



Mental Health Services Report

**The Carers Centre for Brighton and Hove
Jan – Mar 2019**

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Introduction & Aims

The Carers Centre for Brighton and Hove have as part of their remit, a requirement to conduct a number of surveys and report findings back to the Clinical Commissioning Group (CCG) each year. For the first consultation of 2019, The CCG have requested that each member organization select a subject from recent work completed by the Sustainability & Transformation Partnership which identified five priorities to target. The focus is to be forward looking, identifying not only carers current feelings regarding services but also highlighting changes that could be reasonably made as part of the STP's planning.

An area of concern for carers and therefore the subject of this consultation is based on Mental health services and how these may be targeted closer to home, along with methods for communication and co-ordination.

In conjunction with Amaze we have chosen to focus on this subject with the primary goals of:

- Establish the current level of use of Mental health services among our carers *and* their dependents, comparing the responses between these groups, since this **disease is one of the five diseases** leading to 75% of deaths and disabilities in Sussex and East Surrey.
- Establish the locality of services and the effect of them not being local to the client.
- Establish the ways in which carers and dependents believe services should change.

This report details the methodology used and response total, the challenges faced, Equalities Monitoring, the results by question with initial conclusions, comparison between The Carers Centre and Amaze results and the full conclusions and recommendations.

Methodology

During Jan to March in partnership with AMAZE who are conducting the same survey with Parent Carers, we ran a survey comprising 10 questions. The results from both organisations surveys will be compared and collated into an addendum to the reports. Differences to responses due to the demographic group will be highlighted where possible for comparison.

The survey was sent to our client base via an e-mail with a link to Survey-Monkey. If the Survey-Monkey response had been low, we were also planning to carry out a postal survey, however, the response was very high so this was not actioned.

The number of questions were kept to a minimum while maintaining maximum impact. Experience has shown that shorter surveys taking 5 to 10 minutes to complete, attract greater numbers of responses. Questions were designed to be as simple as possible to avoid confusion. They were accompanied by a cover letter explaining the purpose of the survey and that this topic was in response to many feelings expressed in previous consultations.

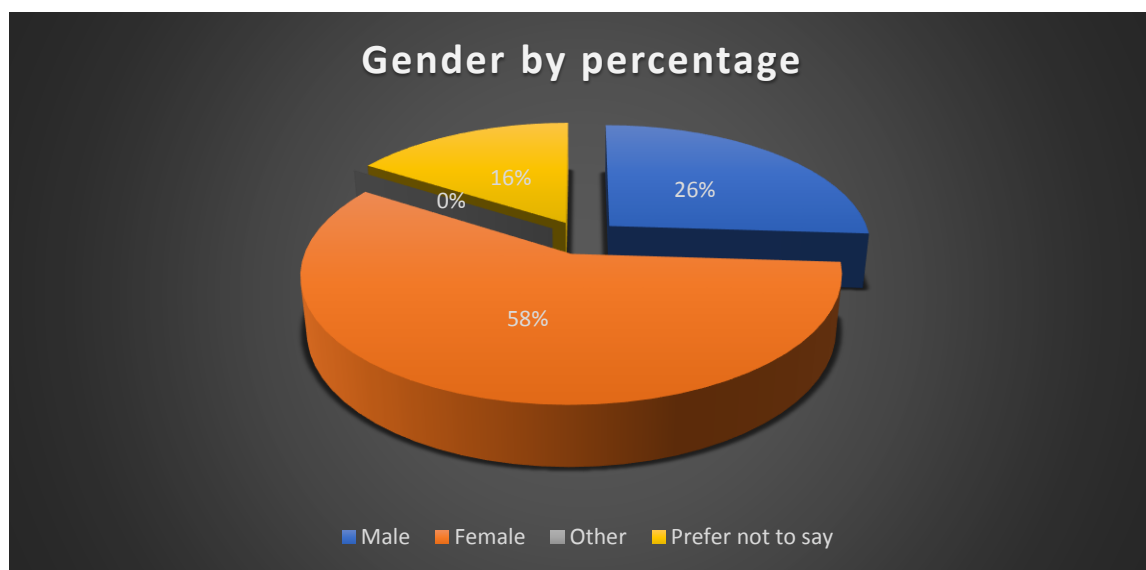
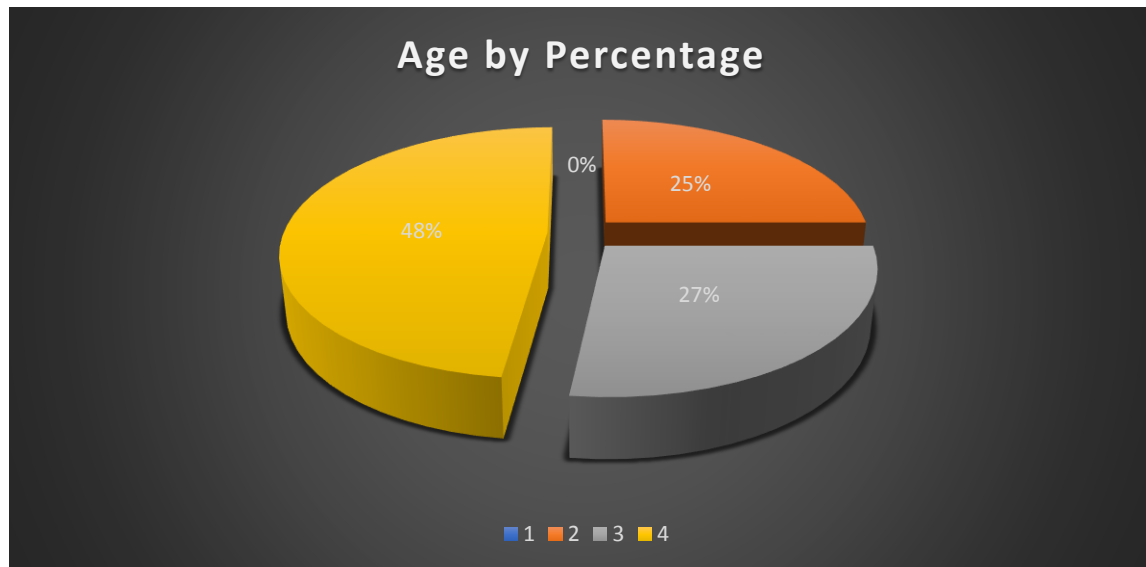
The questions were created using a format that allowed users to choose from subjects and also add their own comments.

In total, the Survey Monkey link was emailed to over 1200 carers currently registered with The Carers Centre.

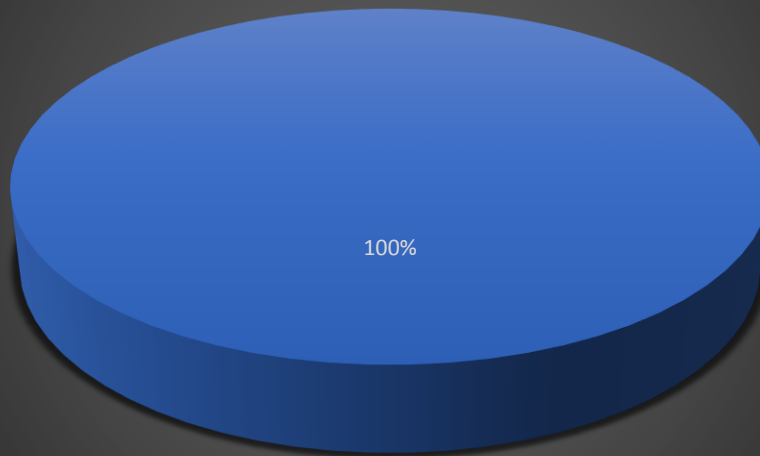
We received 80 responses within the first week many of which were accompanied by detailed experiences and comment.

As will be seen in the results below, use of Mental health services and just in time access is a serious problem for carers and dependents.

Equalities Monitoring

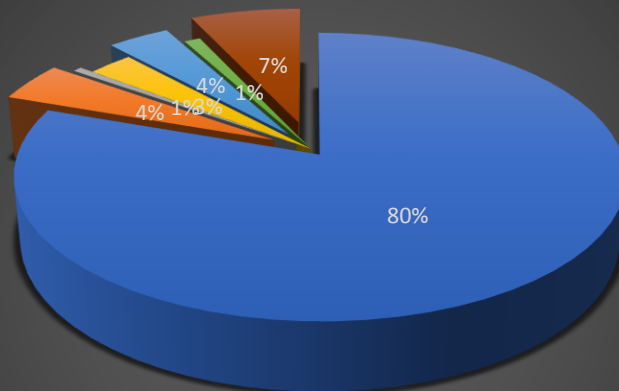


Do you identify as the gender you were assigned at birth?



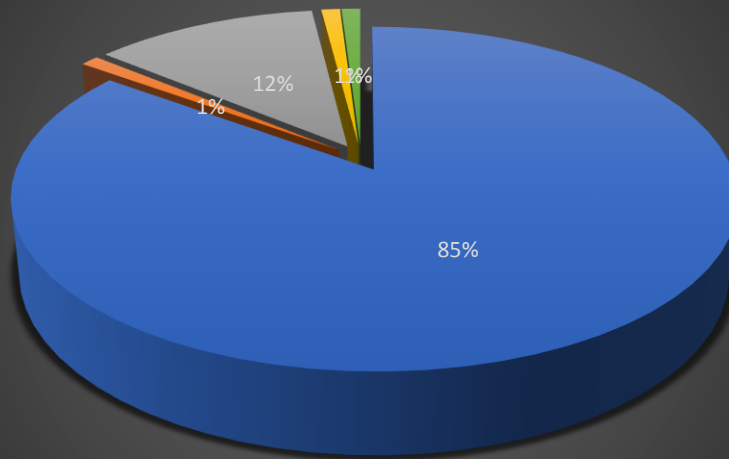
■ Yes ■ No

Ethnic Origin by percentage



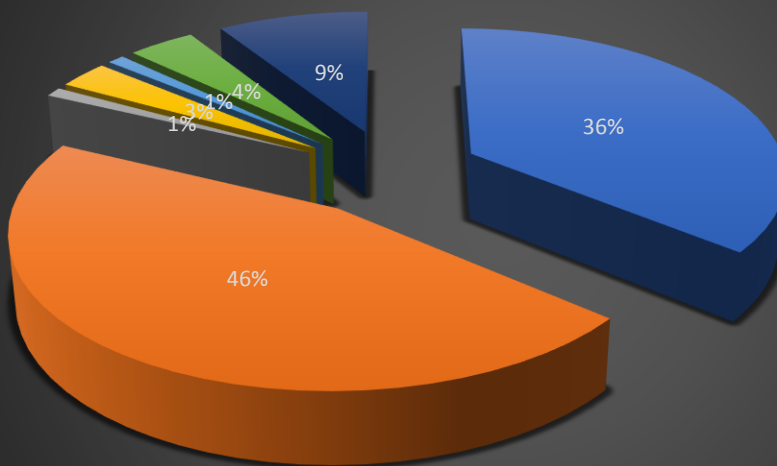
■ White English ■ Asian ■ Black or Black British
■ Mixed background ■ Other ethnic group ■ White Irish
■ Gypsy or Irish Traveller ■ Any other white ■ Prefer not to say

Sexual Orientation by percentage



■ Heterosexual ■ Lesbian/Gay Woman ■ Gay Man ■ Bisexual ■ Other ■ Prefer not to say

Religion by percentage



■ No religion ■ Christian ■ Jewish ■ Muslim ■ Atheist ■ Prefer not to say ■ Other

Results

There were 80 total responses to the survey for The Carers Centre.

Question 1. Does your dependent currently access services relating to Mental Health and Wellbeing?

This question received 80 responses with nobody skipping it.
This question had three options:

Response	Actual	Percentage
• Yes	44	55%
• No	34	42.5%
• Prefer not to say	2	2.5%

	80	100%

It is problematic to accurately combine the figures from Q1 with those of Q5 which is the same but for carers, as the total number of responses were not identical (80/76), however we can discern patterns of service use:

Situation	Actual
• Dependents access services but carers don't / unknown	24
• Carers access services but dependents don't / unknown	7
• Both access services	20
• Neither access services currently but there are comments	25
• Neither access services currently and there are no comments	3

Analysis and Initial conclusions:

The main items to come from Q1 (and consequently Q5 since they are the same question with a different demographic), are:

1. That there are high numbers accessing *some* form of mental health service.
The questionnaire does not distinguish between services provided by the local authority/NHS and those accessed via other means such as counselling or coaching sourced privately or through charitable organisations.
2. 25% of the time, both the dependent and the carer are accessing mental health services.
3. Services are required on a “just in time” basis since a high number of responses indicate there is no “current” need but comments on the services were provided, which logically shows that these services have been used previously and given the nature of many mental health problems, may return.

4. There were also a small number of responses that did not wish to say if services were accessed or not by either dependent or carer but included comments on the services provided.
5. From 80 responses, there were 3 that completed the survey but provided no detail at all other than for Q9 and Q10 which relate to specific need and knowing where to source help. This indicates that the survey provided a portal for these carers to know who to contact for help.

Based on the survey alone, we cannot determine if care duties contribute to mental health issues (though it may seem reasonable to conclude that they are a factor), however, we can see that more than half of the dependents in this response group are accessing support and a third of carers are also accessing support.

Question 2. If you responded Yes to the above, are these services local?

This question received 59 responses with 21 skipping it (some answers were provided by those who answered no to the previous question as they have used services but are not currently doing so)

This question had three options:

Response	Actual	Percentage
• Yes	41	69.49%
• No	14	23.73%
• Prefer not to say	4	6.78%

	59	100%

Analysis and Initial conclusions:

Although almost 70% of respondents indicate that they access local services, there are still at least 23% who are prepared and able to access services that are not considered local. This perhaps indicates how seriously mental health issues are considered by those either in a care role for someone with these conditions or suffering themselves, since they are prepared to travel to obtain the relevant service.

1. The high number accessing local services indicates there is an ongoing need for these.
2. With almost a quarter responding that the services are not local, there is an obvious gap in patient care / treatment provision. “Local” is a subjective quality and for some anywhere in the city may be local.

Possible reasons for this are:

- Local treatment is not suitable or ineffective.

- Not available at the time needed.
- Deemed inferior, where the patient has the ability to travel for a perceived superior service.
- There has been a breakdown of trust between patient and provider.

Question 3. If these are not local services, what difference does this make to you accessing them?

This question only offered a comment box as we did not wish to give guidance which might skew answers.

There were 19 responses, though a number of these were “N/A” or indicated that the service was local to the respondent.

The applicable responses have been grouped into degrees of impact where possible, using the respondent’s own selection of words and emphasis.

No impact:

None / None yet = **3**

Some impact:

More travel = **5**

Severe impact

Completely impossible / not offered = **3**

Comments:

None/Not Yet

- None.
- Not a lot.
- Not applicable (My son does not have uncontrollable mental health issues as he lives at home with me, and he is generally happy and we TALK for ages about everything, often repetitively! When my 27yr old Asperger’s son moves out and has a more independent life, I know BOTH our mental health’s will go off the scale as we both have anxiety and depression ALREADY.

Some impact

- Sometimes hard to get there. We had to source Psychotherapy for trauma privately as this is not offered for dissociative disorders and trauma locally My biggest plea would be for NHS teams - ATS and crisis team to liaise with private professionals. Encountering huge distrust by NHS of others outside their own service (in spite of the private therapist being an expert in her

area and working for years within the Trust). Lack of communication and agreed sharing of information, when requested by client and Carers leads to significant increase in risk.

- More travelling.
- Transport.
- He can't access them (NB. unsure if this is due to the services not being local or a statement that non-local services will not be accessed).
- It would be preferable if they were local, but I have to support my daughter everywhere anyway. It would be more difficult for someone who is more independent.

Severe impact

- Very difficult, but they were local, and he will be attending University from Sept to May. He was discharged locally and has had to go through assessment to join new MH Services.
- Completely impossible as relative unable to travel.
- I have to travel to London for the service.

Analysis and Initial conclusion:

The most common issue relating to services not being local is perhaps an obvious one – travel! This leads to a range of outcomes depending on the individual's circumstances. In some cases, we see very little impact or at least a resignation that this is the current situation. At the other end of the spectrum, we see patients who are not able to access services at all.

Travel is also not always simply solved by providing transport, that is only one factor. Other relevant factors are: willingness and ability of the patient to travel and the time required, especially where a carer may be working;

Moving, from one location to another also presents the problem of being discharged by one trust/provider, having to be assessed by the new trust/provider and then having to be reassessed by the original service provider if/when they return to the original area. This is especially relevant for the Migrant, Gypsy/Traveller and Student communities.

Another potentially serious issue which is perhaps a symptom of other issues that have been described by carers in previous reports, is that of communication and trust between service providers particularly where these communication lines are between private and NHS providers. The example given above indicates that there is a ring-fencing of services in some cases or at least this is the perception that has been given.

Question 4. If you could change the way services are currently provided, what would you like to see? Please tick all that apply.

This was a check-box list with an open comments section. Multiple boxes could be checked.

There were 70 responses. 70 completed tick boxes. 17 of these, added information in the comment sections.

The check-boxes were:

Suggestion	Percentage	Actual
Access the services when my dependent needs them	71.43%	50
Always seeing the same healthcare provider	52.86%	37
Not having to repeat the issue/need again and again	68.57%	48
Great communication and follow up	67.14%	47
Coordinated services, so I am not spending time chasing	58.57%	41
Your dependent's issue being fully understood	70.00%	49
Receiving more support at home	50.00%	35
Other (please specify)		17

Comments:

- Better understanding of trauma and dissociation. Some psychiatrists and mental health workers appear not to follow NICE guidelines and have very little knowledge of this.
- There is no communication within the services and other services/professionals to help with life skills and wellbeing. To me the NHS is like a theatre set with no substance behind it. They have all the titles, but nobody to actually coordinate correctly the skills needed to improve wellbeing.
- Having a known familiar contact who could help in a mental health crisis would help.
- Not necessarily at home but support in general. One point of contact, easy route to contact etc. The worst feeling is not knowing who or where to go to or being sent around the houses when one is feeling desperate for help to help the person who needs help.
- My dependent is only ever offered a few sessions, when she needs longer support for PTSD. She has been given a list of private counselling services, but they are not affordable on our low income.
- For ALL practical and social issues for my son....THAT'S a different story!! I withdrew asking agencies to help as we got nowhere, ESPECIALLY with Social Services and Council Housing needs. For social opportunities I had to take him myself to activities that he expressed interest in as waiting for "buddies" was a 5-year waste of time and I knew so much personal preference stuff about my son it was impossible to locate/select/arrange payment for and inform over and

over all the relevant needs he had at that particular time. Telling unfamiliar people over and over your and your son's history was SOUL DESTROYING and kept me in a state of fight or flight all the time. My body's chemicals now have a PTSD setting!

- Mental health becomes unobtainable once they have discharged you as an outpatient. A discharged section three patient receives three outpatient's appointments and then is discharged with no other follow up until the next crisis. At present Mental health is broken and not fit for purpose.
- Sometimes trying to actually achieve an outcome is a job in itself and time is the thing I have very little of. There is a lot of well-meaning talking and little action.
- Not having to fight for help. My daughter's condition is known for its mental health issues and yet we have to get to breaking point to ask for help - which is too late. Having a health care professional that understands her condition would also be a benefit - plus a central bank about her which they can access so I don't have to constantly repeat the issues (often in front of her which is uncomfortable for us both).
- We have never been offered services (Alzheimer's), Even the assessment was poorly handled. Recently my partner was invited for a 'dementia review'. When we arrived, for what we were told would be a 20 -minute appointment, the GP had no idea why we were there. The practice states that it is dementia friendly.
- My views being taken seriously when I need a service such as the crisis resolution home treatment team. My expertise as a carer should be recognised and taken into account.
- Not having to pay for private psychological counselling because of this facility being available only for limited number of sessions through Hospital Renal Counselling (who are otherwise excellent and exemplary).
- A regular contact just to ensure we are OK and not forgotten. Never hear from anyone unless we make contact.
- That CAMHS clinicians were competent in autism. They are useless. They don't understand autism at all. They can't diagnose ASD or ADHD and have no clue how to communicate with autistic children or engage them. They don't understand what therapies are wrong for autism either. Until there is expertise in neurodevelopmental disorders at CAMHS they will continue to fail children.
- Clear guidelines on who to contact to if you are unhappy with the treatment you are receiving. I had to obtain a report from a private specialist in London to get local services to provide the antipsychotic medication my daughter desperately needed.
- My dependent receiving organised and routine "homework" to help her become more independent preventing a crisis. Providence of specialised therapy for BPD and EUPD patients, like my dependent (e.g. DBT)

Analysis and Initial conclusions:

From the statistics, we can see that the top issues are:

1. **Accessing services when required**
2. **The need being fully understood**
3. **Not having to repeat the situation again and again**
4. **Great communication and follow up.**

These top four items show the requirements of the carers and patients and also the perceived failings within services with a high degree of clarity. Although other tick boxes also received high percentage answers, the top four, provided us with a “life cycle” of healthcare provision, from the initial service having to be available right through to follow up after treatment.

From the comments sections, we can ascertain several themes.

- Communication can be significantly improved and knowing who to contact is not always clear especially if you are unhappy with treatment provided.
- Carers feel they have to fight and are not taken seriously in some cases.
- The competence of some health professionals is not highly viewed. Carers feel that they are often in a position of knowledge while some service providers do not have either the knowledge or skill to offer suitable treatment.
- Carers/dependents often do not have the time and/or money to research and pay for treatment options which are not offered via mainstream NHS.
- Follow up support is frequently of limited duration and therefore efficacy.

Q5. Do YOU currently access Mental Health services?

This was a multiple-choice question with 3 options, and it received 76 responses with 4 skipping it:

Answer	Percentage	Actual
Yes	34.21%	26
No	63.16%	48
Prefer not to answer	2.63%	2

Analysis and Initial conclusion:

See Q1 conclusions.

Q6 If you responded YES to the above, are these services local?

There were 3 multiple choice answers. There were 39 responses with 41 skipping this. Since there were only 26 positive respondents to the previous question, it is necessary to highlight that only 33 actually answered either Yes or No. It is not initially clear why there are differences in the number responding Yes to Q5 and then choosing to provide an answer re whether these are local services.

The possible answers were:

Answer	Percentage	Actual
Yes	69.23	27
No	15.38	6
Prefer not to say	15.38	6

Analysis and Initial conclusion:

It is difficult to ascertain the reasons for the differences in the numbers between Q5 and Q6. What we can determine is that there are at least 26 (based on Q5) and up to 33 (Q6), carers accessing these services and a high number of these are using local services.

One possible reason for the difference between the figures in Q5 and Q6 is that Q5 asks about current access while Q6 does not make this stipulation, therefore those carers who have previously (and may in future) accessed services may have responded.

The percentage of carers accessing local as opposed to non-local services is almost identical to that of the dependents, most likely due to the carer trying to access services that they are aware of, having helped their dependent obtain them.

Q7. If these are not local services, what difference does it make to you accessing them?

There were only 11 responses to this question with 69 skipping it. Some of the responses were simple N/A answers. Relevant responses are shown below.

Reasons for this low response are difficult to gauge without evidence from the carers themselves, however, logically, there are at least 4 possible reasons:

1. It may in part be due to the carers focusing more on their dependent's questions.
2. It may also be due to simply not wishing to answer questions relating to Mental health about themselves.
3. It may be related to them feeling that the issues are the same as in Q3.
4. Survey fatigue, especially given the detailed responses in previous questions.

Comments:

- I would also be unable to travel.
- My GP doesn't fully appreciate my situation as a carer, she takes one look at me and just steers me to doing mainstream stress relieving ideas as I just need to relax, don't I? I look young and presentable for my age (I'm 53) and I honestly think this has been massively detrimental to being fully believed AND helped! So, now I use online support, read self-help books/articles, receive newsletter emails from charities/groups. I don't like having to travel out of town as I'm more anxious outside now than when younger.
- I have to travel to London with my daughter and cover travel expenses.
- I don't use them as much as I would like as they are on the other side of the city, taking me away from home for too long once public transport travel is factored in.
- Harder to (access them).

Analysis and Initial conclusion:

As per Q3, we see that travel is once again a relevant barrier to access of services where these are not local. "Local" is also subjective, since we have seen answers that relate to travel from Brighton to London, while for some, a significant distance is travelling from one side of Brighton to the other.

Time away from their dependent is always a significant factor for carers. This is also reflected in a slightly higher percentage in Q8 below, indicating that in-home services would be beneficial.

One respondent highlighted a possible age/appearance related issue. They feel that they are steered towards simple mainstream stress relief exercises by their GP since they are perceived as relatively young and presentable and therefore only in need of relaxation. This is significant as it relates to the carers issues being fully understood which is the second highest requirement listed by carers in Q8 below.

Q8. If you could change the way services are provided, what would you like to see? Please tick all that apply.

This question had multiple check boxes and an open comment section. There were 57 responses and 11 comments, which are shown below.

The check-boxes were:

Suggestion	Percentage	Actual
Access the services when I need them	70.18%	40
Always seeing the same healthcare provider	57.89%	33

Not having to repeat the issue/need again and again	63.16%	36
Great communication and follow up	63.16%	36
Coordinated services, so I am not spending time chasing	61.40%	35
Your issue being fully understood	68.42%	39
Receiving more support at home and/or in the community	52.63%	30
Other (please specify)		11(9 relevant)

Comments:

- I feel like you have to jump through hoops to get to mental health or well-being services. Starting with the GP, waiting a least a week to get an appointment, to get a referral to the service. Then waiting to get contacted from the service for the opportunity to make an appointment. An appointment which may or may not happen within a week or two. With someone suffering from depression, as I do, it is just too much trouble.
- The changes from a carer's perspective when one's dependent reaches 18 are huge, especially when the dependent is living with his/her Carers. A better and joined up policy that is adhered to, regarding information being shared with the Carers would lead to increased safety.
- Not a mental health issue but as a carer the most difficult aspect is having to be with spouse constantly so cannot go out for my own needs without arranging care. As we are self-funded there is no practical assistance
- Mental health services next to useless. crisis team send you to A&E, get there & wait 5 hrs & leave without seeing anyone. it's a disgrace.
- I am happy with the help I have received. Thank you. You're doing a good job.
- It needs to be more joined up, there are too many different people to contact and too much chasing to get anything truly achieved.
- Having to stop all medications as they have contra-indications, I am having to cope with multiple withdrawals alone The effect on my mental and physical health have greatly impacted on my family and person I care for.
- Knowing how to access it and not having to go around lots of organisations - some joined up thinking.
- A more local facility - the service is good, but I would be able to use, and would value, a local provision more.

Analysis and Initial conclusion:

The questions asked here were designed to mirror those in Q4. With the emphasis this time being on the carer rather than the dependent. This allows for direct comparison between the requirements of the carers for themselves and their dependents.

As per Q4, the top answers were the same for carers issues as for dependents with very slight differences in percentages (usually slightly higher for the carers).

1. **Accessing services when required**
2. **The need being fully understood**
3. **Not having to repeat the situation again and again**
4. **Great communication and follow up.**

As in Q4, from the comments sections, we can ascertain several themes.

- Communication can be significantly improved and does not appear to be joined up between services. This can even lead to having to stop medications as they have contra-indications.
- There are frequently delays in receiving appointments and/or treatment. When someone is suffering with depression, they will often decide to not take appointments that are too far off.
- Being referred to A&E services when in crisis is viewed as disgraceful. The example provided also did not result in treatment after 5 hours waiting. NB, it is unknown if this is due to triage not prioritising mental health or some other circumstance within the relevant A&E department on that occasion.
- Local facilities are or would be highly valued.
- There was also one carer who praised the service they received.

SECTION 2. NHS Questions:

Q9. Do you have any needs the Carers Centre can help with? If YES, please provide details in the box.

There were 66 responses to this question with 14 skipping it and 27 comments. Where there is a direct action, The Carers Centre can take, these have been dealt with. Due to anonymity in the survey, very individual needs cannot be addressed unless the respondent provides a contact point. This was stressed in both the covering letter and also in the opening to the survey.

	Percentage	Actual
YES	33.33%	22
NO	66.67%	44

Comments:

NB: Many of the answers given do not relate to services that the Carers Centre or Amaze can or do provide but are additional answers relating to services that Carers would like to see.

- Training for Carers and MH professionals.
- If assessments both social & financial are completed could they be available EASILY for another member of the team to refer to later! This would make my life SO much easier - thank you!
- More support for my mental health and wellbeing during such a stressful time. 3 elderly relatives to care for.
- Counseling and respite for as long as needed.
- I was called and told I would receive a carers meeting last year for my needs and my daughter but have heard nothing more. (NB. There is no further information to show which service called this respondent).
- To allow carers to give supplements to patients. To recognise thyroid T3 and allow it to be given in hospitals.
- PIP and ESA support for my brother, for whom I am the sole carer - my own mental Health has started to deteriorate due to the worry/anxiety of filling in the forms/assessments for my brother as I am his appointee.
- Being a carer my whole headspace goes to looking after spouse and find it difficult to find help privately - agencies don't seem to have spare capacity - so rely on family to 'sit'.
- To have a walk-in clinic with Doctors as well as nurses because sometimes you need a doctor and I can't take my son with me so I have to go when I have someone to care for him and my GP (who have a good practice) is generally full anyway.
- I'm going to "rejoin" the Cares Centre and use the Carers Hub and Carers UK, as I went to my 1st support Coffee morning today in more than 10 years, and I feel SO glad I did! WHY did I not go sooner?!
- Why must a crisis be fully developed before help is available? early prevention would keep them out of hospital.
- Just finally had my own review, however, carers assessment no longer included? What happened to joined up assessment?
- Bereavement counselling.

- I need a support worker. To leave me to cope with multiple withdrawal and expect me to cope is disgusting. My mother and autistic son have had to cope with my response to this, it has not been good.
- Coping with the range of problems my family unit has.
- Helpline to get support as issues arise.
- Anticipate the need for a disabled parking permit in the next year.
- I need to know that if anything happens to me my daughter will be listened to and get the care and support she needs.
- More support is needed for carers when a crisis is building up. We need a crisis service which responds to carers in a compassionate and helpful way to try and prevent the crisis from escalating. Time and money is being wasted because the service does not respond early enough. This is not a difficult thing to achieve.
- No point as all self-funders are just told to do it themselves.
- Get some autism expertise. There's more but I think it would be pointless putting it here.
- As the relationship with the local learning disability psychiatrist became untenable because of his failure to provide treatment we no longer have access to a psychiatrist with learning disability experience and have to access mainstream services. We are currently waiting for our third mainstream psychiatrist as two have left the service. Lack of continuity and learning disability expertise is a great concern.
- More help with my wife who has severe dementia, like going to a day service.

Analysis and Initial conclusions:

This question resulted in a number of responses which provided extra detail to the main survey questions. The responses mostly focused on the issues that carers encounter though there were also praise for support services such as The Carers Centre coffee mornings.

It is felt that a crisis support service for carers to help alleviate their own build up of stress/depression is required. This needs to include services that dependents can attend to allow for carers to have some respite. Existing helplines will be promoted via all possible means.

There is a requirement for specialist trained support workers to understand the stresses that carers are under and provide real support as being left to cope impacts on the dependents.

Services being available before crisis point, with compassionate help for carers struggling to cope with every situation from filling in PIP forms to dealing with bereavement is seen as essential and also a good measure to prevent carers conditions from tipping over into crisis.

Better joining up of services for example “social and financial” assessments being available for reference to all relevant parties. This confirms previous answers about the necessity for better communication between services.

Q10. Do you know where to get support when you need it? (e.g. information, practical help or emotional support)

There were 75 responses to this question with only 5 not answering. There were 14 relevant comments. As per Q9, where action is possible, The Carers Centre has already taken it.

	Percentage	Actual
YES	65.33%	49
NO	34.67%	27

Comments:

- I would go to my GP. But if I felt I needed immediate help I would contact the Carers Hub.
- Many of these seem to serve in/occupy much of the same territory so an indexed directory would be helpful.
- The Carers Centre would be a starting point for me.
- Yes, but time to think about my needs is very difficult, leading to isolation.
- I’m using the Carers Centre and Carers hub from now on as you guys are THE ONLY PEOPLE who understand my situation and give me hope!
- Have Carers Hub and carers emergency back-up plan.
- Signposting is not readily available. I have my GP Surgery (wish) ask me why I was telling them that I am a Carer!
- I would guess the GP but again the time and dedication it takes to get an appointment are exhausting. You need to make it easier to access these services for the people who really need it.
- Have had to go private in order to get help needed as long waiting lists currently for psychiatry.
- Knowing this I am entering a game of pass the parcel mental health line pass to dr. dr. pass to mental health I am not coping so cannot be part of the game sadly.
- The obvious source would be via our GP practice.

- In theory yes but in practice my attempts have been rather dispiriting. Example - When I contacted the Alzheimer's Society enquiring about memory cafes, I was told the funding had ceased.
- There is nothing available for carers by way of counselling or support. I have had to go to the service for substance abuse for counselling and this is not appropriate. Carers are helping the NHS in mental health and it goes largely unrecognised.
- I do now because of previous failings but before the crisis in my daughter's care that information was not provided and I had to turn to the private sector to get help.

Initial conclusion:

From the percentages and comments, we can see that messages from providers and sign-posters such as The Carers Centre and Carers Hub, about where and how to find information and support are reasonably well communicated. Many of the comments provide positive reviews of The Carers Centre and Hub services.

GP's are also seen as an initial point of support, though some of the comments indicate that while the carer knows to see the GP, they then feel that the treatment is not what is desired. In some cases, the GP has questioned why the carer is making it known that they are a carer.

Conclusions

1. Local and in-home services are likely to result in greater take up by carers and dependents, since travel, arranging respite cover and cost in money and time are all major factors currently preventing access of services.
2. Services are not seen as ongoing and accessible, rather they are viewed as only becoming available when on a "crisis" basis and even then, there are felt to be many gaps and barriers and limited follow up.
3. There is strong feeling that services are not connected and communication between them is poor. This is seen as a major need moving forward. It is possible that there are good connections between services, however, this is not the impression that carers have.
4. Services and sign-posting provided by the Carers Centre, Carers Hub and other charitable organisations are generally seen as highly beneficial and providing cover where some GP surgeries currently do not. Carers appear to be broadly split into two groups, those that can self-fund and therefore are either denied support services or have the means to access private support and those that are wholly reliant on NHS services. Most confusion and dissatisfaction with services seems to emanate from the second group, leading to a reliance on charitable organisations.
5. Groups, coffee mornings and other activities are seen as highly beneficial in helping to combat some mental health issues (this is echoed in the recent report on loneliness and isolation). They offer a shared experience for carers who feel they have nothing other than caring in their lives. There are still issues

around access even to these events due to the problems listed in conclusion 1. Dedicated helplines were viewed as desirable.

Recommendations

1. What: Future services must take account of the high need for in-home services.

Who: STP/CCG/NHS trusts and Primary Care Providers.

When: As soon as possible as part of the STP plan.

How: Promote in-home services that already exist. Where these cannot be provided, local alternatives must be available. Carers are shown to be willing to travel to seek appropriate services but the will to travel is often greater than the ability to travel, especially in an ageing demographic. When promoting non-local services, benefits must be clearly stated along with all possible travel options for Carer and Dependent.

2. What: Connection and communication between services is crucial both within and outside the NHS.

Who: STP/CCG/NHS trusts.

When: as soon as practically possible given this is likely to be a long term goal rather than an immediate fix.

How: Clearer pathways for care must be put into existence and be communicated to patients via every possible means. A way of reducing divisions between the NHS and private organisations must be sought as a matter of urgency as this is promoting:

- increases in cost
- time between appointments
- distrust between carers and service providers
- potential risk to patients

3. What: Services must not only be crisis based but must demonstrate a clear and ongoing pathway towards patient health. This is not the perception at present, therefore where these pathways are clearly defined, they need to be communicated to patients in every possible way.

Who: The Carers Centre and Amaze.

When: By end Q4 2019

How: TCC and Amaze will look at producing a clear, simple process map for carers to follow.

4. What: Mental health can have extreme consequences in a very short period of time, therefore just in time services must be available other than A&E. Many symptoms can be mitigated by simple measures such as inclusion in groups/events, being listened to, feeling support is available. Services need to be tailored to provide these measures many of which are currently fulfilled by charitable organisations. A dedicated MH helpline was suggested as likely to be of great benefit.

Who: The Carers Centre will promote the Brighton and Hove Wellbeing Service, The Mental Health Rapid Response Service and The Sussex Mental Health Line. We will provide brief explanations as to these services and the contact numbers.

When: Immediate and ongoing.

How: Promotion will take place via social media, email distribution, at group meetings and in the next available issue of Carers News.

SECTION 3. Comparison between The Carers Centre and Amaze results

To follow.