living room, which would have meant people opening the front door of the house and walking straight into a bedroom. We warned that all the neighbourhood yobbos would be able to see in the window. During the assessment one of the yobbos went past, threw a coathanger at the window, and so it was then thought it was not viable to have a bedroom in the front room.” [The bed was eventually placed in the dining room at the back of house].

Four service users reported delays or mismanagement of care, mostly before home care was first arranged, that had prevented them getting help when they needed it.

One service user’s relative reported “nearly a year’s wait to get a Parkinson’s diagnosis”, while another service user was awaiting a full assessment from a GP around suspected dementia, leaving his wife having to deal with “frustrating” symptoms in the meantime.

In two other cases, service users found their care improved only once they switched GP practices. A new GP rediagnosed ‘indigestion’ as thrush, in a cancer patient whose eating and drinking problems had led to her becoming very frail and having to move in with relatives. The new diagnosis triggered a range of palliative care, nursing support and equipment.

In the other case, a service user with diabetes, who had switched practices after decades with the same doctor, received a home visit from nurses who discovered she had not received new leg stockings for two years, when these should have been changed every six months. Despite this improvement, the service user had also experienced at her new surgery, a delay of “weeks” for her regular vitamin B12 injection, despite her home care worker ringing the GP surgery twice to chase up. She had also not been told of her entitlement for free podiatry, which she was paying for.

c) equipment and other supplies

A common problem reported by service users was NHS equipment and other supplies, which were either the wrong type, not made available straight away, stored incorrectly, or not taken away after use.

“The wheelchair they gave me meant I couldn’t open the front door - the feet stuck out and I couldn’t reach the lock.”

“It took months and months and months to get a special walking frame with a seat from the NHS. In the end [the service user’s daughter] drove to [the provider] myself to get the frame. I didn’t understand why they couldn’t have told me that I could’ve picked it up myself, from the start.”

“There was a lack of co-ordination around equipment with different people involved in assessments and then supplying different things. When [the service user] moved from her own home to [relative’s home], she had a hospital bed which needed to be moved. The store service said this would take several days, so we made our own arrangements using a borrowed truck. When [the service user] died, the bed was collected but smaller pieces of equipment weren’t after several months and despite several reminders. In the end, we just took things down to the nearest Age UK shop. There also seemed to be a lot of unused and unopened medicine which was just disposed of at the end. Seems a wasteful system.”

“The NHS sent a month’s supply of incontinence pads, and I said, ‘Where do I put all of those?’ I didn’t want them sat in my living room. I didn’t know until much later that they’d piled the boxes in under the stairs - it was full to the brim with boxes and the electricity meter couldn’t be seen [by meter readers]. I don’t use the big pads - I like the smaller ones and I asked for them to be changed but when the order arrived, there was only one box of small ones and a packet of the thickest ones I don’t use. I’m not going to order any more from the National Health [service]. I contacted Tena and bought myself the small ones.”

Other service users praised RBC for adjustments they had made.

“Social services have been excellent in arranging small but necessary adjustments such as handrails and wide steps for access to the back garden, and two walking frames.”

“The council have been a great help to me. They come and cut my hedges. They put in a new path after that because they could see how rickety it had got. My daughters don’t worry about me.”

In addition, most of the home care users welcomed the service they received from local pharmacies, who arranged home deliveries of their medications, either to the front door, or external safeboxes.

d) Co-ordination of care

Service users placed a high value on individuals, particularly district nurses or home care workers, who appeared to take charge of all the different aspects of their care.

“There was one particular district nurse who did a lot of coordinating and chasing to get services lined up. It seemed as though she just took on the responsibility for this rather than it being expected of her. She seemed to have good relationships with everyone else involved in care. For example, she would go back to the surgery to let the GP know if she felt a prescription needed to be changed and was able to get this written out and then filled very quickly.”

On the other hand, a lack of joined-up working had a negative impact in other cases. One relative said information did not appear to be shared between different health professionals, leading to an assumption being made by one nurse that a family knew their relative was dying, when they didn't, leading to the news being broken in an abrupt way.

Good coordination of care could also be hampered by service users' own disengagement from services or unwillingness to seek help, because of access issues. One service user expressed a lack of confidence in ringing her GP surgery for help, fearing that she would not be understood because English was not her first language. She also found it difficult to remember which menu option to select from the prerecorded message she heard when phoning the surgery [e.g. 'Press 1 for appointments, two for repeat prescriptions...etc.']. As she had never learnt to read English, she relied upon waiting for her son or home care worker to visit to read appointment letters from the GP or outpatients department, and to then confirm arrangements. This service user said she would find it useful, if offered, to have one designated, named contact, such as a nurse, who she could ring about all her various care needs.

Social isolation

Three of the interviewees were too frail to go on outings from their home. Two of the three service users who had some mobility, were not interested in going to day centres or other local activities to meet their peers, preferring the company of relatives, their local visiting priest or longstanding friends.

Overall most service users wanted more frequent visitors, and expressed an interest in befrienders coming to their home.

Readibus was known to all service users, but used regularly only by one. This service user enjoyed the journey and chatting with others on the bus, but because the journey times were not specific, she often missed dental appointments. A carer also reported using Readibus to get back from regular swimming classes.

“I don’t want to go to the day centre. I wouldn’t want to be with new people, I want to be with people I care about it. I’d be happy to chat to anyone who came around.”

“I was involved with the church for years and I’d rather appear with a walking frame than in a wheelchair. I don’t want to be one of them [group of wheelchair users] at the front of the altar.”

Three service users (or relatives) mentioned how much they missed spending time in their garden.

“He likes to sit in the garden but as the weather gets changeable he is at risk of getting wet because of not being able to get himself in and out of the house easily.”

“Until I was 80 years old I looked after my tiny garden, allotments, and a friend’s garden for hours every week. Now I can’t get into the garden.”

The voluntary sector and neighbours were highlighted as important sources of additional support.

“A lady from Crossroads comes in to do cleaning ‘the old fashioned way’ and she helps me walk up the back garden path and back.”

“The neighbour across the road puts a newspaper through the door every morning.”

“He used to go the Age UK lunch once a week [before health deteriorated] and travelled by Readibus.”

Summary

The findings from this series of interviews echo the themes of the 2012-2013 research. In particular the latest findings re-emphasise the importance of punctuality of care workers' house calls, especially for the first visit of the day, as this will follow the longest duration spent alone, for many service users. As before, the need to train care workers to communicate effectively is also highlighted, especially with those who are hard of hearing.

Overall, service users send a strong message on the importance they place on the social contact that home care workers provide, especially for those unwilling or unable to leave their homes. Service users say the best care workers don't just complete tasks, they also make a cup of tea, chat, make appointments on their behalf, help them out to their back gardens and seem to 'really care'.

On social isolation, service users uniformly would welcome more visitors to their homes, which reiterates earlier findings on the need for potential investment in befriending services.

Recommendations

Service users' views on the way health and social care professionals work together, inform four new recommendations, as outlined below.

1. Ensure home care service users, can benefit from local pilots testing out multidisciplinary team working, so they are assigned a case coordinator as a single point of contact to call about ongoing health and social care needs and to prevent future unplanned hospital admissions.
2. Ensure the new frail elderly pathway in development, considers how to secure effective equipment provision, in terms of prompt delivery, prompt help to transfer large items when service users move homes, correct size/specification of equipment or supplies, considerate storage of items in service users' homes, and collection of items no longer needed.
3. Ensure the new frail elderly pathway considers how to meet the needs of people who do not have English as a first language or who have other communication challenges, to ensure equity of access to support.
4. Ensure health and social care professionals share information about sensitive issues such as end-of-life care.

Response from health and social care representatives to the recommendations

This summary report was presented to the Reading Integration Programme Board in February 2014 for representatives of health and social care to consider the findings and recommendations. The co-chairs of the Board issued the following response.

We welcome this latest feedback report from users of home care services. We acknowledge that service users place a great value on these services in remaining independent in their homes. We also acknowledge that health and social care services do not always effectively work together to provide the best possible package of care for this group of service users.

We will draw on the evidence from service users collated in this report to inform the ongoing development of a new 'frail elderly pathway' in Reading. This pathway aims to support people to stay in their own homes for longer, prevent unnecessary admissions to hospital, and help them recover after periods of illness or injury. New local multidisciplinary teams will meet regularly to agree joint health and social care packages for service users, and a named, lead professional will be allocated to each service user. Based on this feedback, we will seek to improve the care handover process from Community Re-ablement to ensure that information is shared and communicated earlier to make for seamless transition when the time is right.

We will also use these findings, and the previous larger study of home care users' feedback, to inform our ongoing talks with home care agencies about improving the quality of services, particularly around issues of punctuality of visits and the way home care workers communicate with service users.

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