Carer friendly Communities

October 2018

Carers and the community - Disclaimer

This report is based on conversations or responses freely given by members of the public. Where possible quotations are used to illustrate individual or collectively important experiences.

Engagement officers collect responses verbatim and we also present these in our final report as an appendix. This is important in showing the accuracy of our analysis, and so that further work can be done by anyone wishing to do so.

A full explanation of the guiding principles and framework for how we do engagement and analysis can be found online on our website www.healthwatchbolton.co.uk.

Please note that this report relates to findings observed and contributed by members of the public in relation to the specific project as set out in the methodology section of the report.

Our report is not a representative portrayal of the experiences of all service users and staff, only an analysis of what was contributed by members of the public, service users, patients and staff within the project context as described.

Carers and the community - Background

- This research project is intended to inform future projects with carers looking in more detail at what makes a carer friendly experience in the following different domains; Housing, Health, Care and Support, Education, Work and Community. The project intended to scope out in which domains carers feel that they face the most challenges and where they feel either more or less supported.

- Bolton Carers Strategy was launched last year with clear implementation plans to enable carers to access support and opportunities to provide good care, lead a good quality of life, and access the support they require at the same time the Greater Manchester Carers Charter has been developed to embed Carer's voice and rights across the transformation work streams. We hope that this project will contribute some detailed ideas about what a carer friendly context looks and feels like for carers to the Bolton context ahead of the launch of the GM Commitment to Carers and Carers charter, set to take place on Carers Rights Day in November 2018.

- The theme of Carers was voted the 3rd most important priority for 2018-2019 by Healthwatch members and the public. Healthwatch Bolton has done the following previous work on the theme of Carers;
  - Young Carers (2017/18)
  - When Caring Ends (2017)
  - Living with Dementia (2017/18)
  - Work with Prescription Pricing Authority resulting in a carers group being established (2016)

Carers and the community - Introduction

The aim of this report is to show how various areas of people's lives are affected by having a caring role.

In the report comments are related to specific issues and allow readers to understand how being a carer can influence a variety of daily tasks and interactions.

While there are examples of positive comments, the nature of being a carer and also the questions asked, has prompted people to provide many critical comments, or examples where things did not go perfectly.

Key Findings

Carers and the community - Key findings

There were areas where people felt supported as a carer, examples include local support groups, healthcare workers, and services that provide assistance.

However many people expressed difficulty in managing the physical and mental effects of caring, particularly as this role often lasted many years.

The challenges people faced due to being a carer were compounded by difficulties in getting respite from their daily roles. There are a variety of reasons here, not all related to what type of formal respite are on offer.

There is an opportunity to improve awareness of support groups and knowledge about caring. Technology might also be able to play a part, though there should be alternatives for those unable or unwilling to use it.

Methodology

Carers and the community - Methodology

What are we asking people ?

- We conducted an initial scoping survey asking carers about how caring affects aspects of daily life.

- This project is designed to help Healthwatch Bolton develop one or more focused pieces of work, this will enable carers to share their experiences with a wider variety of stakeholders in implementing the carers strategy.

Who we spoke to?

- General Public via survey monkey promoted through our membership, website and social media and via a snowballing method. Also at relevant events; Bolton Carer’s Information Event; Cancer Information Event & Changing Minds Mental Health Awareness Event (Day 3 carers); Neighbourhood Health and Wellbeing Market Places in Farnworth/Kearsley, Breightmet/Little Lever, Horwich and Blackrod.

Carers and the community - Methodology

Bolton is estimated to have over 30,000 unpaid carers. We are looking to engage with anyone with a caring responsibility. We aimed to reach around 60 carers as part of the scoping exercise.

The scoping exercise was carried out using a survey available online and in paper format. Engagement officers supported people to complete surveys at a variety of events.

Data was analysed on a 'Domain' Level with the 8 Domains being ;

- Housing
- Education
- Employment
- Transport
- Community
- Health & Support Services
- Technology
- Respite

The report maps strengths and gaps against each theme. The most recurrent strengths and gaps will be used to inform the in-depth engagement.

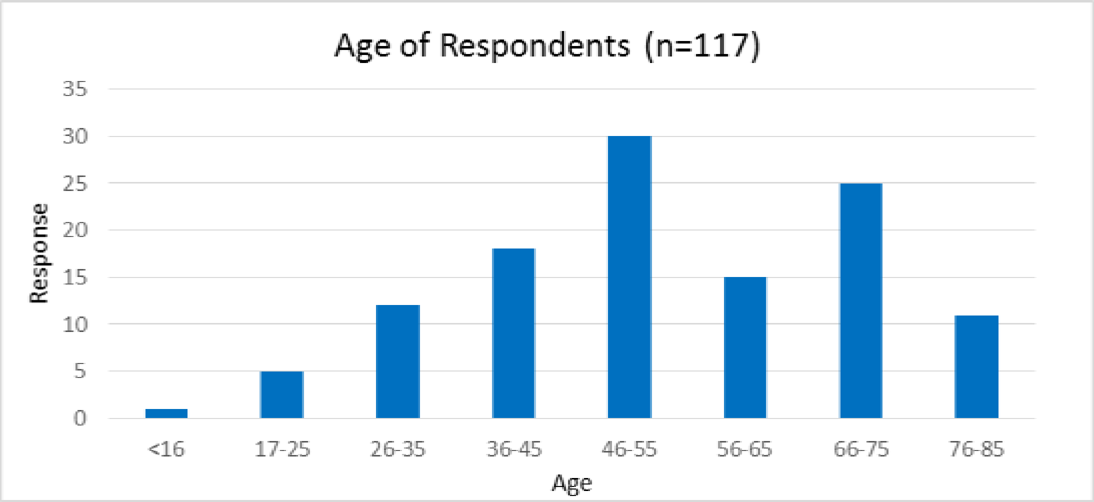
The questions

1. Please describe your situation.
2. Please tell us your experiences of housing.
3. Please tell us your experiences of education including adult learning.
4. Please tell us your experiences of employment.
5. Please tell us your experiences of both patient and public transport.
6. Please tell us your experiences within your community as a carer.
7. Please tell us your experiences of health & support services.
8. Please tell us your experiences of using technology, either in your caring role or to support your individual needs.
9. Please tell us your experiences of respite care.
10. Which support/services have been most invaluable in supporting you with your caring responsibilities and why?
11. How do you feel being a carer impacts on your own health and wellbeing?
12. If you have any other comments you would like to share with us please do so here.

Analysis

Carers and the community - Who we spoke to

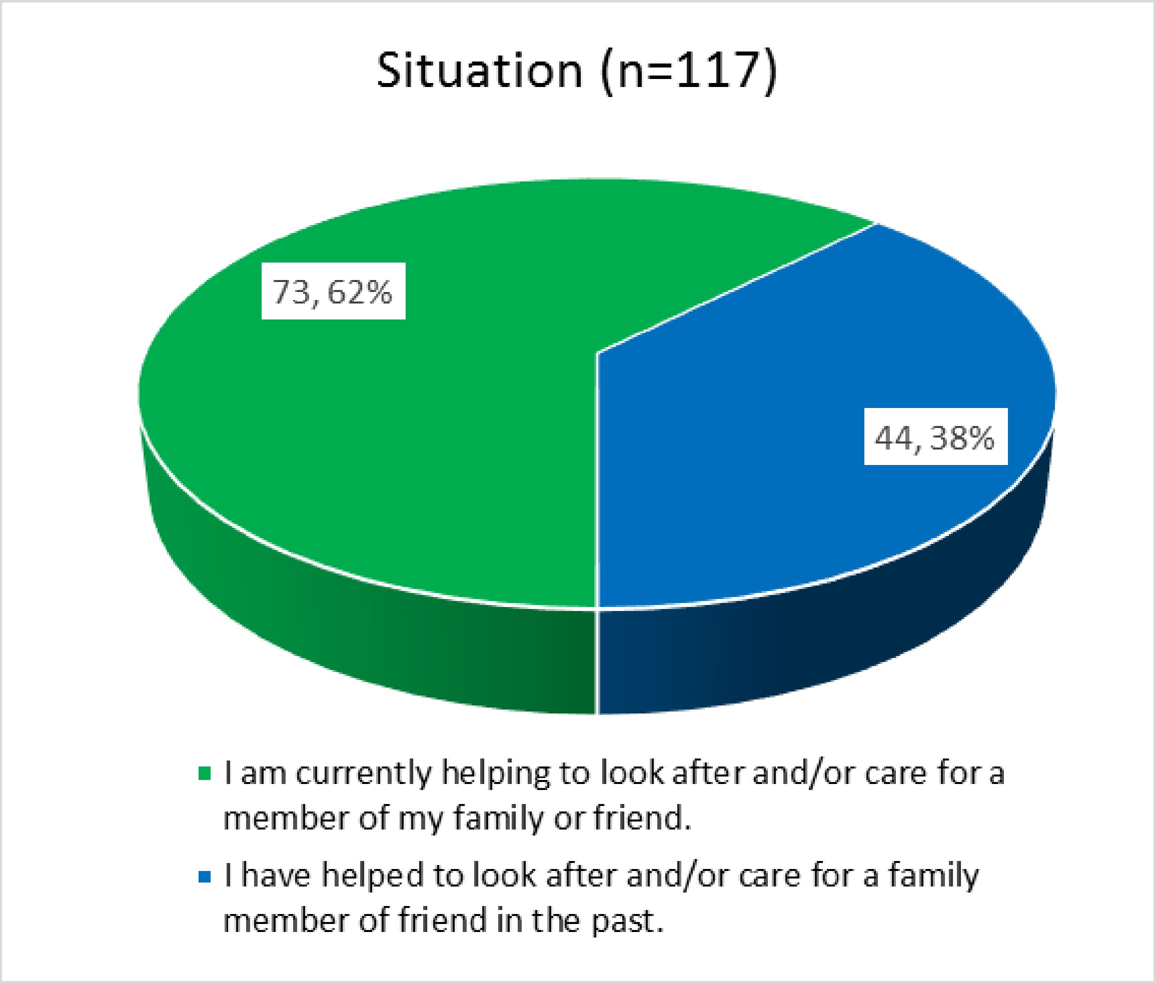
We had 119 respondents to the survey, 117 of these sets of responses were used in this report.



- The majority of our respondents were aged between 26 and 85 years.
- 35% (30) of the respondents were 46-55.
- 29% (25) of the respondents were 66-75.
- 5% (6) of the respondents were under 25

- Of the 117 respondents, 78% (92) identified as female and 14% (16) identified as male in this study. Other respondents selected n/a.
- When looking at ethnicity 93% (108) of the total 117 responses indicated ‘White British’, with 7% (9) people selecting another ‘White’ category, or BAME category.

Carers and the community - Analysis - Situation



Over half of the responses in this study come from people currently caring for someone.

Just under half had experienced being a carer in the past.

Whilst there are common experiences in being a carer, it should not be forgotten that there are many variations as well in terms of the many different possible situations, conditions and people involved.

*note that non-carers were screened out of this project.

Housing

People mentioned the importance of adaptations which could support those they care for. Examples include grab rails in bathrooms, handrails for stairs, wet rooms etc.

Some people had been impressed with the service offered to support them to get housing adaptions, however other people did leave comments suggesting long waits for home adaptations.

The type of housing people live in (social rented, private rented, own home) appears to play a part in the speed of achieving adaptions.

For some people they had finally organised and paid for adaptions themselves, whilst others were considering taking this step.

There was also a group that did not want any adaptations, in some cases people recognised that the design of their house enabled independence and minimised need for additional adaptions.

Carers and the community - Analysis - Housing

Adaptation

“Just had a wet room fitted for my husband, on the advice of Bolton at Home, by Independent Living Services. Also have received toilet and kitchen aids, to help my husband’s mobility.”

“Currently renting private. Not entitled to council property due to working. Need adaptations but don't currently have them.’

“We live in a bungalow. I needed some rails outside the door and in the bathroom. I rang Bolton at Home who arranged these very efficiently. The lady did an assessment and has arranged for us a wet room at no cost to us. Very impressed with this.”

Waiting

‘We own our own house. We had a visit from Occupational Health early on but they said it could take 18 months to get a stair lift, so we rented one privately (fitted within a week). They also said bathroom adaptation would take a long time to organise, so again we paid for our own. Even the handrail they said they would fit never happened. I think they loaned us a perching stool and a bed rail, which was unhelpful.’

“When my 82 year old mother who is house bound due to arthritis needed a wet room it took 10 months to approve. She has waited over 5 months for it to be fitted and still waiting. She's not had a shower for over 1 year.”

“Found it (adaptions process) frustrating/longwinded. Ended up paying for what was needed ourselves.”

Not needed

“I have not needed adaptation in housing.”

“Access is clear because of the design of the house; no adaptations necessary (as yet).”

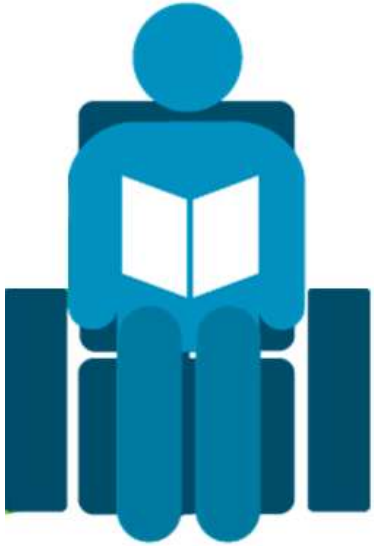
Education

Education was a broad topic and so we had a range of answers.

Most people did not answer with respect to formal education, though some considered that their caring roles might have impacted on their opportunities here. Though there was a comment about how schools (education providers) manage the needs of young people and the impact this can have on carers.

Informal learning, such as from experience, having experience at work and self-study were mentioned. People found support from local caring related groups or charities that provided training useful.

A finding was that carers could be supported to engage with either formal or education more easily, if they could take some regular respite from their responsibilities.



Carers and the community - Analysis - Education

Not had the chance

‘Have never done any but probably would have been useful. Training in accessing health care, it takes a long time to find things out and get connected.’

‘There have been no opportunities offered.’

Support in schools

‘It’s very stressful. my daughter is a young carer and school don't have much support.’

‘We had young children. The school were not adequately trained in how to support children who had a parent who needed care and then how very young children react to bereavement..’

Work based/Self study/informal

‘I have training within BAND a mental health charity. We learn to be aware of the client issues and background.’

‘I have been on a self management course run by Parkinson's UK.’

‘Personally, working in hospital setting, annual, moving and handling update. This is something which should be made available to all able carers, as even retired I still use my skills in everyday life. In fact NHS training which seems excessive, are all life skills. Invaluable.’

Access

‘As a working carer you can't access anything else- info re caring/being a parent of (condition) can't be accessed because it doesn't fit in. An online course would be flexible and easier to fit in ‘

‘A sitter service would be useful. I can never leave the house for more than an hour or an hour and a half so I can never access any opportunities. There’s the travel on top of the actual training. ‘

Employment

Within the comments there were mixed views on support from employers. There were many examples of understanding, supportive and flexible employers. But there were also numerous counter-examples of passive, inflexible or unsupportive behaviours among employers

Ultimately some people said they had had to leave their job because of the needs caring brought for them. Sometimes this was in spite of long term support from employers. Some other carers felt employment was out of reach for them without additional support for the cared for.

Some people responded to this question by explaining the difficulties faced by the person they cared for in finding employment or being supported at work.

Carers and the community - Analysis - Employment

Supportive Employers

My employer was very good with me when I was caring - they allowed me to reduce my hours and leave work as and when necessary my caring responsibilities required.

As the person I care for is elderly and disabled rather than a child, I find my employer rather unsympathetic to my needs as a carer. They always try to force me to use my own time despite that I'm entitled to some time off (even if it was unpaid).

My manager at work didn't want to know when I asked her if it would be helpful if she knew what my caring responsibilities were. My colleagues understand as they too have caring responsibilities and frequently need time off work. Support from employer is limited.

Well supported by manager and my colleagues

Loss of employment

I was lucky enough to have very flexible working conditions. Now I am unemployed I think self employment is my only option.

I've had to give up work. Dealing with hospital appointments for 3 children is extremely draining mentally and physically how can we work.

My employer was very supportive allowing me flexible hours beyond what we already had and time off when needed. Eventually I had to give up work and become a full time carer and I was able to take a career break to keep my job open.

Without a PA support / employment won't be a reality.

Employment for the cared for

My daughter has never been given the opportunity to work, no employer would be able to offer her the support and supervision which she would need.

Our sons employer knows very little about autism even though we have tried to impart knowledge, therefore they are unaware of any health/social care he may require. They do not seem to want to know.

Transport

There were mixed views on public transport with some pointing out that being able to use public transport gave them freedom, whilst others struggled to access public transport and felt that transport providers did not always behave helpfully.

There were some comments on specialist transport such as school transport, Ring and Ride, and patient transport; again these comments were mixed with some citing them as reliable and helpful and others feeling that they did not work well for them.

Carers and the community - Analysis - Transport

Public Transport Positive

Public transport is quite good and it's easy to get to somewhere you want to go.

Bus drivers need to be more considerate- wait till people are seated

Buses, trains, trams are brilliant. The new interchange in Bolton is fantastic. It offers us free days out which is really important to […] recovery. You can get online and download timetables which is useful.

...You can get assistance on trains - with your patient and luggage. I used them and it was very helpful.

Public Transport Mixed or Negative

Terrible bus service, unreliable, unrealistic timetables, and certain areas inaccessible for appointments to health centre etc.

As a wheelchair user using a bus by herself was impossible as no locking devices to hold chair in place. As her carer it was difficult to also hold her chair.

Generally poor. Accessing buses is difficult. Drivers are occasionally aware but generally don't like to lower the ramp/tilt the bus; will not wait until wheelchair is parked and brakes are on before setting off; like you standing with wheelchair out by the door ready to stop. If there is a buggy in the wheelchair space they generally drive on by rather than get the buggy folded or moved to the other side. Few taxi drivers actually know how to use the wheelchair space.

When I'm working (Clients with Learning Difficulties) although the clients carry bus passes we as carers are sometimes asked to pay and sometimes told to get on and not pay.

Specialist Transport

Because my mother is able to walk 10ft to the end of the drive, she is not entitled to assistance, even though the nearest bus stop is at the top of a hill with a steep gradient.

There is no easy way to get to Salford Royal from Bolton. Patient transport has improved but not a great deal

My daughter goes to Bury college and gets picked up and dropped off daily. I think it's Ring and Ride. They are good and always on time.

Ring & Ride poor service.

Community

Isolation was a common issue for those in a caring role. A number of people described how their social life ‘dropped off’ and their opportunities to participate in community life receded as a result of their caring role.

People were often aware of various support groups that offered help in Bolton. Some of the groups mentioned offer support for carers only and some for carers and the cared for together. People who had accessed these groups often felt that they helped them to manage their responsibilities. But lots of people felt that groups didn’t always meet their needs or weren’t accessible to them.

Information about community activities is felt to be not readily available by many and opportunities to support carers with relevant information or support is not always acted upon.

Carers and the community - Analysis - Community

They have some things on but it's 2 buses away so I can't go I don't want to pay for a taxi it's too much. I do knitting and crochet and rag rugs but at home.

Time poor, so we, my husband and I, just coped!

I feel there are too many financial restrictions to fully support all community needs.

Challenges

Not many people know I'm a carer but am on council list and also doctors but don't get a lot of information from anywhere about help and breaks for me.

Lots of information out there but I still find a lot of communication with various groups/mental health needs to be addressed.

In Bolton there are lots of support groups if you can find them - more details and info needed - singing, cafe, dementia groups etc. More advertising needed in public spaces so more info to go out to people.

Information

Isolation

For most carers I know isolation is a problem as no one to talk to.

Although there is some awareness and consideration for the person I care for within the community, I have found there is none for myself as a carer.

Its very isolating. I no longer have the same network of friends as they don't understand.

Support groups

As I belong to a support group, I have gained experience, but am also aware that there are many many carers out there who do not know where to go for help or even if help is available. Hence they are very isolated.

One of the most important things was when I started going to Bolton dementia support each week which gives an hour to chat and talk about our own practical experiences.

Health and Support Services

About half of the comments suggested people felt supported by the health and care services they came into contact with. Though there were some frustrations around referral times, time limited (single issue) GP appointments and the slow progress of services being put in place.

Lots of people referenced carers health checks, some seeing them as positive, others being more ambivalent. A number of respondents did not know the checks were available and had not been offered them.

People identified a number of opportunities for supporting carers with relevant information about community activities, support groups and entitlements. These suggestions included CANs, at Carers Health assessment and when short term specialist support ends (e.g. at hospital discharge or at the end of intensive rehab).

Carers and the community - Analysis - Health & Support Services

Annual check ups are fine and are automatic but getting to see a GP for an appointment is extremely difficult. Ridiculous appointment situation sometimes and only appointment available is 3!! Week in advance - no good whatsoever.

GP health checks excellent, support plans at Day Care excellent, respite excellent.

Never received any annual health care checks. Always told you had to be 74yrs and over for this. The doctors knew I was my husbands carer but I never got any special treatment

I am aware of most of these services but do find social services exceedingly slow. No continuity.

Again very slow to get correct support in place. Once there ok but over the years support has become more as one/integrated with one another but there is still a long way to go to interlink services.

Mixed views on services

Connecting people to support

You have to become clued up and search things out for yourself, then push relentlessly for any services at all.

Again not enough awareness and understanding. More support needs to be available.

You're only offered support for between 3-6 months after a stroke and then nothing is really available, 6 and a half years on nothing at all.

I am lucky with my GP services . Everything, that I have needed has been dealt with, without any problems. Online service excellent. I feel that Community Asset Navigators are the way forward, that a 'hub' would be an asset in Farnworth, as we all would benefit from not then being sent from post to post.

Annual health checks done. They send me a reminder, they phone me up. They didn't tell me about any groups I could go to for support.

Technology

Technology was being used in many different ways to support caring roles. Examples include Careline, a telephone service that is installed in the home and can be used to call for assistance, also use of the internet to order prescriptions, make appointments etc. Some people were using apps, CCTV cameras, and other gadgetry.

On the other hand there were barriers to the use of technology for many. Confidence seemed to be the most significant barrier but also lack of understanding prevented people considering potentially useful support and previous bad experience could also lead to avoiding specific technology.

Some older people, specifically people with dementia find it harder to adapt to technology suggesting that being introduced to the options earlier (i.e. before the onset of illness) may improve people’s uptake.

Carers and the community - Analysis - Technology

Uses

We bought cameras to keep an eye on mum, which we could access via phones. We also had a PIR and buzzer from Careline to alert us when she got up in the night, but it did not really work very well. While mum was still able to communicate, I bought a tablet and downloaded picture match, jigsaw and other interactive dementia-friendly apps, which she enjoyed for a while. We bought a speed dial telephone with pictures on the keys, but she couldn't cope with it, even early on.

Careline were very good. The service provided was excellent and gave me some peace of mind when I was not with the cared for person.

Barriers

I find technology difficult as I am 59 myself and have no younger family members to assist me. Remembering passwords etc. is difficult for me, and I find it incredibly frustrating having to negotiate Press 1 for …Press 2 for...and being unable to speak to a real person. Older people find apps etc. impossible to understand. Not everyone has smart phones, tablets, printers etc.

I feel I only have basic technology experience; my Grandma struggles to understand anything on-line. However my 5 year old is brilliant with it

I don’t like technology, every time I try to do something with it the computers are down.

Very little availability of assisted technology without great cost.

She got a letter inviting her to Henshaw's and there was a lengthy discussion about all the different technologies available. Phones, monitors, computers, smartphones you could set to beep in certain places in the super market so you could do your own shopping. So much available for those with sight loss. She didn’t feel like any of it was for her because of her age. it was just too much. She did use a talking watch though. Careline pendants are really helpful

Respite

Respite is important even for short periods to give carers a break from routine. We did find examples of good respite that people had used but in the main people had either not used respite, not been offered respite, or not been particularly satisfied by the respite options available.

The use of respite was complicated by several issues. For some the quality of the respite did not match their or the loved one's expectations, this led to them not using it in future. Other points that were raised included not being offered respite, finding it difficult to access short-term, regular respite and inflexibility of respite services.

Carers and the community - Analysis - Respite

The respite care has been very good.

The respite care has been very good.

Withins Lane - son used and I thought it was very good.

Positive experiences

Never given advice on it even though asked for it.

Respite care was a big help, not always available locally, easy to organise. Not always given a choice of location.

Mum went into respite care on one occasion, as a trial. It went okay as far as we know, but the rooms felt a bit cell-like, to be honest. Also I sat in with her for a couple of hours and it seemed like people either just sat there in their own little worlds in front of the TV, or were arguing with each other/staff!

We just can't access respite because of the unreliability of carers. I've had to find a private charger and pay for it ourselves because when we've booked carers to come in so I can have a break it's been a disaster. There no consistency it's never the same person. I book them 3 days before I go so I can show them how things work and what needs doing and so they can get to know each other and they never send the same one, they write on their time sheets they've been there half an hour but they never stay more than 20 minutes. This is organised through social services and it's still substandard care. He's ended up in hospital for 2 weeks last time I went away because they just didn't look after him properly.

Challenges

No not used it but we did explore it with the care coordinator but decided the places that were available were not suitable.

Couldn't access any. Had an assessment - I wanted a couple of hours a week to access something but couldn't take him myself as I was caring for my other child but it was refused. Your needs as a carer fluctuate depending on people's conditions. When they are ok it's fine, I can manage when they go into crisis it's really hard but services aren't responsive to that.

Carers and the community - Recommendations

In developing this piece of work Healthwatch Bolton wanted to explore how carers lives were impacted across different areas. The hope was to help to inform service providers in different realms about careers specific needs in the hope that a variety of different kinds of providers can consider more carer friendly approaches.

We suggest that the Bolton Carers Partnership considers the issues raised and adopts some of the recommendations in particular we ask that Bolton Carers Partnership consider the following:

- Education – to 'audit' the courses available to support carers in their caring role and consider a) if these respond to carers needs b) if alternative or additional courses could be procured or supported c) how theses opportunities could be better promoted.

- Technology – to work with the Bolton TEC strategy group to consider how to enable carers that are willing to improve their digital literacy.

- Services – there are opportunities being missed to support known carers with information about community activities and statutory rights. We would like the Carers Partnership to consider this issue and make some suggestions as to how, for example, the carers health check, carers assessments and short-term rehab programmes can better link into long term support (such as can be offered through CANs).

- Housing adaptation – More exploration regarding adaptation and inequalities around how and when people achieve this. Experiences seem to vary considerably depending on type of tenancy.

Carers and the community - Recommendations

Healthwatch Bolton has committed to doing further investigations into areas highlighted by this research.

We propose to do further work with carers on the following 2 issues:

- Social isolation – To investigate further how carers experience social isolation in order to help those working with carers to better understand how they can respond to this problem. To help those working on social isolation to better understand the specific experiences of carers in this context.
- Respite – With a view to informing future commissioning, to investigate in more detail the types of respite care on offer, examining carers experiences of these services and of accessing these services, examining carers preferences in terms of the types of respite services available, the available information and advice about respite services and the mechanisms for requesting, organising and booking respite services.

We hope that the results of these two pieces of engagement will provide some more detailed conclusions and recommendations to the Carers Partnership in due course.

Healthwatch Bolton would like to thank all those that took part in this research or facilitated it to take place.

Data for demographics

Age	Response
<16	1
17-25	5
26-35	12
36-45	18
46-55	30
56-65	15
66-75	25
76-85	11
86-95	0
96>	0
TOTAL	**117**

Ethnicity	Responses
White British	108
White Irish	1
White and Black African	2
Pakistani	1
African	2
Other	2
n/a	1
TOTAL	**117**

Gender	Responses
Male	16
Female	92
n/a	9
TOTAL	**117**

List of groups contributing/asked

Bolton Adult Autism Support – BAAS
Farnworth Foodbank
AFC Masters – disability football club
Senior Solutions
Bolton Carers Support
Golden Oldies
Tonge Moor Carers Group
Videobox Film Club
Bolton Parkinson's Group
Flower Estate Residents Association
Prescription Services
Macmillan Cancer Support
Bolton Pulmonary Fibrosis
Band
Handful
Dementia Support Group

Also asked:

Bolton GP Federation – sent to all Practice Managers

Carers Strategic Planning Group – let all members know, asked to circulate to members, local groups and put in minutes.

We also asked in excess of 80 people/groups to participate as well as shared on social media.