

Healthwatch Bolton Home Care Report

Why we did this piece of work

How the report came about

This report derives from a planned process of engagement about home care which has been a long term priority for Healthwatch Bolton and its predecessor organisation Bolton LiNK.

Strategic drivers

The engagement work and ensuing report falls within the Priority area of 'Care and Carers' identified as one of Healthwatch Bolton's Priority Workstreams for 2015/16.

Bolton LA are in the final stages of re-tendering Home Care provision and we wanted to bring some service user experience to inform this process, in particular the quality monitoring and incentives processes which we understand to be integral to the newly tendered service framework.

We are aware that there is interest at both local and Greater Manchester levels in a complete overhaul/transformation of home care services. We therefore hope that this report will provide food for thought in any deliberations on this subject as well as act as a spring board to wider service user engagement.

Purpose of the Project

To communicate with home care service users and their families about their experiences of using home care.

To comment on the current state of home care services in Bolton.

To elaborate some of the specific problems that arise for service users both in relation to working with the current system.

To identify what home care service users consider to be valuable in defining what a good service might look like.

Who We Spoke To

Healthwatch Bolton routinely gathers comment about any aspect of health and care experienced by individuals through its website, social media applications, its routine 'Corridor Events' and specific communities.

In looking to gather experiences of home care services we spoke to individuals in the following settings in Bolton:-

- Sheltered housing
- Healthwatch Bolton Volunteer Forum attendees
- Stroke Support Group
- Luncheon Club

With assistance from the Stroke Association and Bolton Carers Support three long case studies were collected and comments extracted from these are included in.

We spoke to people who received home care themselves, who cared for people who received home care or who had friends or family members who received home care.

We spoke to self-funders, people in receipt of Direct Payments and others whose care was provided directly by the Local Authority.

We spoke to people with both physical and mental health disabilities, people with long-term conditions and people who had used reablement services following hospital discharge.

All the data from this report, including the long case studies, can be made available in an anonymised format on request to Healthwatch Bolton.

For the 'Home Care Report' comments were collated and presented to members of Healthwatch Bolton Board of Engagement and External Relationships who identified the themes, priorities, conclusions and recommendations to be included within this report.

What Good Care Looks Like

'The carers stay long enough and it is usually the same staff that come. I like my carers.'

We asked people for any comments on care services, positive negative or neutral . Some people had positive experiences to share and were able to articulate the components of good care and a good relationship between client and service.

People who use care service and their families tell us that care relationships are based on understanding, friendship, good communication, connection and trust and that this comes about by working with the right individual carer/s.

They tell us that experience, cheerfulness, flexibility, empathy, good communications skills, cleanliness and efficiency are important attributes among carers. For Home Care organisations reliability, consistency, flexibility proper time and task management, approachability, value for money and efficient administration are important features.

Testimony on what good care looks like

"She is an excellent carer and I have an arrangement for her to come in the morning. After she has helped me get up she also cleans for me two mornings. It's a relationship based on friendship. I think what makes a good carer is good time keeping, cheerfulness is important, a sense of humour is necessary and efficiency too.'

'They are passionate about what they do and we both trust them.'

'Trust is the main thing – I've had things happen to me in my life that shouldn't. All I can say is that they (the carers) are brilliant.'

'I have carers once a week and they have never let me down - Big help.'

'I don't have carers myself but my neighbour has them. They come 4 times a day and are paid for by the family. She doesn't remember them coming but the family are happy with their care. They bring her lunch. I see the same faces on the corridor so it must be the same carers who come.'

'Comments about the care I had from nurses who came to see me after my discharge from hospital • They had a key as I was housebound • They came at roughly the same time each day • They were really kind and gentle when changing the dressings.'

'(The carers are) not distracted. Look after us well. Respected. I can voice my opinion – they are very cooperative. Help as much as they can. Friendliest of staff, Very accommodating.'

'Carers have been coming to see my daughter who has schizophrenia - they provide respite for me and my wife three to four days per week. We have the same carer now - she has been coming for two months - she has a good relationship with my daughter - she takes a real interest.'

'My current agency provider has a very approachable manager, When I first started with (named company) the manager came out and we had a good chat, I have had no reason to complain (Previous Named provider) carers were good it was just their administration that was difficult and let them down.'

The Reality of Care

There are examples of good care in the testimony, these generally arise in relation to short-term packages (reablement) or, for those with long term care needs, instances where people are able to exercise choice either in direct recruitment of individual staff or via successful negotiation with the home care agency.

Unfortunately, however, in the main the testimony describes a poorly managed system of service provision ill adapted to the needs of the client group. This leaves many people with insufficient, inappropriate, inflexible, unperson-centred and, in some cases, undignified care.

A Job Half Done

“It depends which one you get. My husband’s back has been left wet on more than one occasion. There are four good ones though so if they come its ok.”

The most frequent complaints centre around inadequate visit lengths, poor monitoring of time spent providing care and a ‘slapdash’ approach to specific tasks.

Cared for individuals are frequently left feeling that some carers don’t work to their full capacity, don’t go beyond the absolute minimum necessity and work to the letter rather than the obvious or expressed needs of the individuals they are working with.

Some clients recognise that these weaknesses are caused by the organisation of the service and not by the individual carers. However there is also too much variation between individual carers and too little quality monitoring so clients can feel like they are in a lottery and hoping for ‘the good ones’ on any given day.

Testimony on ‘a job half done’

‘One of the team of carers is “fantastic” and will be on time. If she finishes her jobs early she will sit and chat. The others don’t turn up when they should and don’t do what they are supposed to do.’

“They don’t dry me properly and I end up sitting in wet clothing. I told the carers team leader who supported me. It’s the office who should be telling them. It gets on my nerves and it puts my blood pressure up.

“One carer will not change the continence pad if it is not soiled. If on occasion, bed sheets are soiled there have been instances where carers, having provided personal care for X, will not remove the soiled sheets.”

'Although the carers came at times that were suitable it was always a rush job. They came in and just did what was needed. There was no real connection with my Father. They usually stayed just about long enough to do what they were supposed to do.'

"My morning carers never seem to stay for their 30 minutes and there are other things they could do for me; part of my mental health illness is not feeling comfortable enough to ask them."

'My carers come every day. They help with my laundry and shopping. The carer I have now is really good. The only thing is they don't always have time to deal with my laundry fully. It's not their fault as they may be late and miss my slot.'

Timing, Flexibility and Choice

Timing, flexibility and lack of choice continue to be a cause for concern. Apart from people feeling that carers do not always stay for the full amount of time issues around scheduling of visits also arise. This is particularly evident in relation to morning and evening visits when some agencies seem to schedule work to suit their own staff rotas rather than to respond to the needs described in the clients care plans.

Testimony on Timing

'My husband has Parkinsons Disease. We stopped the carers because they were coming in too late to get him dressed.'

"She makes her own meals as she is diabetic and often cannot wait for the carer. She gets up each day at about 6am but often the carer turns up at 11.30 to help with breakfast."

Choice of gender of carers is seen as important by some as is the ability to exercise choice over what a carer does. These issues need not only be discussed at care planning stage but should also be open to negotiation.

Testimony on Choice

'X has asked that the care agency do not supply a male carer as he feels this compromises his partners situation in the home when care is provided in their bedroom.'

'I have a friend who has carers now. I think you should have the choice of a female carer but my friend has to have a male carer. I would refuse a male carer.'

'I've been told by two carers that I don't need a shower every day but I do need one every day. I want one every day. My wife made them put it in my notes. We've been asked by them where it says I have to have a shower every day.'

Some clients reported a lack of willingness on the part of care organisations to be flexible or to adapt to unusual circumstances or occasional specific requests. Moreover, in these cases it seems that the agencies concerned have not only not complied but also ‘made an issue’ out of a request for flexibility.

Testimony on Flexibility

‘Communication is not very good – I cancelled my carer as my son was coming up for a week and I knew I wouldn’t need them. But she turned up anyway and then I rang them to tell them and they told me not to speak to them like that, got really angry, really not good.’

‘On the morning of Remembrance Sunday, despite particularly asking for a visit which would enable them to attend services locally, X’s visit was delayed and he missed the Remembrance Service. A senior carer’s response was I would have the care when she could get there.’

Continuity

“the other thing is its different people all the time.”

Continuity of care staff is seen as important in terms of effectiveness, ability to develop a connection between carer and client, trust and general wellbeing.

However many home care service users have experienced complications with regards to continuity of staff at some point during their experience and in the most extreme circumstances staffing is so precarious that people see many, many different individuals.

Testimony on Continuity

‘The carers stay long enough but it is different staff every time. The carers help with medication. There is a language barrier with most carers.’

‘We have the same carer now - she has been coming for two months – she has a good relationship with my daughter.’

‘Not Satisfactory....Can’t get regular carers or carers you’re comfortable with.’

‘It’s hard for people with dementia if they don’t see the same faces.’

Respect and Empathy

Clients value it when carers respect their home and neighbourhood, mentioning small things like discretion, sensitivity to the environment and sensitivity to personal space.

Testimony on Respect and Empathy

'The reablement team were brilliant and fantastic. My biggest concern was that they put a key safe outside my Mum and Dad's and they would use the key to enter their home even without knocking.'

Page | 7

'At first they kept changing the times and let me down which left me feeling very anxious. I've got a new carer who gives me a time and rings before she comes to ask if it's ok to visit.'

"They are banging on the door at 7.20 am - the neighbours complain at the noise. They complained where my grandson had left his car and their language was definitely not always appropriate. The way they asked my husband to use his urinal wasn't good or dignified"

Staffing the care industry

'They've got people with no experience working for them, just kids.'

The provision of effective care is seriously affected by care staff employment determinants - such as age and experience of staff - and contractual issues - such as hours, training and wages offered.

Agencies difficulties in recruiting and retaining committed staff who are able to build a relationship based on trust with the cared for person directly impacts on the perception (and reality) of the quality of care individuals receive. The client can be left with the feeling that carers are inexperienced, do not receive sufficient training or supervision and are not empowered to do a good job.

Testimony on staffing issues

'It's lots of different faces. Its new management – they've not got a clue about what's going on. They could improve with better training. The girls are sent out once or twice with someone and then they are on their own. Some of them can't open a tin even – they've never seen a tin opener but have always used cans with pull lids! When you get new carers they don't seem to know what they are doing. The continuity is important. Some couldn't care, they are coming into the job for the first time and they only come for the money.'

'It seems to be young carers that come out. They don't know how to handle it as they can find people on the floor sometimes so they don't last long. I think that they put too much on them. They want them to go on to people's houses right up till 11.30 at night. If they are so seriously ill they should be in hospital.'

Both clients and frontline care staff recognise the failures of the industry to attract and support good staff and appreciate that the current business model does not lend itself to attracting and retaining people in the long term.

Testimony on structural staffing issues

'We used carers three years ago before my father passed away, they were a godsend, most were very caring and conscientious. The main drawback with carers are that they are so poorly paid and the hours are unsociable, so they cannot afford to stay in the job for long, so the person being cared for is constantly having to get new ones.'

"There are not enough staff to cover areas as a lot go off sick and also the pay depends on the company and is low; you don't get fuel expenses. If you are given 10 clients for the night you cannot spend 30 minutes each as they all need to be in bed by at least 11pm and may need doubles to do this...time is little and staff are few...this is the true scenario....'

'A few weeks ago the agency were not able to supply carers for X due to levels of sickness in their team and X's partner had to provide care for X for three days. This impacted significantly on her own serious long term health problems "

Getting What You Pay For

'Carers needed to come at night to see to my husband. Up until then I had cared for him. He died a few weeks ago. They didn't wash him at night but just put him in his pyjamas. We paid over £11 per hour – they only stopped for 15 minutes.'

There is a complete lack of transparency surrounding the payment arrangements in relation to home care. People are confused about who is entitled to what, who is paying, what is being paid for and what the actual costs of care are or should be.

Testimony about 'Getting what you pay for'

'A resident of a sheltered housing complex explained that she is not sure what she is paying for as the charges have increased. The Council send the bill it is more than £140 a month. She is supposed to have an hour each morning and a half hour at night. These are actually 10 minute visits at most and the first thing they do is use the residents' landline to phone and book in. They don't do that when they leave they use their mobile. She feels they are not being open about their leaving times with the service provider. Within her package of care she gets two showers a week. If she requests an extra shower or some shopping she is charged an extra £15 for each activity.'

"I've filled in five lots of envelopes in a week about finance and I'm no further on. We have been told we now have Attendance Allowance."

'The costs of the care from the agency proves a challenge and a pressure for X in managing the family budget. The council rate allowed for assessed care is £12.80 per hour. X found that the rate charged by the two agencies which could provide her partners care varied from £19 to £13 per hour. At weekend the rate with their current agency is £15 per hour with the bank holiday rate being £30 per hour. X pointed out that over the Christmas and New Year there would be seven days where the care rate had the potential to need a subsidy from their family budget which was not covered by their assessed costs.'

'Following an audit of their direct payment it was established that the account was £10k in credit.; there has been a request for £5k to be returned. X's view is that this funding should have been accessed for care, particularly respite, access to a family visit and a holiday. Despite repeated requests for spending on these activities approval had not been granted. X feels that these activities would have enriched her partners life and allowed him to take part in family life.'

The lack of clear information on costs and payments makes it extremely difficult for anyone to effectively monitor billing and value for money. The most obvious people to do this are the clients, however if they don't know what is being paid for how can they monitor if they are being short-changed?

Testimony on 'Being short changed'

'This carer is a lot better she replaced the other one who was doing her own shopping and on her phone and this was supposed to be my time.'

'The family have complained and told them (the carers) they will be checking the job book and calling in adhoc to see if things change before they formally go to their organisation about it.'

The lack of transparency goes beyond the transactional aspect of care services and extends into a general lack of knowledge and information about what people should or could be entitled to and how they might go about accessing relevant support. More information is needed and more support for people in terms of decision-making involving care services.

Testimony on lack of knowledge about entitlements and available services

'Mum and Dad are self-funders. No one tells them about being entitled to a social worker. Somehow they got an occupational therapist; I think it was part of the discharge process or the Reablement Service. She (the OT) didn't know anything about where to get incontinence pads from. I had to ring myself to sort that out with the district nurses and to get dietetic support. She didn't know anything about how to find a care agency but just told us to look on the internet. How do people go on who don't have a 'me' or a family? I think there is a big lack of knowledge about support generally.'

'I wouldn't know where to look for our own carers. The only help I had from the council was to be given a sheet of paper!'

Impact on Family Members

“I’m 48, I feel 98. I’m exhausted. They just expect you to cope.”

A lack of consistency, confidence in care and information can impact emotionally, physically and logistically on partners, children, main carers and other family members.

Page | 10

Multiple needs (health, social support, welfare support and care) fragmentation of services, information deficits, poor communication and a seeming inability of service providers to recognise wider family members as principals in a caring situation can cause main carers to be physically and mentally overwhelmed by the burden of decision-making and the stress of trying to interact with services. This adds to the emotional impact and practical workload involved in caring for a loved one and can contribute to poor health and wellbeing outcomes for carers and family members.

Whilst we may all agree that it is vital that main carers are well informed, empowered and supported to fulfil the role (and provision is made for that within The Care Act), it is clear that many of the people we spoke to did not feel that the current system of home care supports them, or the wider family network in any meaningful way.

Testimony on impact on carers and family members

“All this doesn’t help my mental health – it messes with my head.”

‘Our son cannot cope with living at home. He feels he cannot cope with the impact of someone different who keeps coming in the house all the time.’

‘After considerable effort got one session of day care at a local centre which purports to provide care for people with dementia – without this would not be able to access any statutory care as such a convoluted process and don’t have the energy or even know who to contact to get up to date information...asked for second day at centre – not kept up to date with progressing of this request. Long periods between meetings with social worker when heard nothing – created great emotional distress for me which had a knock on effect for X (the cared for person).’

‘I live in Bristol and am here to visit my 90 yr old father who has been a patient at Laburnum Lodge. I have been in Bolton all this week and yet no professional has made an attempt to speak with me about my father. Yesterday I managed to speak with his OT who told me she has left a message on my home phone (in Bristol, even though she knows I am in Bolton for the week and visiting daily). My father is being discharged to his first floor flat today. No-one has been out to assess his home circumstances but the OT has now said she will go home with him. She says he can climb stairs but he has only been practicing on the 3 wooden stairs at Laburnum Lodge. Climbing stairs to a first floor flat will be quite different. I have also been told that meals on wheels has been arranged for him even though I had already told them that he does not like. The issue is basically lack of communication with the main family contact (myself)..’

Lack of Respite Care

'18 months ago (August 2014) X was told that she was entitled to 4 weeks respite care but she has not yet been able to source any.'

Page | 11

Due to the responsibility and impact of caring the families we spoke to felt that respite care was essential for their wellbeing, however getting respite care is a tortuous and disappointing process with many people unable to access appropriate respite even when they have been assessed as entitled.

Testimony on lack of respite care

"X's partner spoke about her need for respite care for X and how difficult it was proving to source. In August 2014 she had been told that she was entitled to four weeks respite care but has not yet been able to source any.'

"Huge difficulty in getting respite so she can have several good nights' sleep. Has excellent family support but even they struggle to get the respite for her that she needs."

'I've had three weeks respite care in seven years. X should have gone to (named respite care) last August (2015) but we're still waiting to hear. I'm allowed six weeks break a year and I'm tired now.'

'We need some (respite) hours in the week and on the weekend. It would help me as well. I like to meet up with my daughter and go shopping on a Saturday so I feel punished.'

'In preparing for a planned hospital visit X had contacted social services seven weeks prior to the appointment, requesting respite care. Ringing each week she was told the week before her treatment that she had left the request too late. Eventually an hours extra care was authorised.'

Conclusions and Recommendations

Home care services are not working well for many people. While it is clear that many people like their carers and find their assistance invaluable, it is hard to read the testimony without feeling that too much of the current provision is shoddy, slap dash and poor value for money.

The current business and contracting model for home care is not fit for purpose and no one we have spoken to; clients, family members, care workers or commissioners think that it works well.

Home Care provision should take a more holistic view of the client. Home care services need a much better appreciation of their client's personal preferences, connections and interests (as well as their needs) and should be empowered to encourage and support their clients to maintain and develop them.

The current contracting and provider model works directly against the policy intention which leans towards increasing personalisation of care. In the current

context clients are recipients of 'pre-designed' care packages, they are not adequately supported to manage or even influence the terms of their own support, even if they are self-funders or on direct payments.

Many people expressed concern at the costs of care. Some felt that the care they received did not match what was paid for and questioned the value for money when the job was left half done. Lack of access to information about care options and care financing and lack of support to make decisions is a key problem for many people.

The professionals most directly involved in the care of individuals are ill-informed, badly connected and disempowered as are the clients themselves and their nearest and dearest. If this is to change the site of day-to-day decision making and problem solving needs to be radically shifted.

Partners, main carers and other family members are especially dissatisfied with the current arrangements. They feel that they are not listened to, badly supported in terms of essential information and advice and generally put upon to make up for the inconsistencies and inadequacies of the services to which their loved ones are entitled. On a personal level they appear to have been, as yet, untouched by the personal support promised to them by the Care Act.

Our research showed up serious problems with regard to the supply and organisation of respite care with a number of respondents simply not getting the respite to which they have been assessed as entitled.

Providers

Serious staffing issues among home care providers cause a lack of stability in the market and mean that home care clients have to put up with a parade of individuals entering their homes and assisting in their personal care. In addition poor logistics planning, staff management and customer care skills are all evident.

There is no doubt that professional care work has been badly undervalued both socially and financially and that this reality has caused serious workforce challenges for care agencies dependent on local authority contracts. However there are examples, in the private sector and in the international field, of home care organisations that achieve unparalleled (in any sector, not just in Care) workforce and client satisfaction results. So it is possible.

Changes to the minimum wage structure have the potential to change the game in workforce terms. At the moment the narrative around this issue in the care sector is doom laden, but serious and committed home care organisations could and should be championing this change and using it wisely to better support and empower frontline staff.

Recommendations

1. Major improvements are needed in rota planning so that sufficient staff are available at the right time to ensure people get the right care when they need it.
2. Home care organisations need to radically re-evaluate their human resources cultures and strategies, talk to their staff, get to grips with how the market leaders do it and transform themselves into ‘great places to work’.
3. Power to negotiate and manage the day-to-day needs of the clients needs to be given to front-line staff.
4. The Local Authority should support (through the market-shaping process) home care organisations to make radical improvements in their approach to human resources.
5. Non traditional providers should consider what they have to offer to people receiving home care and explore how they can contribute to improving the overall offer of support to home care clients and their families.

Commissioners

The commissioning environment is equally to blame for the current situation conceptualising and contracting the home care ‘business’ as the *supply* of ‘units’ or ‘packages’ of care is a direct cause of many of the current failures.

When an individual’s personal care requirement is enumerated as a list of how many showers a week they can take, how many times they can be dressed or have a hot drink or have their sheets changed it is hardly surprising that the care does not feel that personal.

Travel time, pleasantries or asking how someone is do not appear in care plans and are thus not ‘valued’ in the business model. If even the basic wrap around tasks of getting to someone’s house, talking to them, finishing the job off (drying after a shower, tidying the kitchen after making a meal) are not quantified as ‘units of care’ then they cannot (under this model) be paid for and so do not happen. And if basic wrap around cannot happen how can the system possibly deal with exceptional - though still relatively common occurrences - such as dealing with a spilled drink or a dropped cup, picking up a neighbour who has had a fall, contacting a relative to raise a worry or calling an ambulance if someone is found on the floor.

Care entitlements and carers time are defined and paid for in hours, whereas the ‘units of care’ defined in care plans are valued and ‘delivered’ in minutes. This type of approach is bound to lead to clock watching for everyone in the situation and an unworkable situation in relation to contract monitoring. Nobody knows if they are getting what they’ve paid for, nobody can sensibly invoice for what they have provided and everyone is spending too much time and effort worrying about this problem instead of investing that time and effort in providing better care.

Recommendations

1. Commissioners should completely re-invent the terms of the commissioned service so that it is based on client and main carer outcomes (clients feel well supported, are happy with their carers, are able to negotiate around approach to tasks and tasks of choice directly with their carers, clients and family members report better wellbeing, better relationships and greater connectedness with family friends and community) and not, as at present, on providers ability to deliver 'units of care'.
2. Commissioners should consider, support and approve a much wider framework of suppliers. Personal care, domestic support and support to engage with family community and society should all be transparently available and clients should be able to 'mix and match' the type of support they access.
3. In order to make this happen Commissioners need to genuinely and openly engage with, and invest in, the possibility of creating social prescribing on a broad framework. And develop a way of effectively financing this kind of approach.
4. From a client's perspective personal budgets offer a potential solution but the roll out of this method needs to be supported by a big investment in 'market -shaping', information, advice and brokerage.
5. **Commissioners need to urgently address the undersupply of respite provision.**

Partners, Main Carers and Family Members

A seeming inability to see family members and carers as an integral part of the arrangements is a cause of tremendous frustration.

Partners and main carers may have health issues themselves, they may be elderly, they may have other family, work place and community responsibilities. In addition close family members and significant others are much more likely to be themselves older and to/or live farther away that they may have done in previous generations. This in turn is likely to impact on the kind of care and support they are able to offer their nearest and dearest.

The patterns and tools of familial caring are changing and systems and services provided by the state need to recognise, value and accommodate this reality.

Recommendations

1. Someone needs to Invest in a programme of information / education about care options and care financing so people know what to expect and understand their options.
2. Partners, main carers and family members need to support this work by sharing the knowledge they have and supporting others by acting as 'experts by experience'.

3. Partners, main carers and family members need to support Commissioners to develop services that recognise the realities of modern family and community life and realise the promises of the Care Act.

Home Care Clients

Healthwatch Bolton appreciates that people who use home care services are in a vulnerable position in the current system. We thank all those who have shared their experiences and encourage you to continue to do so and encourage others to do so to.

It is very clear from this report what is important to you - trust, personal connection and respect for yourselves, your nearest and dearest, your personal space, friends and neighbours. We hope that you will feel you have been heard in this report.

Recommendations

1. That home care clients continue to be frank, open minded, forward looking and forthcoming in their comments on how services work for them and how they could be improved.
2. Healthwatch Bolton to set up a face book group to support continued interaction with home care clients.

Our Thanks and Acknowledgements

We at Healthwatch Bolton extend our thanks to everyone who contributed to this report for their openness in sharing their personal experiences.