

Healthwatch Birmingham's response to Birmingham City Council's Consultation –Birmingham Carers Vision and Commissioning Strategy 2018+

Healthwatch Birmingham welcomes the opportunity to respond to Birmingham City Council's consultation on the '*Birmingham Carers Vision and Commissioning Strategy 2018+*'. Healthwatch Birmingham's key role is to make sure that patients, the public, service users, and carers (PPSuC) are at the heart of service improvement in health and social care. In line with our role, we have focused our comments on:

- The involvement of patients, the public, service users (PPSuCs);
- Whether the proposed strategy is responsive to the needs of Birmingham residents.

We welcome that Birmingham City Council is developing a strategy that will ensure that Birmingham carers feel valued and supported in their roles by working in partnership with carers. In addition, working across agencies to ensure that the needs of carers are met in the most appropriate and effective way. We welcome that the strategy will address a carers journey from before they become a carer to becoming and living as a carer including moving on from caring. From the feedback we have received, we know that carers face various problems that affect their health and wellbeing, finances, relationships, social life etc.

Between 2017 and 2018, we have listened to service users, the public and carers about their experiences of accessing health and social care in Birmingham. We have heard concerns on assessments (timing, quality); carers feeling ignored; patients with complex needs (i.e. dementia) being told to remain in their home when the carer also has needs of their own; social workers not having the expertise of the illness to carry out assessments; carers being told that they do not need certain services or that the council has no money to support them anyway; financial assessments driven by what social workers can get for carers and service users; care agencies not reliable as service users are left without care; respite care not given to carers and no joined up care between health and social care. Below are some excerpts from the feedback we received:

Social worker came out. Did not know what for. Filled in a few forms. Asked us if we were ok financially. When I said we thought we were she said that's ok, because there was not any money on offer. We found that she had travelled on 3 buses to get to our house. When it was time for her to go, my husband and I had to help her to get out of the chair she was sitting on (6th November 2017)

*My general feeling throughout being a carer for my husband was that no-one was interested in me as a carer and my wellbeing. I have serious health conditions but all they wanted to ensure was **that he would stay at home as long as possible**. I had to look after him on my own 24/7 including waking up at night time, getting him ready to move and go to appointments by bus. He would leave the house and*



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not go back, I had to lock the doors, and then could not ever leave him alone. My GP referred me to Alzheimer's Society, who called Social Services to request the care assessment but I only got the assessment done much later - just before my husband went to hospital. I got a 'phone call from social services first and they asked a lot of questions, but they did not give me full information for example 'What I am entitled to'. They then came to do an assessment a month later, but still did not get enough support. They offered help but they only offered help for one and a half hours in the morning and one hour in the evening, but that was not that helpful as it did not suit his routine and did not free my time. I also had to pay for the service after 6 weeks. My husband refused to get dressed and put his incontinence pants on etc. Called the emergency Community Nurse, who came in and because my husband's urine was fine and he didn't have any physical symptoms she said "That's just his dementia" and left. Four days later called 999 as my husband had a strange shaking experience. Ambulance Service didn't see anything physical, but they could not see that I could. He was taken to the QE dementia ward and I had to tell them that if they send him he was supposed to have a Social Worker. He was sent to a care home in Balsall Heath but after a week they sent him to Bromford Lane Care Home because of his aggressive behaviour. Social Worker came to see my husband at Bromford Care Home, but they never talked to me as his wife. When they assess someone they should give information about themselves, but I only found an unopened letter amongst his possessions that was addressed to him, but no-one consulted me about any of this. It makes no sense to give information to a demented person. After he moved from Bromford Care Home he didn't have a Social Worker. I had to find him a home myself as I was self-funding. Social workers didn't help me at all (12th January 2018)

Carer actively discouraged by Social Services saying "you don't need that". Carer provided reasons for needing direct payments. It's a battle to get social worker to come and assess, even when they come they do not listen. Support is "Given in an ad hoc way". You have to prove the tasks you need it for, if you don't fulfil the criteria, they won't give it. Direct payment is meant to give freedom. Assessment need to be done for both carer and patient at the same time (11 January, 2018).

Voice of the carer is nullified. If the carer has Power of attorney, they are spoken to differently.

- 1. Assessment: Service user assessment. How care package is assessed. They use a prescriptive approach.*
- 2. Care package, level of care support are not aligned to stage of conditions such as dementia. Is there social value determinant? Care package is based on budget considerations.*
- 3. Carer - NHS and Social Care disjointed. No integration of care. Continuing healthcare - professionals deal with health condition. Social care they are not able to deliver. Social Care write up reviews - just form filling.*
- 4. Financial Assessment. Seem to be overwhelmingly driven by what they can get.*
 - a. Assessing carer needs directly and assessed to person cared for. Carer has*



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- indirect expenses, e.g. dementia patient floods bathroom floor. Carer has to fix this. Financial assessment - directly related to care fails to consider indirect expenses. Person coming to assess - following guidelines. If I have to call emergency carer - this is paid for by carer?*
5. *Physio, occupational therapy (person cared for) - doctor prescribes that. Workload of arranging therapy, delays in getting appointments, 8 months of weight management (carer).*
6. *Leaving the person with dementia at home “can’t do”. Carer’s don’t get respite care - in 5 years - 2 weeks only. Have to ask for it.*
7. *Care agency - has changed ownership 3-4 times. Carer off for 2 weeks therefore for 4 days didn’t have care (11 January 2018)*

We note the aims and objectives of the strategy, in particular plans to facilitate the carer’s voice in care provision. We welcome the idea of co-designing with carers’ in order to develop a menu of engagement options and we note the different options for communicating and engaging with carers that have been outlined within the strategy. Recently, Healthwatch Birmingham produced a case study report¹ following engagement with two Dementia Information and Support for Carers (DISC) groups in Harborne and Sutton Coldfield. Carers expressed two key issues regarding communication and engagement:

- Carers told us that there was a lack of information available to support them in their role as a carer - *“I wish I had had more information about what to ask and what my/our rights are to make more informed decisions.”*
- Most carers didn’t know about their rights under the Care Act or what support they should be getting. They told us the lack of information and support across health and social care made them feel isolated and impacted - *“How am I supposed to know what I want if I am not being told about it?”*
- We heard mixed experiences of the level of social worker support, with some carers having support, with some visits, whilst other carers told us there is a lack of access, regular communication or support. Some carers told us the number of forms and paperwork they are given is confusing and feel very impersonal, with no time to explore the range of support available to them.

The feedback that we have presented above highlights the importance of communicating and engaging with carers and those they care for. It also highlights the importance of engaging so as to understand the needs of people and ensure that support and care is personalised. Whilst this strategy mentions the idea of co-design and engagement options, it is not clear what the purpose of engaging is. We believe that the Council needs to be clear about the following:

- The key decision points within the positive pathway, assessment process etc.

¹ To read case study, click here: <https://djmoc0hjs7vsb.cloudfront.net/2018/08/10163725/HWB-CE-Case-Study-DISC-F.pdf>



- Be clear about how communication and engagement will inform each key decision point. How will it help the Council understand the needs of different service users and groups (especially seldom heard groups). How will engagement and carer's feedback be used to understand needs and wants before caring, when someone becomes a carer, when living as a carer and when people are no longer caring.
- How will 'carers/those cared for' feedback be used in planning and shaping priorities, shaping ongoing decision making, implementation and evaluation.

The positive pathway approach is a necessary addition to this strategy. If implemented effectively, it should ensure that services for carers are joined up. The Council's recognition that for the pathway to be effective, it will be reliant on continual feedback from carers, those cared for and citizens, is positive. As stated above, there has to be a strategic approach to using carers and service user feedback. Specifically, how feedback will help the Council identify, understand and give due regard to the needs of carers and those they care for based on equality, access and outcomes. It is important to unpack what continual feedback will look like.

We note that the Council has outlined in the strategy that it will take due regard to the Public Sector Equality Duty (Equality Act 2010). We believe that one way the Council can meet this duty is by linking equality issues to its engagement activities. Thus, ensuring that the Council's engagement and communication activities involve listening to carers and service users in order to identify, understand and address inequality (i.e. health) and barriers to improved health outcomes including increased independence and the prevention of worsening ill-health. This could also include understanding the communication needs of different groups. We hope to see in the final strategy a plan of how this will look in practice, especially in ensuring that the diversity of Birmingham is captured in these activities and how their views will impact plans

As regards joined-up care, carers told us about the lack of joined up services between social care, their GPs and hospitals. Some carers told us about delays in obtaining care for the person living with dementia who is in a care home and GP services coming in to provide clinical support. We also heard about delays in follow ups for community based care.

We note and welcome the activities that have been outlined in the strategy, for instance access to short breaks, leisure and other facilities. Considering the cuts to the health and wellbeing budget (2017+) and adult social care and health budget (2018+), we are unsure how the Council will implement this strategy effectively. The 2017+ budget proposals presented cuts to health and wellbeing of at least 42%, which included the withdrawal or reduction of the carers grant. The carer's grant provided access to respite and a much needed break for carers. This has a positive impact on carer's wellbeing which enables them to continue in their caring role. It is therefore difficult to see how this strategy will be implemented if it is not fully costed.



11/09/2018

Yours Sincerely,



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