

Perceptions of Health and Adult Social Care services

Research into the views held by culturally and ethnically diverse communities

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The Trust for Developing Communities



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Executive Summary

Mixed perceptions. This consultation reveals a mixed range of perceptions towards and experiences of Adult Health and Social Care services.

Positive perception of services and support workers. The majority of respondents welcome and appreciate the services they receive. Individual social and support workers made a key contribution towards how positively services are perceived.

Communication issues. Dissatisfaction is felt when service users believe they are not understood, or their views are not considered when decisions on their care are being made. Difficulty in contacting and engaging with support workers or perceptions of having to wait a long time after making an inquiry were cited as areas for improvement.

Desire for more influence over services provided. Service users wanted more impact and influence over the support and services they receive. Many felt that they had to accept what is offered, even when they had stated strongly that the service is insufficient. It should be noted that some service users are reluctant to be critical about the services they receive.

Cultural considerations. It is important for service providers to be aware of cultural and ethnic background factors that could influence how a service user wishes to be engaged. However, many service users do not want to feel singled out or 'different' because of their background. There are important cultural considerations services providers should ensure they are aware of including faith, gender considerations, attitudes towards older people and family values.

Living independently. All respondents aspired to living independently. The route to greater independent living for some respondents is unclear as it involves multiple areas of need and support such as housing, health, and employment. Many respondents have unclear or unrealistic expectations about what Health and Adult Social Care services can do to promote increased independent living. To obtain a more realistic assessment, service users would benefit from further knowledge and understanding of the scope of support they can receive.

Respondent Recruitment. The recruitment of respondents who use Brighton & Hove City Council supported accommodation and care homes proved challenging. Further exploration is recommended to understand why there was difficulty and whether there was reluctance from these respondent types to take part in the research.

The absence of this respondent type represents a missed opportunity to further explore opinions, perceptions, and experiences of those who rely on Brighton & Hove City Council for their living arrangements.

Recommendations

1. **Service users from culturally and ethnically diverse backgrounds should have ample opportunity to discuss their care and support needs with Adult Social Care staff.** Allowing additional time to ensure service users fully understand issues around their support needs may be necessary and appropriate. For some language barriers make it difficult to fully contribute to these discussions and interpreting may be required.
2. **Clear and accessible information about services is needed to ensure service users have realistic expectations.** A lack of knowledge about Health and Adult Social Care provision affects service users support expectations. Service users need to know the nature and extent of care and support they can expect to receive. They need to understand what can be offered and what can't. This will help reduce perceptions of a poor service based on previously high and unrealistic expectations.
3. **Consider greater joint working with health, housing and employment providers.** The extent to which service users from culturally and ethnically diverse backgrounds can live independently is dependent on factors beyond the scope of health and care support. In many instances improved independence is related to housing, employment, and transport. Social prescribing offers would enable service users to navigate and deal with these other elements of life. This would require increased close working with other providers across health (NHS, primary and secondary care), housing and the Department of Work and Pensions.
4. **Increased cultural sensitivity.** Questions of cultural sensitivity is of itself sensitive. Whilst respondents want to feel their culture and ethnicity is not a barrier to effective services, they do not want to feel singled out either. All respondents believed that it is important for service providers to have knowledge of cultural factors that influence the lives of culturally and ethnically diverse service users.

Consideration should be given to exploring how Health and Adult Social Care can become more diverse in its staff and through initiatives supporting culturally and ethnically diverse advocates and support groups. Training in cultural sensitivities and working with people who have English as an additional language could be provided for staff.

Introduction

Brighton & Hove City Council commissioned the Trust for Developing Communities to research the perceptions of Health and Adult Social Care services held by members of culturally and ethnically diverse communities.

This research is part of an on-going process of consultations which inform future health and social care services for the city.

The City Council Commissioning team wish to ensure their plans reflect the experiences and perspectives of all the city's population who have accessed or may relatively soon require Health and Adult Social Care services.

The Commissioning team identified gaps in their knowledge and data regarding ethnically and culturally diverse communities. This research has been commissioned to help fill this gap.

Research topics

The key topics for research were: what works well; what could be improved; whether the support reflected cultural needs; and what support would enable more independence.

The questions asked were:

1. *When considering the adult care service you, or the person you care for, currently receive, what works well?*
2. *When considering the adult care service you, or the person you care for, currently receives, what could be improved?*
3. *Do Adult Social Care services support the person you care for in a way that reflects the individual needs, including the background, cultural life and religious beliefs?*
4. *In the future, what care and support services could be put in place to enable you, or the person you care for, to live as independently as possible?*

Participation in the research was confidential. Respondents' comments are anonymised, and individual respondents are not identified in this report.

Methodology

This consultation uses qualitative research methodology; timescale and resources allowed for twelve one-to-one in-depth interviews.

Reflecting the diversity of Brighton & Hove

Brighton & Hove has a culturally and ethnically diverse population comprising of many nationalities. They include people who have lived in the city for decades (since the 1960-70s) and others who have become residents comparatively more recently (1990s onwards). The City's population of those not defined as White British /UK has seen much growth in the past 20 years. This population of Brighton & Hove in 2001 was 5.8% and in the 2011 Census it was 19.5%. Indications are that the 2021 Census results will reveal a further increase in the non White British/UK population in Brighton & Hove.

This research is unable to fully reflect all views of the City's culturally and ethnically diverse communities because of the sample size and qualitative nature of the consultation. However, the sample is broadly representative of cultural and ethnic groups in the city and the research can be viewed as a valid and accurate account of opinions and experiences of Health and Adult Social Care services in Brighton & Hove.

Representative Sample

For the consultation to provide up-to-date, relevant data and findings a representative sample of interviewees was identified. The sample was

- Female 50% (6)
- Male: 50% (6)
- 6 (50%) Households/respondents where English is not their first language
- 6 (50%) Households/respondents where English is the primary language spoken
- 9 (75%) Users of Adult Social Care services
- 3 (25%) Non-users of Adult Social Care services (including lapsed)
- 6 (50%) Residents of Brighton & Hove for more than 31 years
- 6 (50%) Residents of Brighton & Hove under 30 years

The following cultural and ethnicities are interviewed in this research

- 4 Arabs
- 2 Asian: Asian British (Indian Pakistani, Bangladesh)
- 3 Black: Black British (African Caribbean, other)
- 1 Chinese
- 2 Eastern Europeans (including one from a Jewish background)

Recruitment

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The respondents were identified and recruited via the Trust for Developing Communities' (TDC) city-wide networks and service users. TDC also explored options for identifying and recruiting residents in care homes.

The planned consultation included additional respondents recruited with support from care home and Supported Housing Managers and staff in Brighton & Hove City Council.

Unfortunately, it was not possible to secure interviews with significant numbers of respondents who were residents of Brighton & Hove City Council supported housing or care homes. Although this was an intended feature of the research, the recruitment of these respondent types proved challenging. To accommodate for the lack of respondent types in this category, respondents were interviewed who use and access Brighton and Hove City Council Adult Social Care services and those who live in supported housing accommodation.

The research also intended to include interviews with care home and Adult Social Care managers in order to get their perspective on care services for these communities. These interviews were not conducted because of the difficulty in recruiting respondents who currently live in Adult Social Care accommodation.

The interviews were conducted using a discussion guide, this ensured consistency in questioning and helps to focus the conversations around the main questions required from the consultation. The discussion guide can be found in the appendix to this report.

Background

Most respondents engagement with Adult Social Care services was because of a physical illness or poor mental health. Most were experiencing difficulties and this affected the extent to which they felt satisfied with their lives generally.

Care from family and friends

The majority of respondents lived with other family members, typically spouses and children. A few lived on their own typically in supported housing.

For these respondents, the family environment represented their greatest pleasures and motivation for seeking improvements in their life and health circumstances. Family, and to some degree friends, represented a significant element of the care and support respondents received.

Some respondents expressed concern that they relied on their family so significantly; Adult Social Care services were seen as not fully meeting their needs. This was particularly so for respondents whose children provided care and support. In many cases, this care and support was insufficient because of other pressures and priorities such as work, education, and their families.

Many respondents welcomed the support they received from their children but also wanted to ensure that they were not a burden. This view was expressed more so by female respondents.

For some respondents, the need for the children to support them was a reflection of the statutory services' failure to fully meet their needs.

Confidentiality

Generally, the people receiving the care participated in the interviews rather than their carers or family members.

Some respondents needed reassurances that their involvement in the research was anonymous. It was confirmed that the respondents' comments would only be used collectively and there would be no adverse repercussions of anything critical they might say. It was also clarified that the interviewer was unable to advocate on specific issues.

Feedback on services

Many respondents commented that they did not have opportunities to feedback or comment on services they receive. The exception to this was initially discussing their health and social care needs with their designated worker.

Several respondents had to be encouraged to feel confident in speaking openly and frankly. There was a reluctance to be critical of the services they received and a concern that they were being demanding with potentially unreasonable requests.

Respondents were appreciative of the services and support they received. Some spoke only positively and made little if any adverse comments. Others were clearly uncomfortable appearing to be too critical of the support and services they used. However, there were many respondents who expressed frustration and unhappiness with aspects of the services and support they received.

Main Findings

1. When considering the adult care service you, or the person you care for, currently receive, what works well?

Roughly half the respondents were easily able to offer examples of the adult care service working well for them. Examples given included:

- Access to equipment that aided and improved the quality of life
- Provision of safe accommodation
- Support to explore opportunities for training and possible employment
- Access to a caring support staff team
- Being in an environment where they can socialise with others
- Having an adult care support worker who is aware of the problems they face
- Having a choice of how much or how little support they are given
- Having access to emergency support services if needed

Some respondents referred to specific members of staff they considered to be highly supportive and caring of them. For many of these respondents, it was this sense of personal care and understanding from a specific support or social worker that caused them to think highly of the overall services and support they received.

The support workers try their best, and sometimes they tell us there's nothing they can do, even if they want to help us more sometimes, they can't.

She [Support Worker] is so kind and helps me when I'm feeling down and when there is no one else to go to.

The staff are good. They do a lot for us

They bought some equipment which made my mother find it easier to look after her personal care. This made a big difference to her mood and attitude as she did not feel so helpless

I want to get a job and be more independent and they gave me some details on where I can get training as I want to go into computers.

It is good here. I feel safe with good people to make friends with. It's better than being homeless and staying in hostels

Some respondents found it difficult to answer what worked well because they didn't feel they could be objective. They generally felt that the service was good or acceptable but felt there could be improvements too.

I don't know. I think it is good, but sometimes I am not sure because I don't always get the answer when I need to.

Yes, I have good service but sometimes I must wait a long time for it. And when I wait a long time, it is not so good because it makes it difficult for me and my family.

I know the staff are trying their best, but it is hard because they may be short staffed, and they have a lot of work to do and people to care and support.

In conclusion there was broad acknowledgement amongst respondents that Health and Adult Social Care services were committed to providing a good service.

2. *When considering the adult care service you, or the person you care for, currently receives, what could be improved?*

When addressing areas of improvement, a common theme mentioned by many respondents, was the extent to which they felt Adult Social Care services did not provide consistent and comprehensive support.

Examples of this were

Lack of time with service users. Support staff and social workers were unable to spend enough time with service users.

Not enough service user influence over support received. Service users believing they have little control over how much support they receive. Some respondents said their support needs were concluded before they felt they had been adequately addressed. Many feel that they have little impact on influencing what is ultimately provided for them as a support care package.

More accessible and culturally aware support staff required. Many believed that their cultural or ethnic background is a barrier to making their needs fully understood by social workers and support teams. Many had trouble contacting support staff or social workers. Some gave examples of having to make numerous calls to speak to somebody regarding their support.

There is a perceived reluctance amongst some social workers and support staff to accommodate language barriers. Often this is seen as an unwillingness of staff to go slowly through the information they are sharing so that it is understood. This results in service users having difficulties understanding the service and what is expected from it.

There is an overall lack of staff from a culturally or ethnically diverse backgrounds like the service user. Some believe this lack of diversity prevents the service developing a better understanding of the general and specific cultural needs of service users from diverse backgrounds.

More information needed for understanding and realistic expectations.

Insufficient information provided on what to expect from a support care package, and how to judge what good looks like.

The perception that there is long, waiting times to see and gain access to social workers. Further when access is obtained, respondents felt only minimal progress was being made in addressing the issues.

I am not satisfied with Adult Social Care as I need more support, there is massive delay and I need more equipment and support.

Bad services are the ones when they pass your case to a new worker and this leads me to establish new relationships and repeat your situation again and again which makes me feel more stress and traumatize.

I feel they do not know how to communicate with us as we come from different cultural backgrounds and the system is not suitable for us.

My mum felt emotional to sleep in her room upstairs as my mum has been waiting for two years and the whole family was upset.

Adult social workers do not have good communication skills talking to us as they (didn't) allow me to express myself well.

The things I do not like is chasing services and waiting for them call me back and when I am stuck I do not know where to go and who to ask for support'.

Overall, it was a minority of respondents who felt negative or dissatisfied with aspects of their care and support. Nevertheless, in most cases, this minority expressed their views strongly, and the levels of dissatisfaction appeared to be acute. These respondents were those who had complex needs such as co-existing physical and mental illness, language barriers, degrees of social, isolation and limited extended family support.

3. Do Adult Social Care services support the person you care for in a way that reflects the individual needs, including the background, cultural life and religious beliefs?

There were mixed views on the response to this question about whether services reflected cultural life and backgrounds.

Roughly half the respondents felt there was no need for services to be any more culturally aware than they were currently. Others felt strongly that they did not believe their cultural or ethnic background warranted any significant or specific attention.

I don't think it makes any difference; I don't want to be seen as different in the service I want the same service as everybody else

Not much really, my English is good, and I understand what I'm being told as long as people are not racist, I don't think there is much more needs to be done

I have lived here almost all my life, I am not excepting to be treated differently

However, when probed further, some respondents, who initially expressed no concern on cultural sensitivity, changed their opinion. They acknowledged that cultural background, ethnicity, race, and past or personal circumstances, especially those of a traumatic nature, should be factored into assessments, decisions made on services and support provided. This included the following:

- Awareness of the limitations imposed in communication for those whose first language is not English
- Importance for many people of faith considerations when advice is given on managing their support
- Cultural significance given in some communities for natural respect for older people
- Perceived communication barriers which are inherent when feeling racialised or discriminated against
- For some respondents, feelings experienced due to no or limited connections with their cultural heritage such as a sense of loss or isolation.

We read the Quran everyday it is important to me and my family.

It is difficult, they speak very fast and sometimes I cannot understand but they are so busy, and we cannot get them to speak slowly or tell me again.

In our community we have a lot of respect for our elders. It is our responsibility to look after them, we do not want them to go into a home.

Amongst some respondents there is a reluctance to highlight their culture or ethnicity as a factor affecting the social care and support they receive. This reluctance can prevent service users from being fully open about the cultural needs that they have. Most respondents agreed that those with limited conversational English should be afforded more time and attention until their English speaking skills improve.

Many respondents believe basic information around care and support services for service users should be provided in accessible formats for people from culturally and ethnically diverse backgrounds. This might include substantive information in different languages. Access to basic knowledge enables service users to begin to understand and navigate the services they need.

4. In the future, what care and support services could be put in place to enable you, or the person you care for, to live as independently as possible?

Most respondents struggled to give a clear, coherent, and at times relevant response to this question. In many cases, this was because respondents were unclear on the extent to which suggestions they made were practical or viable. For example, some mentioned the need to move to somewhere that was adapted to accommodate their mobility needs whilst another said easy access to transport. Low income levels were perceived to be a major barrier to living independently.

If my husband had a car that would make it so much easier for us. I can't do shopping now because it takes too long with the buses, and I can't walk far.

The house is too small. I need my equipment and it takes up the space in the living room. It affects me and my children because I need the privacy.

I am not working and I have no income. All the time I am depending on the services. I cannot pay for the things I want, so I have no independence.

Underlying physical and mental health conditions were important factors in potentially living more independently. Most respondents felt that living independently was dependent on good health. For example:

- Routine and timely access to GPs
- Efficient referrals and treatment for medical procedures to address chronic conditions
- Access to treatment to improve poor mental health that did not cause lethargy or other side effects that prevented people being active.
- GP practices that were more responsive to the cultural and language needs and related communication barriers.

Many respondents felt the possibility of living independently would be highly challenging unless their chronic health issues were addressed. One respondent said that if there was a delay in having an operation to address their chronic back pain, regardless of the care and support they received, they would not be able to live more independently.

Some respondents reiterated the ongoing need for the support and services. They wanted services to conclude only when they, the recipient rather than the provider, believed the service was no longer needed. Some gave examples of incidents when staff decided the respondents no longer wanted the support and withdrew it. This was despite the respondent feeling more support was needed.

If they improve services, they will improve our quality of life and improve our mental health and will allow us managing our life.

I would be happy if my carers stays longer so I could give my children who looks after me day and night a break and take the sense of guilt from me.

Other examples given included:

- No substantive follow-up after an initial meeting when the respondents thought there would be
- Services perceived as ending abruptly, despite no change in service user's circumstances.

Appendix – Discussion Guide

Interviews for Adults accessing Adult Health and Social Care services

Our Introduction:

Please begin the session by letting the respondent(s) know who you are and who you work for. You should provide the respondent(s) with a brief background to the research and reason you are speaking with them today:

*‘The Trust for Developing Communities has been commissioned by **Brighton & Hove City Council** to conduct research to help inform future health & social care services for the city.*

The City Council Commissioning team wish to ensure their plans reflects the experiences and perspectives of all the city’s population who have accessed or may relatively soon require Adult Social Care services.

However, the Commissioning team have identified gaps in their knowledge and data regarding ethnically and culturally diverse communities. It for this reason the research is being conducted’.

Please also ensure you inform the respondent(s) that their contribution (responses) to the research will be used anonymously.

‘Their comments will be used with others who are taking part in the research and used in a way that they will not be identified. Taking part in this research will not have any negative effects on them’ or the services they use’.

Interview Respondent’s Background:

Ask respondent to tell you a little about themselves

- How long have they lived in Brighton & Hove
- Have they family in the city: if so, who are they
- What are the things they do during the day (how do they spend their day?)
- What are the things they enjoy doing – Why: How do they feel when they are doing these things?
- What do they enjoy doing **most**; or what things are they good at doing:
- Who do they spend their time with (friends and family? – Who are they?)
- What are some of the things they do not like doing – Why: What is it about that thing they dislike? How do they feel when they are doing it?

Ask who or what is important to them – Why –

- Explore why this is ‘important’
- What it is they get from this thing/relationship?

When they need help with things who do they get help from?

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- Why this type/source help.

Use and Awareness of Services:

Our four key questions for the research are

1. 'When considering the adult care service, you, or the person you care for currently, what works well?'
2. 'When considering the adult care service, you, or the person you care for currently receives, what could be improved?'
3. 'Do Adult Social Care services support the person you care for in a way that reflects the individual needs, including the background, cultural life and religious beliefs?'
4. 'In the future, what care and support services could be put in place to enable you or the person you care for to live as independently as possible'

Ask respondent to list all the social care services they use (re-ask if already mentioned)

- What services do they use, Prompt: Care/Day Centres, Living support (supported housing), community Centres, Clubs/Groups
- Ask for an example of a good a service they feel they used or received
- What is good and bad about the Service they see as good
- How satisfied or dissatisfied they are with the services they used.
- Are there any services they have stopped using (they used before? – Why
- Ask if they have any experiences of a poor Adult Social Care services

Ask respondent what support and help, is the most important thing for them. -why

- What should service providers do more of – why,
- What difference will it make
- What are some of the things they cannot do (but would like to) because it is difficult for them (ensure they identify what and why it is difficult)

Ask the respondent(s) if there is anything more, they would like to say.

END: Thank the respondent(s) and close the interview.

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