



**Care Assessment for Physical, Sensory or Neurological Impairment  
Report**

**The Carers Centre for Brighton and Hove  
October 2019 – January 2020**

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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 last consultation of 2019, Brighton and Hove City Council have requested that we work in partnership with Possability people and in place of a consultation for the CCG, we conduct research on their behalf.

The subject of this research is the care needs both current and in the future of people living with various forms of disability, either physical, sensory and/or neurological who are under 70. This is due to the knowledge that there are numbers of people under 70 being placed in unsuitable care situations, where being cared for outside of residential care or with a different care package would be preferential.

The Carers Centre will focus on the requirements as outlined by unpaid carers while Possability People will focus on the cared for person.

The aims are:

- Identify the current needs as identified by carers
- Identify the future needs
- Get carers views of what works well and what can be improved with the current care package

Survey questions have been kept to a minimum following discussion among the steering group and a focus group of Carer Experts. The questions asked by The Carers Centre are very similar to those being asked by Possability People, with whom we will share main findings if possible, to establish if commonality exists.

This report details the methodology used and response total, Equalities Monitoring, the results by question with initial conclusions, the full conclusions and recommendations and an appendix containing full quotations for reference.

## Methodology

Starting in September 2019 we met with Possability People and the BHCC commissioner and team. Also attending these meetings was Dr Philip Rankin.

These initial meetings provided the basis for our discussions about their requirements. Possability People then formulated the basic questions, and these were discussed, and some adjustments made.

A series of further meetings and several test events were run during October and November to ascertain the effectiveness of the questions. Results from these were fed back and further adjustments made.

Due to the variety of possible care package situations, the questions to be asked either by survey, face to face interview or in focus groups were limited to three but the number of possible scenarios number seven. The main questions, added to the equalities questions and a further section which asks about short term residential care requirements, results in a survey which runs to many pages even though the number of questions to ask is low.

Questions were also compiled to be open, providing respondents the opportunity to detail as much or as little as they wished and to aid facilitators using these when conducting focus group or one-to-one interviews. Themes to consider when answering, rather than checklists of answers have been used as the detail of a situation is desired rather than a superficial answer.

The survey was sent to our client base via multiple e-mails with a link to Survey-Monkey and also a link to Possability People's survey should the cared for person wish to answer directly. Postal surveys were also issued and several face to face meetings arranged or requested including with some protected characteristic groups such as Travellers and LGBTQ+. The Trust for Developing Communities were also included in late November to provide outreach to their cohorts where these may not have been in direct contact already with The Carers Centre and Possability People.

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. Due to the open nature of these questions, response time varied between 5 and 25 minutes.

Questions were designed to be as simple as possible to avoid confusion. They were accompanied by a definition of each type of care package, instruction as to how to complete the survey and a cover letter explaining the purpose of the survey.

In total, the explanatory email and Survey Monkey link (including the Equality Monitoring questions), was emailed to over 1400 carers currently registered with The Carers Centre. The subject was also raised at a quarterly Carer Expert meeting, with the attendees indicating that they would respond and provide detailed answers.

A longer than normal timescale of six weeks was allowed for responses due to Christmas and New Year falling in between. This deadline was included in the email along with information that the survey results are anonymous and that carers would need to provide a contact point if they wished us to follow up with them re specific actions, be involved in further work or receive a copy of the final needs assessment report from BHCC..

We received 39 Survey Monkey responses all of which included the equality questions within the time period.

3 postal surveys were also returned and included the equality data and two case studies were completed. One via skype and the second from detailed survey responses. Total responses = 44.

All respondents fell into either the "Home Care" or "Direct Payments" categories. A number were self funding. This was expected since most carers cease to regard themselves as carers if their dependent transfers to a different type of care package such as Supported Living, Residential or Nursing Home.

For the survey, the total number of responses per question vary greatly depending on the section being completed. Where sections have been completed, they were accompanied by detailed experiences and comment in a number of cases.

## Equalities Monitoring

### Q1. Who is completing the survey? 42 total responses



### Q2. Age Range? 42 total responses

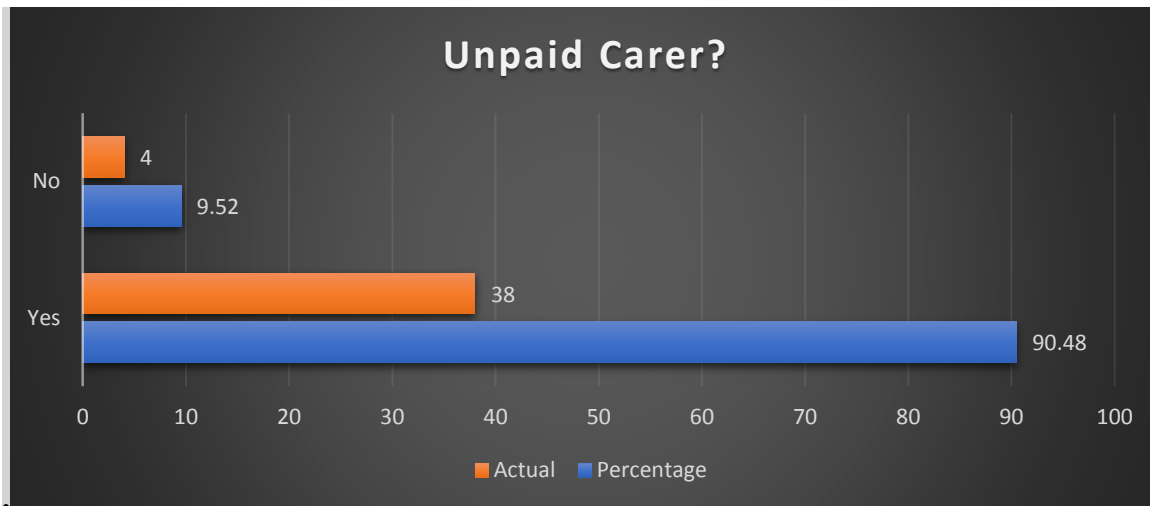
Ages of respondents ranged from 20 to 74.

Average age is 53.8yrs

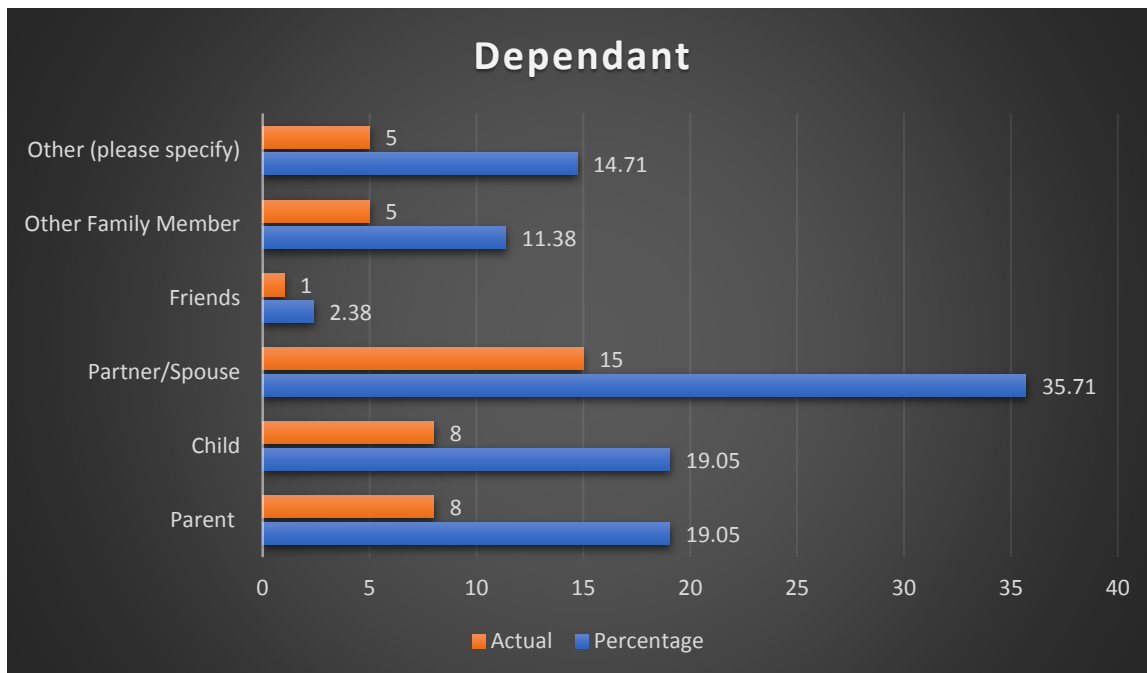
Since these are carers responding, the age restriction of 70 years does not apply.

The age of the dependant in the case study is 54 and the carer is 48.

### Q3. Are you an unpaid carer? 42 total responses

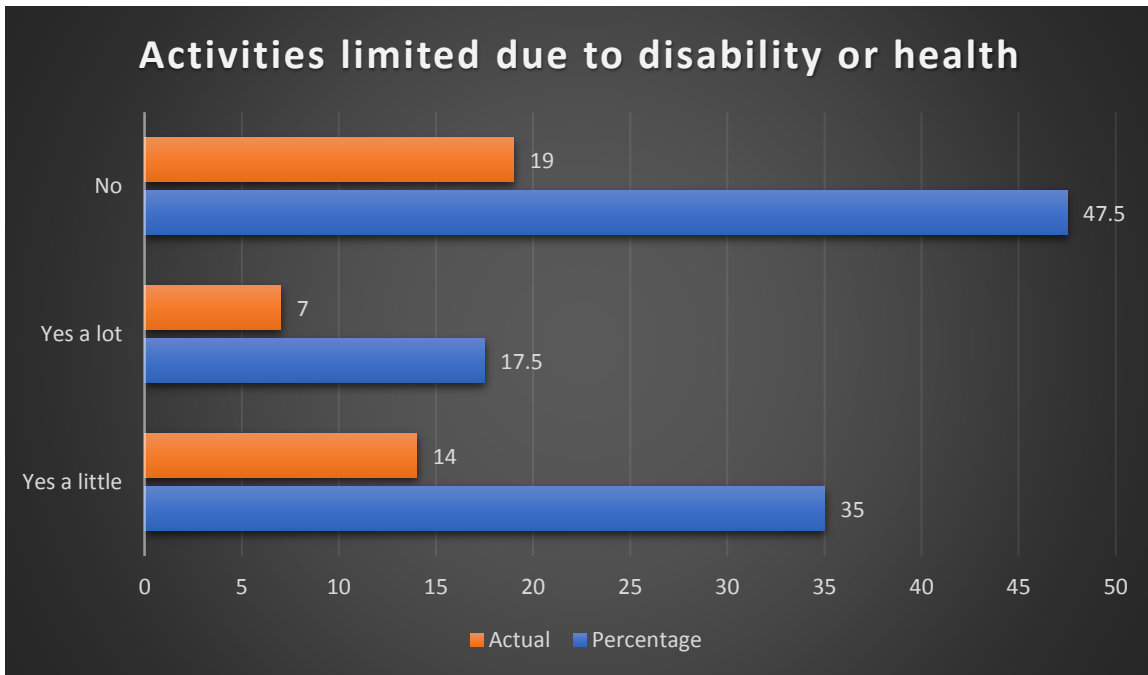


### Q4. If Yes, who do you care for? 42 total responses

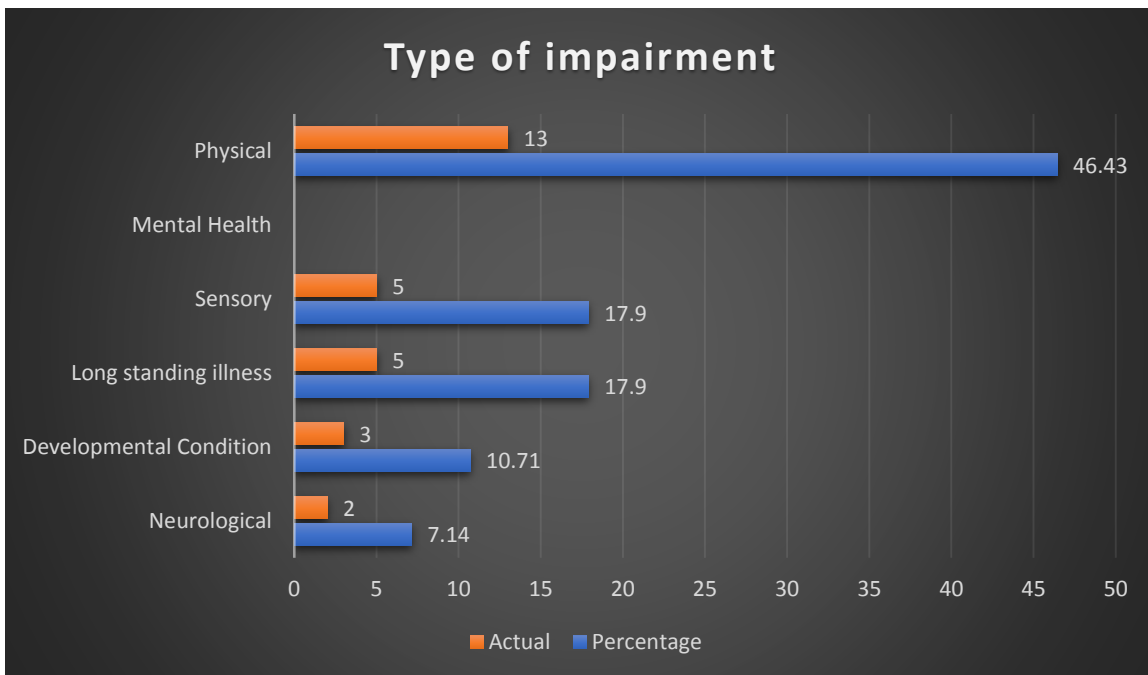


The "Other" category was completed by 5 respondents online, however, all specified dependents actually fall within one of the other categories.

**Q5. Are your day to day activities limited due to being a disabled person or due to a health condition? 40 total responses**



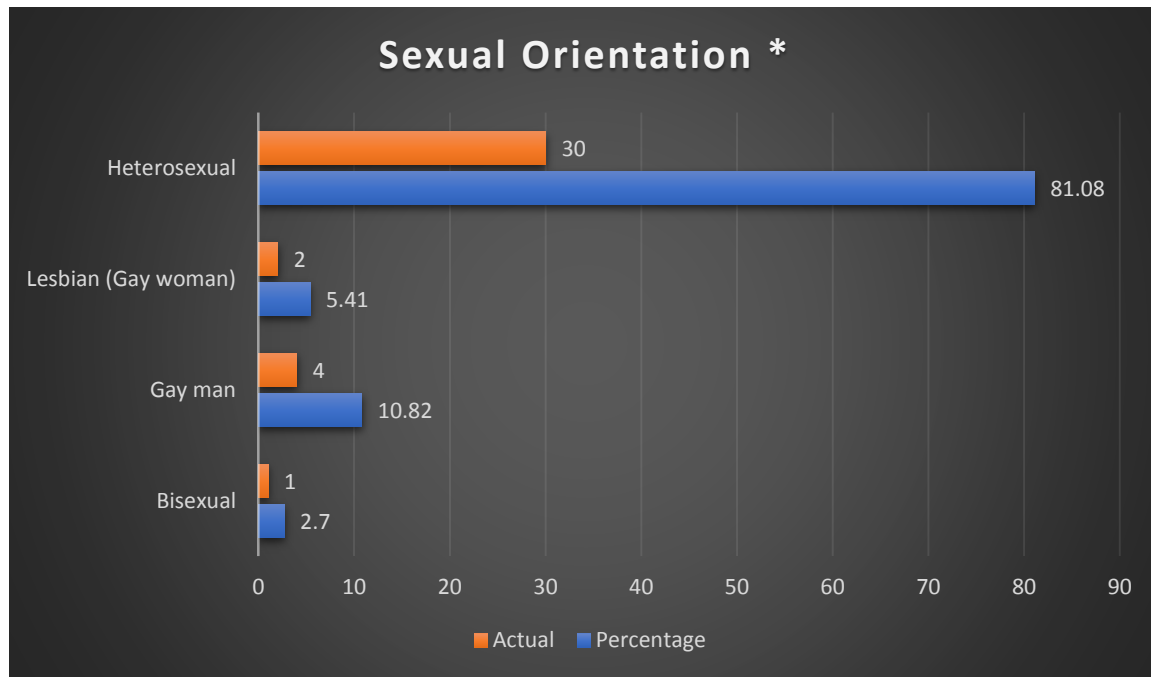
**Q6. If yes, please state your type of impairment (tick all that apply) 24 respondents and 28 conditions indicated**



### Q7. Listing of conditions

A listing of conditions related to Q6 above, was completed by 22 respondents online but was not included in the paper survey or the case study.

### Q8. What is your sexual orientation? 37 total responses



\* Only sexual orientations indicated are shown

### Q9. What is your gender? 39 total responses

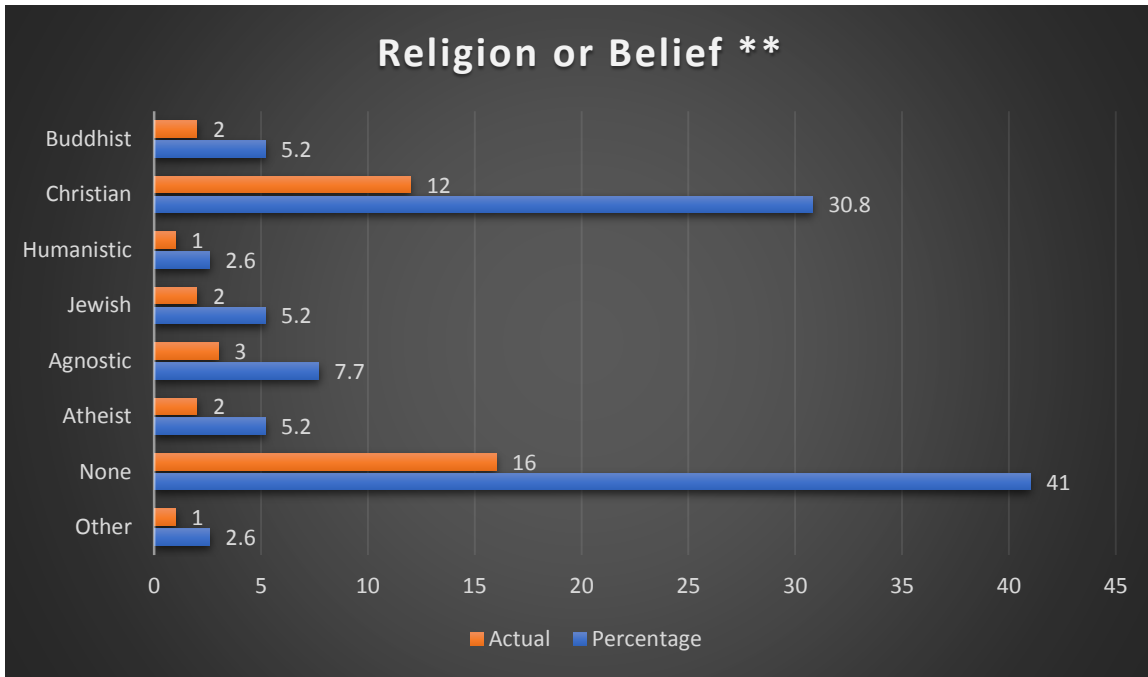
Male	17	43.57%
Female	22	56.43%
Other	0	

### Q10. Do you identify as the gender you were assigned at birth? 40 total responses

Yes	40	100%
No	0	0%



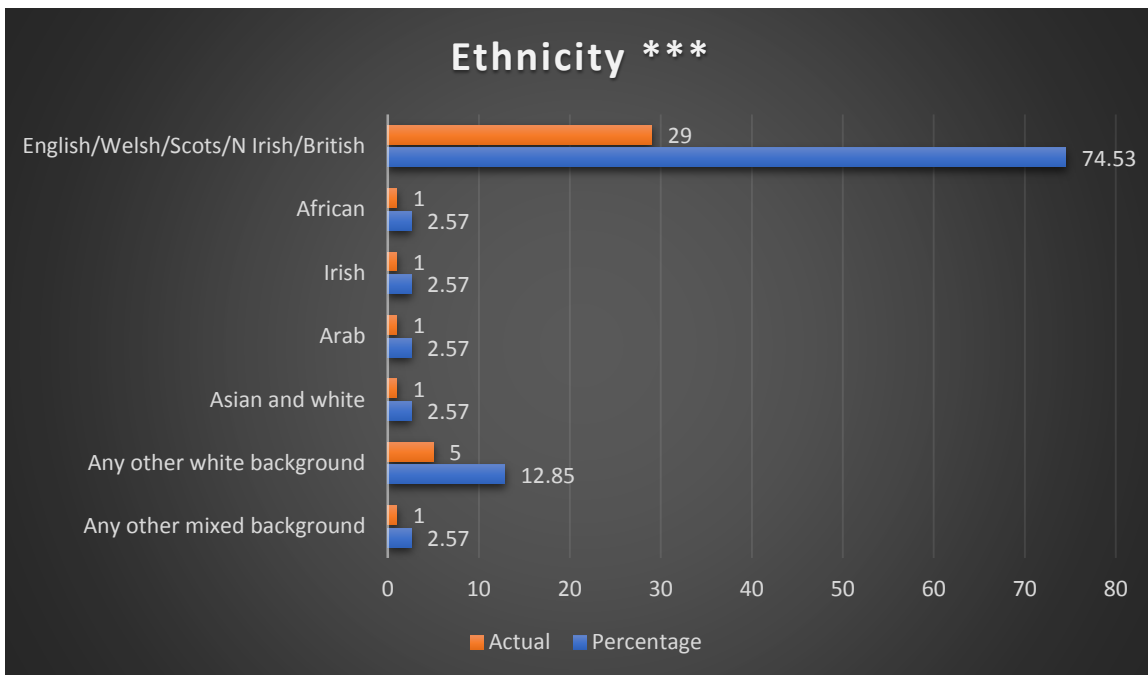
**Q11. What is your religion or belief? 39 Total responses**



The “Other” answer was “Eclectic”.

\*\* Only religions and beliefs indicated by respondents have been included

**Q12. How would you describe your ethnic origin? 39 Total responses**



\*\*\* Only ethnicities indicated by respondents have been included

### Q.13-15 Armed Forces Service?

- Q.13** 39 / 100%      responded that they are not current members of the UK armed forces.  
39                      total responses.
- Q.14** 37 / 92.5%      responded they had never been members of the UK armed forces.  
3 / 7.5%              said they had been members.  
40                      total responses.
- Q.15** 39 / 97.5%      responded that they're not a member of a current service persons close family.  
1 / 2.5%              responded that they are.  
40                      total responses.

### Q.16 Do you have access to the internet? 40 total responses

100% responded "Yes".

### Q.17 Do you receive support from an unpaid carer or family member? 35 total responses

6 / 17.14%      Yes  
29 / 82.86%      No

The paper survey and case study did not contain this question.

The answers from the online survey to this question should not be taken at face value since in Q3, 38 respondents stated that they are unpaid carers. The difference between Q3 and Q17 may be explained by carers responding that they do not receive *extra* support from *another* unpaid carer or family member.

## Part Two: Current and Future Care

### Results

The questions asked were divided into the following care package sections:

Home Care including self-funding

Direct Payments

Live-in care

Supported Living

Extra Care

Residential Home

Nursing Home

All answers from carers fell into 2 types of care package example. Only these sections are included.

#### Q18 - 21. Home Care (includes self-funding).

Definition: Care provided in their own home by paid care workers to help them with their daily life.

This is also known as domiciliary care. Home workers are usually employed by an independent agency and the service may be arranged directly by yourself or through the council.

#### Q22 - 25. Direct Payments.

Definition: Money that is paid to them or you (or someone acting on behalf of your cared for person) on a regular basis by the council, to enable you to arrange their own care or support.

Instead of receiving social care services arranged by the council, you and they decide and organise the support required, to meet the needs identified in an adult social care assessment.

### Case Studies

Two case studies were completed. One was conducted via skype, with one disabled resident and their carer. The second is based on an extensive response given to a paper survey, with the carer of a disabled young adult and speaking with the carer at a peer support group. In the first study, the disabled person is 54 years old and the carer, their spouse is 50. They live in a housing association adapted bungalow which is currently being assessed for further updating/adaptation.

In the second study, the carer is in their mid-sixties and cares for their adult child in their own property.

#### Case Study One Context

The disabled person suffers from Cerebral Palsy in a rare form which has affected their movement ability (permanent wheelchair user) but no speech or other symptoms, associated with CP. They have extremely limited arm movement and no lower limb movement. They are able to work from home, and have also worked in a bank and as a computer manufacturer call centre manager with the aid of a motorised wheelchair and taxis. They now choose to work at home as are unable to visit the bathroom unaided which makes out of home work painful if not impossible.

The carer (they do not use this term and object to its use), also has multiple long-term heart and allergy health conditions though these do not affect mobility.

## **Question Responses from Case Study 1**

Situation: Home care – self funding

Responses to both case studies are as near verbatim as possible with summary points at the end.

### **Q19 (from Survey questions). What is working well?**

#### **Carers Allowance.**

The carer receives a care allowance and I receive PIP but they are providing a full twenty-four hour care package which would cost the council far more than the money they receive. The carer is providing maximum support but is restricted in the amount of hours they can work. Payments have always been on time and correct.

#### **Independence.**

We have no outside interference or at least very little and we like that. We are autonomous. Because of this we don't need to justify if we want to do something.

We don't need to teach anybody anything.

#### **Training.**

When you are being cared for, a new carer, is a new person you must teach how you want things done. Carers often have excellent training how to care for a “disabled person”, but this training is based on the generic needs of a “disabled person”. There is no recognition or at least very little recognition, that we are individuals.

An example is when we have to be helped to use a toilet. Toilets for disabled people are currently thought to be best when raised up. This is because many disabled people now, are disabled because of frailty and age. For an elderly person a raised seat is easier, however, for my condition and for many of my peers a normal toilet seat is actually better. I can shuffle myself with help, from my chair to the toilet. A raised seat makes this impossible. A carer that doesn't know me will try to get me to stand to then move across to a toilet this is the most awkward way for me and requires me to be almost lifted up and then supported. My disabilities mean that my joints and muscles are always cold and stiff. To stand and try to move requires great effort and frequently a long time before my muscles will relax.

#### **Good intentions.**

We both recognise that the council and the Housing Trust want to provide a home for us that will enable us to be as independent as possible.

Currently we are in the process of agreeing adaptations to our bathroom and kitchen. The Occupational Therapist who visited us was lovely. She was very kind and did her best to offer us what she thought we needed. What we need is actually not the same as what she thinks we need. An example is our bathroom. We currently have a bath with a shower and previously I was able to shuffle across to a seat across the bath. The OT wants to change this to a wet room because that is the current perception of what every disabled person needs. A wet room is fine, but I cannot stand in a wet room, I need a seat which I have specified. The surveyor who came to measure for the wet room has created a plan which halves our bathroom and gives me a tiny seat which is unsuitable. I have offered to pay for certain additional items which enhance my independence greatly. These have not yet been agreed, even though they are best for me!

Additionally, in the bathroom, disabled people always have shower units recommended, that heat water to 42 degrees C. A normal shower heats water to 49 degrees C. Clearly, the temperature

difference is to prevent hot water scalding, however, I have never been able to get a suitably hot shower with the disabled shower, therefore I do not want one to be fitted when replaced. The OT could not understand that I should have a choice rather than have this imposed on me.

### **Communication**

This is a mixed bag. The OT and surveyor who have visited have been easy to speak to which is great but there is always a patriarchal tone with these people. It's as if they want to tell me what is best for me but forget that I am the one who lives with my abilities 24/7 and am the absolute expert as to what works best for me. I am the one who should be in charge of my care and telling them what decisions to make. Of course there are always financial considerations to take into account which is where they can advise that money is or is not available but don't keep insisting that I will be better off with something that I know I won't, especially when I offer to buy equipment myself and pay the difference in cost.

### **Q20. What Could We Be Doing More Of?**

#### **Be More Proactive**

Once I left college 30 plus years ago, I found that the onus to make things happen was very much on me. This was very different to the system when I was a minor.

I have had very little communication from the council, which I like as I have said, and I don't want that to change really. The problem with this is that I have probably missed out on some help and support I could have had and though for me at the moment, this is not a worry, it will be a worry if something happens to my wife. Also if something happens to me, what will happen to my wife? This is her home, yet she would certainly have to leave it within a couple of months.

#### **Back Up Plan**

For anyone with a disability that involves someone else having to perform some tasks, a back up plan if the carer is not available is key. This is not just about living independently, it is about being able to live full stop. There are tasks that I cannot do which without a carer could lead me into a life-threatening situation or at least a humiliating one.

I don't feel there is enough emphasis from the authorities, whether council, NHS or GP's to promote this and ensure that a viable plan is always in place with appropriate back up. This links with my previous point about being proactive.

#### **PIP**

Maybe this is not part of this research, but I was born with quadriplegic CP and yet at age 54 I have had to reapply for PIP and undergo an assessment. In terms of being independent in the same way as a working person, this is like having to constantly reapply for your job. Of course, we understand that there are people who will have tried to scam the system, sometimes successfully, but for someone like me, who is obviously not going to suddenly become more able/independent without the use of technology, this is simply ridiculous.

#### **Inter-departmental Communication**

It just seems like the authorities don't talk to each other. I have real doubts if the DLA have ever talked to the council about what they find. Being independent should not be about constantly having to

repeat the same information or even worse not being believed and having to seek an expert to confirm what you are saying.

### **Less Patronising**

Treat disabled people as individuals not as “disabled”. Once you start categorising people there is the danger that you become patronising, especially when you label yourself as the “expert”. One of the reasons we try to have as little to do with the council or housing association etc. is that there always seems to be a patriarchal point of view. It’s like your parents, however, well meaning, that want to tell you what is best for you.

Certainly have ideas how to help people with impairments or disabilities, but be prepared to accept that they know best for their situation.

My wife and I are very capable people and will ask questions and not just accept what we are told as “fact”. There are many of my friends who are cared for, who will just take what they are told and therefore often miss out. One example is a friend of mine (lives outside of Brighton so not covered by Brighton and Hove Council), who is a double amputee and very large due to medications. This person explained to an OT that he needs a bath rather than a wet room as the chairs in a wet room are not suitable for his size and without his prosthetics he just ends up on the floor. A bath is really easy for him though as he is very strong and can transfer himself in and out. The OT told him that he can have a new bath fitted as they take each case on it’s merits. Twenty four hours later they contacted him to say he can only have a wet room and would like to come and measure up. He told them that there is no point as he can’t use a wet room and he was told “well they work for most people.” The issue is that every disability places a different set of capabilities on the individual.

### **Respite/Carer Support**

I care for my husband, but I hate being called a carer, I am his wife and I do things for him because I love him not because I am his carer. We both know though that I am providing a 24/7 service which is saving the council many thousands of pounds, but carers receive very little real recognition. Being able to earn £123 per week in order to keep a carers allowance of £66 is frankly ridiculous.

The lack of financial support gives us virtually no opportunity to get away and remove ourselves from our daily life. For me, respite is not about me being alone away from my husband, it is about being able to take time together to enjoy life. We are fortunate because we are both very interested in technology, so we use this as much as possible to make life easier and more interesting, but I imagine there are people who are not in this position and feel desperately isolated and bored.

### **Q21. In the future, what care and support services could be put in place to enable them to live as independently as possible?**

A care package if tailored would allow me to live more independently as I have to self-fund most of my care aids and my wife provides 24/7 care for me.

There are simple things like being able to visit the bathroom with minimal help. I have aids to help clean myself if needed but if I drop them, what do I do when there is no one around? There are solutions, such as a “Japanese toilet” which has water jets and air to clean the user but these are expensive. Budgets always seem to be a sticking point.

Essentially, anything that reduces the amount of care required is good.

Housing associations repair rather than replace items currently and this means that things like our taps, lights etc. are all rubbish.

Something that allows voice control, such as “Alexa” is very useful for people with physical disability.

### **Case Study Two Context**

The carer is looking after their adult daughter who has Cerebral Palsy and also Learning Difficulties. They receive assistance less than ten hours a week from a housing trust. This has enabled a degree of independence and the possibility to volunteer at a local group for the daughter. The carer currently has a number of health conditions, some physical, including a recently broken ankle and some relating to mental health and well-being.

### **Question Responses from Case Study 2**

Situation: Home care

#### **Q19 (from Survey questions). What is working well?**

My daughter receives nine hours care/help from Southdown Housing Trust each week.

She has bonded well with her support worker who now understands her individual needs and the difficulties she has.

He is positive and makes her laugh and provides good emotional as well as physical support for her which is important.

She has been encouraged to spend time volunteering at Food and Friendship, which she now enjoys very much.

Her time away from me is important to allow her to be and feel more independent and to interact with others rather than just me and the carer.

She enjoys cooking now and the carer helps her to cook in our home which is important for her to learn for when we are no longer around.

#### **Q20. What Could We Be Doing More Of?**

More hours of care is probably the single biggest things as she spends a lot of time in her bedroom when the carer is not here.

I support her the rest of the time but I have injured my leg recently and this has made me realise just how much support she needs which I usually provide. I will be like this for at least six weeks which also means I cannot drive her anywhere.

#### **Q21. In the future, what care and support services could be put in place to enable them to live as independently as possible?**

She would need carers in every day as she needs help with all aspects of daily living.

Our bungalow is in trust for her and she would want to stay here without a doubt.

We do not have any other family or friends that would be willing to take my place when I am not around.

## Initial Conclusions (from both case studies)

### Positives

- ✓ Payments on time for carers allowance and PIP
- ✓ Independent as much as possible
- ✓ Carers well trained but should always recognise that disability is not generic e.g. frailty may require different independence aids to a person with cerebral palsy
- ✓ Good intentions by those involved with council and housing trust to provide aids to independence. Sometimes overly "Parental"
- ✓ Communication generally good but also examples where there is a lack of understanding or inter-departmental communication
- ✓ Carers and cared for, can bond well when it is a regular person, and provide positive emotional support not just physical.
- ✓ Professional carers can encourage independence and help with skill acquisition when they know the dependent well enough
- ✓ Technology can play a role in independence for small cost e.g. "Alexa".

### Negatives

- × Not enough hours of care provided, or expectation that care will be provided by family member or friend
- × Be proactive in offering help and services. Expectation seems to be on disabled person to seek out help
- × Provide a back-up plan even for self-funders. If the carer cannot continue in the role, the disabled person may be extremely vulnerable or even life threatened
- × PIP assessments for someone with a lifelong condition are frustrating at best and seen as a waste of time in the same way that having to constantly reapply for your job would be
- × Communication between DLA, council, housing associations is not viewed as consistently good.
- × A "Parental" tone from authority figures does nothing to increase independence and may lead to some disabled people just accepting what they are offered even when it is clearly not correct for them
- × There is a severe lack of respite available for carers. Respite can simply mean a change or routine rather than being away from the cared for person
- × Fear that sale of house may have to be used to fund care when the cared for person would wish to stay in their own home anyway



## Survey Responses

### Home Care

#### Q18. Do they receive home care?

There were 37 responses across online and paper surveys.

20 / 54%	Yes
17 / 46%	No

No respondents gave details of anything other than home care and direct payments. The total respondents in the Direct Payments questions was 8 which when taken from the “No” answers in this questions, may indicate 9 from 37 total, who are looking after their dependant with no form of support/self-funding.

#### Q19. What is working well?

There were 17 responses across the online and paper surveys.

Comments have been categorised into themes where possible as follows and are summarised.

#### **Consistency**

The same people attending at a regular agreed time for home visits is key. This was echoed a number of times.

#### **Timing of visits**

The carers are good at attending at the expected time.  
Ability to choose the timings is good and this has never been an issue.

#### **Help and Efficiency**

The carers are reasonably efficient.  
Day to day help is essential.  
Carers carry out same tasks each day such as cooking, washing, all ok.

#### **Money**

Money is important for independent living and there is some anger among self-funders at the perceived inequality of those who are denied funding due to having accrued lifetime savings. Political spending on expenditure which seems to be at the expense of social care is viewed extremely negatively.

#### **Support Services/Respite**

I don't know of support other than The Carers Centre.  
The support available is paid for by the family other than The Carers Centre and Possability People who were both described as helpful.  
If there is support available we would have to do this together but our interests don't always match.

Carers come in twice a day which allows “work but nothing else.

The sense that carers are starting to be valued and home and residential respite is being recognised as essential to maintain wellbeing of all parties.

One respondent simply stated that support services were working well.

### **Training/Courtesy**

Knowledgeable staff is essential. Two Polish ladies normally attend but don't know if this will continue with Brexit.

Lack of respect for the person cared for does not appear to be an issue.

We do not talk about our culture and lifestyle with the carers and they have never made comments.

Wife is happy to see the carers.

Carers are kind, courteous and respectful.

Carers are well trained and good at raising any medical issues they notice.

One person who identified themselves as gay, stated that their sexuality had never seemed to cause any issues with the carers.

### **Communication**

They are good at informing if they are going to be late.

Good at keeping myself and my family informed.

Being able to have a chat and have company.

Although most of our carers are from Europe, they speak good English and we have no communication problems, sometimes better than the English carers.

### **Choice**

We chose well but were able to as self-funded.

We were given carers, choice not mentioned.

Choosing who works in our home and when was key.

### **Environment**

Being at home is important to us.

Feel that dependent is safe when carers arrive but sometimes the dependent is frightened.

## **Q20. What could we be doing more of?**

There were 17 responses in total to this question across the paper and online surveys.

Comments have been categorised where possible and are in summary form.

### **Consistency/Suitability**

Keep the same carers and if possible, always same gender.

My partner has on occasion refused to be helped due to a male carer attending.

A check should be required to establish if a same sex carer is required.

Consistency of social workers should be a key point the same as for carers.

## **Environment**

We self-fund, so have made the environment as we want it.

Recognise that aids to independent living cannot be a one size fits all approach. A very similar situation to Case Study 1 was detailed in the online survey. A bathroom being converted into a wet room but without the specific needs of the person cared for being considered was described as a "fight" with the "experts" even though it was being self-funded.

## **Activities/Cultural Interaction**

I dread to think if my partner has to go to a home at any point (not that we could afford one anyway). She would be horrified to not be able to just do her own thing when she is able. Care homes that I have visited all seem to follow the same formula. Bed, board, lounge, trite activities which would be completely unsuitable for my partner who is only in her 40's. They are almost entirely designed around pacifying the elderly and keeping them occupied or at least immobile for as long as possible so that staff do not have to keep being bothered. That is how it seems to me anyway.

Communication sometimes difficult where English is not first language (of the dependent) and disability affects speech.

Carers focus on care things rather than culture. They could learn more by asking but do not normally do this.

There do not appear to be any groups for Asian disabled people.

Explain different faiths, cultures, sexual preferences and races to care staff as part of training to avoid ignorance and even shock (which happened one time).

## **Respite**

Provide more home based respite for those with mental health needs and more residential respite for those with learning disabilities.

Issues re the person cared for getting out to social activities. Taxis no longer feasible and carers driving is too expensive, meaning person cared for misses out and family have very little respite.

## **Funding**

Stop cutting funding and the requirement for ongoing assessment when a disability is lifelong.

Have benefits advisors for PIP and ESA forms as these are daunting and making a mistake severely affects your ability to live.

There were a number of comments relating to having to self-fund due to savings being amassed during a lifetime of work, and the inequity of this situation compared to those who receive funding due to having not saved.

## **Length/Time of visit**

Carers often rushed and do not always fulfill all time they should but this is ok as long as tasks are completed to my satisfaction.

Provide earlier calls.

## **Training and Supervision/Resources**

It would be helpful to have a scheme run by the council similar to Trustpilot or Checkatrade but for care agencies. When choosing which agency to use, we had to rely on friends and relatives experiences.

Carers are up to date and can give medicines but are not able to cut nails as person cared for is taking blood thinning treatment.

Training, supervision and resources for health tasks.

### **Q21. In the future, what care and support services could be put in place to enable them to live as independently as possible?**

There were 13 answers to this question.

#### **Training**

Someone trained to use a hoist.

#### **Adaptations**

Adapting our house. Stairlift, kitchen adapted so nothing overhead, biggest worry is when money runs out as I cannot sit at home and hope work comes to me, I have to be out finding it. When I am not around, my wife is vulnerable if she is having a bad day.

#### **Future certainty/Increased care/Culture**

Need to know that support will be available when we are no longer around.

More care is needed, specifically Asian carers who will understand her needs more easily.

Understanding of cultural needs such as a Buddhist area in a care home and staff that understand different needs based on culture, race, faith, sexuality etc.

Increased care was mentioned a number of times, especially in home care and 24hr support.

#### **Transport**

Transport is required in a number of cases as this prevents current social interaction and is not seen as likely to improve in future.

Supported transport options as even hospice is no longer providing transport.

#### **Companionship**

Companion to help with attending events or sitting at home and keeping company. Crossroads Care was referenced as having helped but described as "limited".

#### **Funding**

Not having to sell home to fund care. Even part funding would be something.

#### **Initial conclusions:**

#### **Positives**

- ✓ Carers are generally described as courteous, friendly, well trained and efficient
- ✓ Consistency of service, especially relating to time of day and actual carers visiting is important especially where there may be fear or distrust of unknown people or those from different cultures, entering the home
- ✓ Home environment is seen as important

- ✓ Being able to communicate in a friendly but knowledgeable and efficient manner is important
- ✓ Choice of time, day, care provider (when possible) is seen as important
- ✓ Keeping family and other carers informed and being aware of medical issues that may require intervention is seen as important
- ✓ Funding is seen as essential but sometimes not available due to savings. There is a sense of injustice due to this from some carers

## Negatives

- × Not always same carers attending.
- × Same sex carers may be required but not asked if needed
- × A one size fits all approach does not always work
- × Care homes perceived to follow a formula which is unsuitable for younger people
- × Carers often focus on process of care (wash, clean, food etc.) rather than really getting to know the dependent though this is seen as a consequence of lack of time
- × “Experts” often adopt a generic approach. Recognise that the person being cared for is expert
- × Not enough respite or lack of opportunity to access respite services
- × Careful lifelong savers should not be penalised
- × Frustrating that carers can give medicines but not simple things like nail cutting
- × Activities do not seem to cater for certain minority groups (Asian was specified)
- × Care homes are not seen as suitable for some minority groups and generally anyone that has particular activities they like e.g. crafting
- × Funding is seen as inadequate and often unfair. There is no certainty that care will be provided in the future or even that money will be available to provide aids and adaptations to allow independent living

## Direct Payments

### Q22. Do they receive direct payments?

There were 8 responses across online and the paper survey.

### Q23. What is working well?

There were only 4 responses to this question, therefore they have not been separated into categories.

The carers chosen are very good but we had to rely on word of mouth as we couldn't find a listing with rankings to choose from.

The carers are professional but the turnover of staff is high. A regular person is always better as they know the needs more precisely.

We have no communication problems.

The timing of the carers is exactly as we want. They arrive early to carry out breakfast and wake-up call and then twice more during the day for lunch and tea before a final late bedtime visit. This covers about 14 hours of the day and is exactly what is needed.

The carers understand that because the person they are caring for is bed-bound, the television is an important source of information and entertainment. They program the tv to show favourite channels and always ensure that it is left on and at an appropriate volume.

The processing of the application for Attendance Allowance was done with assistance and this was a great help.

The Personal Assistance I organised is a great help.

Social care is working well and very useful.

#### **Q24. What could we be doing more of?**

There were only 3 responses to this question.

Respite for me.

Increase in the amount of health care (social care?).

Carers visits could be longer. This would allow more interaction and less administration (washing, cleaning, cooking etc.).

The carer described the visits above as being like taking a car to get washed, ultimately the minimum is to wash the car but it is an impersonal task with a machine. They felt that if there was more time, this would allow them to find out more than just knowing what food is preferred or what to put on tv.

#### **Q25 In the future, what care and support services could be put in place to enable them to live as independently as possible?**

There were only 3 responses to this question.

Nothing as she is bed bound, so independence is not an option.

24 hour support.

Increased health resources and supervision.

A key worker for health

Permanent independent supported living as close as possible to the home environment.

#### **Initial conclusions:**

##### **Positives**

- ✓ **Choice though a ranking list of agencies is desired**
- ✓ **Professionalism**
- ✓ **Communication**
- ✓ **Timings of visits**
- ✓ **Individual needs catered for (to some extent)**
- ✓ **Permanent supported living would be desirable in the future**

## Negatives

- × Respite is needed
- × More care, up to 24hrs
- × Longer visits to allow for getting to know the person being cared for properly
- × Increase resources to allow for greater independence
- × A single key worker to deal with is not an option

## Part 3: If a short-term care home placement was ever necessary

Q46. If a short-term care home placement was ever necessary, what would be important for the care home to offer to enable them to return home?

Case study and survey answers are collated together.

There were 18 responses from surveys and 1 from Case Study 1

I am not sure as I don't know what could be offered that could not be covered by a carer in my own home if my wife was not able to offer specialist care.

Maybe extensive rehabilitation. (This was mentioned by a number of carers.)

My wife and I are both vegan, including not only food but zero animal products in our home. I would not want to be sat in a leather chair or have aids used to help my recovery that involved animal products.

Respect people's individuality. Disability is not a box to put people in.

Medical care, socialising and recuperating.

Physio and the ability to make decisions for themselves no matter how small.

Activities that motivate and keep moving.

Due to complex medical needs, a fully equipped centre would be needed, not just normal care home staff (these were described as "little more than cleaners").

It would be better to go straight home and be cared for by the normal carer even if there was extra help arranged.

Asian people to talk with and maybe be able to do activities like cooking if possible.

A revised care assessment for the carer to see if they can cope and whether more support is required.

Physio at home would be better than in hospital or a nursing home. The needs are too complex and too many things can go wrong.

Financial support for the carer to pay for additional care, especially where they are no longer working.

People to talk to. A plan to show what will happen and when. TV in bedroom in case they don't want to mingle. Space for a wheelchair to move and good internet access as this is a big part of their life and I could stay in touch.

Overnight stay facilities for the family/carer.

## Initial conclusions: Requirements

- **Home care would always be preferred even if extra support or resources are needed**
- **Reassessment of the carers situation**
- **Respect for life choices such as veganism**
- **Specialist support such as cultural activities aligned with the person race, creed, gender etc.**
- **Accurate and appropriate medical and nursing care**
- **Stimulating activities based on the likes of the person**
- **Physiotherapy and a plan to get the person home**
- **Ability to make decisions**
- **Internet and TV access**
- **Overnight facilities for family**

## Conclusions

There were a large number of conclusions to be drawn. Some may not lead to a recommendation that Brighton and Hove Council are able to meet but should be included in a final assessment of need. Top conclusions based on frequency of response are shown here.

- 1) In home care is always preferable to other options unless the cared for person is alone and vulnerable. A home environment is where the greatest level of independence is often found
- 2) Disability is often seen as a label used to categorise people, with generic solutions applied. These can hinder independence rather than increase it
- 3) The person cared for is often the best judge of what is required to live more independently
- 4) Carers require respite and currently there is not enough
- 5) Respite does not always mean having to be separate from the cared for
- 6) Paid carers that have time to get to know the cared for person properly, are able to provide more than just the physical “process” of care such as washing, feeding etc. Emotional support can be provided by a longer visit which in turn enhances well-being (and job satisfaction)
- 7) Regularity of carers visiting in terms of personnel and timings is key (same was suggested for Social Workers)
- 8) Paid carers are generally viewed as efficient, courteous, respectful, friendly and essential for independence though some training around cultural, racial, lifestyle differences was suggested
- 9) Funding is often seen as inadequate, unfair and secondary to the political whims of Government



- 10) The ability to choose care agencies, activities, adaptations etc. are all important to carers and the person cared for. Choosing an agency is often reliant on word of mouth reputation
- 11) A plan for what will happen to the cared for person if the carer is unable to care and/or the carer survives the cared for person passing but lives in a housing trust property is required. There is fear for the future among both cared for and carers

## Recommendations

- 1) **What:** Ensure that choice is always available in terms of care provided and adaptations or aids available regardless of situation. Carers and cared for almost universally preferred to be in their home environment and this should be the default for any care provided. Initial communication followed by review of current training and services. Link with number 2  
**When:** As soon as possible and no later than end of year 2020  
**Who:** Brighton and Hove Council
- 2) **What:** Mandatory training to be provided (possibly by disabled people) to staff to ensure that the disabled person is always recognised as being the expert in their own care. Speak Out, currently provide a similar service for anyone wishing to understand more about people with Learning Disabilities, however, this is voluntary.  
**When:** Roll out by end of 2020  
**Who:** Brighton and Hove Council
- 3) **What:** Mandatory training around culture, race, sexuality, gender and lifestyle for all care agency staff and council employees  
**When:** ASAP  
**Who:** Brighton and Hove Council
- 4) **What:** Review and report on all respite and other activities (including those in care and nursing homes) provided to cared for and carers, to ensure these are relevant and fit for purpose. Increase range of options where possible  
**When:** By end of 2020  
**Who:** Brighton and Hove Council and activity providers
- 5) **What:** A ranking system of agencies should be available with information based on timings available, regularity of staff, feedback from existing service users and any other relevant factors  
**When:** ASAP  
**Who:** Brighton and Hove Council and all other relevant agencies
- 6) **What:** Examine possibility of creation of universal plan for cared for and carers to provide a clear path in the event of significant changes in their situation resulting in for example, loss of care, financial hardship, loss of home  
**When:** 2021 if no existing plan  
**Who:** Brighton and Hove Council in consultation with NHS England, Housing trusts and GPs