Countability

Barriers and Opportunities for Disabled People in Brighton & Hove

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Fed Centre for Independent Living

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Countability 2012: Executive summary

Aims & Objectives

The Countability research project was commissioned by public service providers to address a data gap regarding the barriers and opportunities faced by disabled people living in Brighton & Hove, in regards to key aspects of daily life. The research was led by the Fed Centre for Independent Living and started with one question:

> *What barriers, challenges and opportunities are experienced by disabled adults, aged 18-65, who live in Brighton and Hove?*

The research was guided by the Social Model of Disability, which considers disabled people to be disabled by social barriers rather than their individual impairments or health conditions. The focus of the research was therefore on the barriers, challenges and opportunities shared by disabled people in society.

The Countability project started by gathering available data from local service providers on disabled people, how they used services and their experiences of living in the city. Local data was found to be quite limited, with no consistent approach to data collection on disabled people and varying levels of cooperation received from different departments within individual service providers. This highlighted the need for extensive primary research.

Research methods

- 50 in-depth, semi-structured interviews
- Five focus groups, each with 4-6 people

The methods chosen for the research were based on extensive consultation with individual disabled people, community groups and service providers which was carried out during the first stages of the project.

Research was widely publicised using a variety of media, contacts with existing community groups and through leaflets disseminated across the city. These included:

- An article in The Argus and several smaller community newsletters
- An advert in Friday Ad
- Radio interviews e.g. with Juice radio
- Leaflets in community venues, health clinics and leisure facilities

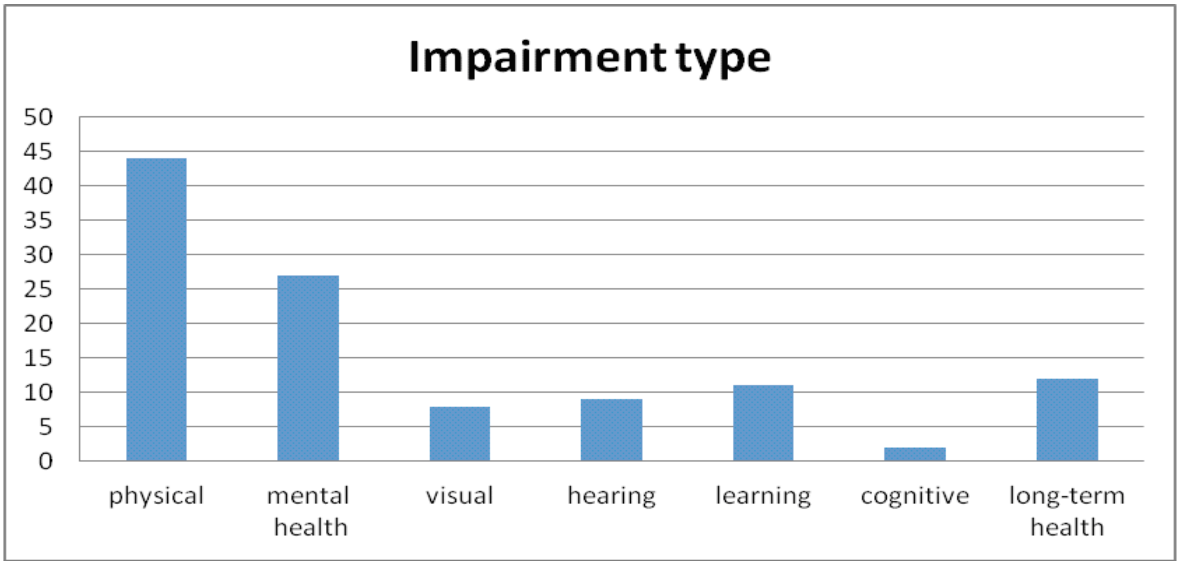
- A mailout to over 4,000 blue badge-holders aged 18-65 in the city
- E-mail and phone contact with community organisations throughout the city

We also ran focus groups to include groups who we thought might face barriers to finding out about the research and taking part in individual interviews. These included:

- 2 “big meetings” facilitated by Brighton and Hove Speak Out for people with learning disabilities to talk about health, work and leisure.
- 2 focus groups facilitated by Mind aimed specifically at users of mental health services.
- 1 focus group facilitated by a sign language translator from the Sussex Deaf Association aimed specifically at people who are deaf or hearing impaired.

Countability participants

The research team sought to recruit a diverse group of people including people with a physical impairment, mental health conditions, learning disabilities and/or long-term health conditions. We spoke to people from different backgrounds and different areas of the city. The sample of people we spoke to does not claim to be representative of all disabled people but does include a wide range of different perspectives.



Findings

We asked people about:
- Community activity such as social activities, groups and organizations
- Experiences of health services
- Support they received with their everyday life
- How they felt about their housing and experiences of housing services
- How they got around the city and experiences of transport
- Barriers and opportunities for employment and volunteering

- Experiences of crime and what made them feel safe/unsafe
- Experiences of benefit services and how people managed with money

Community Participation

> *I would just love something where you can get together with people… in a social setting where you can chat to people because I think that's half the problem just feeling so isolated. (Male, 50-65, mobility impairment)*

- Some participants felt socially isolated, due to lack of engagement in social networks, employment, volunteering or education.
- Some participants lacked the support needed to get out and about in the community, particularly those with a learning disability or care needs.
- Other barriers to community activity included physical inaccessibility of venues, lack of sign language translation and lack of information about what was available.
- Some participants felt there was a lack of choice regarding social activities available particularly in regards to timing and location
- Other participants were more engaged in the community and had networks of friends and family, which typically came from involvement in employment, volunteering and networks of identity based on health conditions, sexuality, religion or faith.
- Peer support groups were particularly important for participants in providing information, social networks and support.
- Participants accessed and responded to information on community activity in very different ways, suggesting there was no single one size fits all approach to information provision

Health

> *I missed all three physio appointments when I was in hospital because I was sitting in the toilet waiting for the nurse to come and give me a hand to help get out of the room, you do the buzzer and you could be waiting, probably twenty five minutes for someone to come and help you (Male,25-50, mobility impairment & long-term health condition)*

- Experiences in regards to NHS health services were mixed between participants, and even despite some clearly identified problems, many were overwhelmingly positive about the importance of the NHS in managing their own health conditions.
- Participants had positive experiences of primary care where they felt GPs had a good bedside manner, spent a longer time on appointments, involved the patient in treatment decisions, and where they felt there was good continuity of care, and negative experiences where these factors were absent
- Participants reported negative experiences in hospital which they attributed to a lack of continuity between nursing staff and a lack of support with personal care

where people needed it. Some specialist centres and surgical wards however were rated highly by participants.

- Some participants had good experiences of community and outpatient services and specialist nurses which tailored their support to people's individual needs. Other participants perceived a lack of disability awareness in health services which prevented effective treatment.
- Several participants had accessed counseling services which helped them work through episodes of depression:, however many participants felt that mental health services provided inadequate preventative support and talking therapies, placing more demand on crisis services.
- Participants perceived poor coordination of mental health services, and a lack of involvement of patients in their own treatment, which increased stress and anxiety and resulted in longer recovery times.

Social Care

> *I've got a really good care package. It's essential. It's really, really important. If I didn't have the care package that I've got now I wouldn't be able to do half of what I do even sort of getting out and about... I would just be even more dependent on the services that I'm already dependent on otherwise. (Female,25-50, mobility impairment, visual impairment and long-term health condition)*

- Effective Direct Payments support provided participants with flexible support from consistent care staff, meeting their needs effectively and enhancing quality of life. Participants found this to be better than other forms of care but some did not want Direct Payments because of the perceived administrative burden.
- Some participants felt they did not get enough social care support, particularly to get out and about and participate in social activity, but also with help around the house
- Many participants relied on friends and family for support with various aspects of their life including personal care, in some cases resulting in inconsistent and unreliable support, and negatively affecting participants' independence, mental health and relationships with others.
- Some participants felt happy where they did not rely on social services support.
- Participants with mental health conditions felt that low levels of ongoing one-to-one support could reduce their need for crisis services but few received this support.
- Equipment and adaptations allowed participants to carry out basic tasks and in some cases reduced risks they faced in their own home (e.g. falls). However there were long waiting times for large adaptations.

Housing

> *I've been on the council housing list for four years and I'm still waiting, I've got the doctors letters, letters from my specialist all saying, you must give her a ground floor place because she can't manage, she is trapped. And it seems it doesn't make any*

> *difference so I'm going to try and find some bigger guns because otherwise I'll be throwing myself out the window (Female,50-65, mobility impairment & long-term health condition)*

- Many participants were happy with where they lived. However, many were still waiting to be allocated social housing after several years.
- Some participants felt the social housing allocation process did not recognise their needs, particularly where health conditions had progressed.
- Several participants were stuck in unsuitable homes where they faced barriers which prevented them getting out and about, or where they feared for their safety due to neighbourhood disputes
- The major issues for participants in private rental properties were recent increases in rental costs and cuts to housing benefit
- Where people tried to move to rental properties they experienced discrimination from landlords against benefits claimants and a lack of suitable housing.
- Participants in their own home or with secure social housing tenancies did not report feeling stress and anxiety about housing issues, in contrast to those worried about their housing security.

Transport & Environment

> *Buses are a bit of a nightmare. Although I'm not actually in a wheelchair they're just really impatient to get off and they drive off while I'm still standing so I've just given up using them. (Male, 50-65, mobility impairment & long-term health condition)*

- Many participants used the bus, with many satisfied with their experiences, but others reported bus drivers who were rude and unhelpful and did not give people time to get seated
- Participants with physical impairments reported barriers due to poor accessibility at some bus stops, malfunctioning ramps, and limited availability of wheelchair spaces on busy bus routes.
- Taxis were felt to be too costly by most participants and were inaccessible to some electric wheelchair users.
- Many participants relied heavily on private cars to get around where they faced barriers to public transport. The most significant barrier to car use was felt to be the lack of disabled parking.
- Participants walking or scooting round the city perceived certain areas to be "no go zones" due to the combination of poor dropped curbs, narrow and broken streets, and street furniture which caused obstacles for wheelchair and scooter users.

Employment and Volunteering

> *Employment and Support Allowance, for me I thought 'Oh that sounds quite good actually, that's what I want', I want some support, but this summer has all been about proving how ill I get, which has made me ill. So, you know, that's been time wasted in*

> *which I could have been trying to get back into work (Female, 20-25, mental health condition)*

- For participants who considered themselves unable to work, the most significant barriers to employment were seen to be aspects of their own health conditions or impairment, particularly where these involved pain, fatigue or fluctuating symptoms.
- Most participants aspired to having a job where they felt capable of work
- For participants who felt capable of work key barriers were a lack of availability of jobs appropriate to their needs, lack of effective support to find and retain employment, and poor provision of reasonable adjustments and in some cases discrimination by employers.
- Participants emphasised the importance of reasonable adjustments such as support workers, assistive technology and accessible working environments to enable people to access employment.
- Volunteering was also felt to be important in providing a route into employment, as well as social contact and an indirect source of emotional support

Crime and Safety

> *You get people beating up old people, something they do sometimes. They haven't started with me yet, they damaged my car but they don't hit me. (Female,50-65, mobility impairment & long-term health condition)*

- Participants reported experiencing problems with crime in areas such as Whitehawk, Central Hove and St Peter's Church, and felt at risk of violence where they perceived themselves as vulnerable.
- Some participants had experienced isolated disability hate incidents throughout the city. Several participants felt unsafe in areas of central Brighton due to groups of drinkers.
- Participants who had been involved as witnesses or victims of criminal cases were generally positive about their involvement with the police.
- Some participants with mental health conditions and participants who were deaf reported negative experiences of the police which they attributed to a lack of disability awareness.

Finances and Benefits

> *I find that most of the benefit services treat you like a criminal, and you should probably start on a dissertation before you embark on the Disability Living Allowance form (Female,25-50, mobility impairment & long-term health condition)*

- Most participants accessed some form of benefit, with most claiming Disability Living Allowance and others claiming Employment and Support Allowance and housing benefit.

- Key barriers to accessing benefit services included a lack of information on benefits entitlements, complex benefits forms and the high level of rejected applications which were later overturned.
- Advice and advocacy services were felt by participants to be important in helping them to challenge benefits decisions, although some felt mainstream services did not meet their needs
- Benefits such as Disability Living Allowance were important in enabling participants to meet extra costs related to life as a disabled person. However, increasing costs in other areas (e.g. increased rent and cuts to housing benefit) meant some participants were unable to meet these costs.
- Many participants were worried about their financial future with upcoming changes to benefits.

Cross-cutting Issues

A number of common themes were also identified by participants across different services.

- A perceived lack of accessible information and adequate signposting from service providers
- A perceived lack of disability awareness among service providers and the general public, particularly for those with invisible disabilities
- Poor availability of low-cost, effective preventative support, as resources were increasingly targeted towards people perceived to be “the most disabled” by service providers
- Poor physical accessibility across the city and poor quality streets
- The importance of involving disabled people in how services are provided to ensure they meet the needs of people who use them

Next Steps

Following the publication of this research, the Fed Centre for Independent Living and providers of public services will continue to work together to improve services and ensure findings are acted on. The Fed will continue to promote independent living for disabled people and strive to insure that disabled people are involved in future design and commissioning of public service

1 Background & Existing Data

1.1. Introduction

The Countability research project was established to address a data gap regarding the barriers faced by disabled people living in Brighton & Hove, in regards to key aspects of daily life. The impetus for this research came from the Fed Centre for Independent Living's "Get Involved!" project, a network of over 70 local disabled people which works together with local service providers to improve services and promote equality for disabled people.

At the time the "Get Involved!" project was launched in 2008, both service providers and the Fed soon realized there was a lack of up-to-date information on the needs of disabled people in the city. Local service providers were working with census data from 2001 and benefits figures to guide their priorities in regards to tackling discrimination and promoting equality for disabled people. Service providers identified there was a major gap regarding the lived experience of disabled people in the city, a better understanding of which would enable providers to tackle barriers and reduce inequality through commissioning activity. For the Fed, the research also provided an opportunity to develop a more coherent understanding of the needs of other disabled people in the city, in order to improve its representative functions.

1.1.1. The Changing Context

At the time the research project was first conceived, the local and national picture of service provision for disabled people was in many ways very positive in regards to progress towards disability equality. The 2005 revision to the Disability Discrimination Act was still relatively recent, having introduced new public sector duties and means by which service providers could be held to account for their actions to promote equality for disabled people. The funding of the Get Involved project reflected an increasing commitment among service providers towards involving disabled people in the commissioning, development and review of services.

The deteriorating financial climate changed this picture considerably, with a significant increase in pressure on service providers to cut public spending. With councils across the country tightening eligibility criteria for services, and national government proposing massive reforms to welfare such as the introduction of the Personal Independence Payment to replace Disability Living Allowance, reforms to Employment and Support Allowance, cuts to legal aid and the proposed closure of schemes such as the Independent Living Fund, the national context for disabled people is considerably less optimistic.

Locally, the context has also been one of change, both as a response to the financial climate and national changes, but also a result of significant reorganisations among local service providers. This includes changes to the PCT to prepare for wide scale NHS reforms, as well as restructuring within Brighton and Hove City Council based around the Intelligent Commissioning model. In this restructuring and repositioning of key public services, there is now a greater need to develop a strong evidence base in order to inform commissioning activities.

Within this local and national context, there is now a greater urgency among service providers to identify experiences of disabled people accessing public services, in order to inform reorganization of services and reprioritise activity in order to improve the allocation of limited resources. For Disabled Person's Organisations such as the Fed Centre for Independent living, it has become a key priority to monitor the impact of cuts and service changes on disabled people, the first stage of which is to identify the current situation. Although hailing from these somewhat different perspectives, both service providers and the Fed identified a need for reliable evidence from disabled people themselves regarding usage of public services. This shared objective led to the funding of a research project, creating a partnership between public service providers and the Fed. The University of Brighton School of Applied Social Sciences were also commissioned by the Fed to provide research expertise in the form of advice and guidance across the project.

1.2. Finalising the research design

Once the project outline was established, an informal steering group was set up to provide general strategic oversight of the project, involving service providers, service users and research consultants. This group worked to refine the research proposal and identify potential funding streams. In time, the proposal was taken to the Public Service Board of the Local Strategic Partnership who agreed to fund a 1-year project to deliver the research.

The initial approach for the research sought to recruit a team of disabled people to conduct the research as community researchers, with training and guidance in data collection and analysis. This aimed to build on the experience of the University of Brighton in facilitating community-led research, as well as building up capacity in the community and voluntary sector to conduct future research. However, in part due to the changing financial context mentioned above, it was considered necessary to scale back the ambitions of the research. While an element of community involvement remained central to the final research design, this was restricted to the use of an ad hoc reference group, and research design event aimed at community and voluntary groups.

To inform the objectives and approach of the research, the very first stage of the project comprised a review of existing data on the needs of disabled people, both locally and nationally.

1.3. Existing research – National Data

1.3.1. Experiences and Expectations of Disabled People

There have been a number of national surveys of disabled people in recent years. The 2007 research into the Experiences and Expectations of Disabled People (EEDP), conducted by the Office for Disability Issues, examined issues relating to employment, education, experiences of discrimination, health and well-being, financial well-being, transport, housing and civic participation. It gathered a wealth of data from disabled people over the age of 16, and so was heavily influenced by the older age profile of disabled people. The research reported significant barriers identified by disabled people, which limited their participation in education, community engagement and social activity. Many participants identified their impairments as a major barrier, reflecting the persistence of the medical model in shaping the way many disabled people perceive their disability. However social barriers including limited accessibility of buildings, transport and lack of money were also identified as significant factors limiting participation.

The EEDP research identified low rates of employment among disabled people who considered themselves well enough to work, and found that disabled people typically had fewer qualifications than non-disabled people despite a relatively high demand for learning opportunities. It also identified high levels of financial difficulty (experienced by one in six disabled people) and extra costs faced by disabled people in heating, transport and medical equipment and prescriptions. More positively, the research also identified lower levels of discrimination perceived by disabled people when accessing goods and services, when compared with research conducted in 2001

1.3.2. Life Opportunities Survey

The 2010 Life Opportunities Survey is an ongoing longitudinal survey comparing the barriers to participation faced by disabled and non-disabled people in areas such as work, education, social participation, transport and use of public services. The research was based ostensibly on the social model of disability, focusing on the impact of social barriers such as cost; lack of opportunities/availability; accessibility of transport; lack of help or assistance; accessibility of facilities; accessibility of information or communications; attitudes of others; and family and caring responsibilities. This research found that in relation to all areas of life examined, adults with impairments were more likely to experience seven of the eight main barriers to participation than adults without impairments. Only family and caring responsibilities posed equally significant barriers to both disabled and nondisabled people.

The Life Opportunities Survey provides useful comparative information on the experiences of disabled and nondisabled people, but has limited insights into the individual barriers faced by people with impairments. While critical in terms of benchmarking disability equality, this is of limited value to service providers seeking to improve the accessibility and inclusiveness of services. In many cases barriers to participation are impairment-related yet non-specific (i.e. respondents simply identifying a health condition or disability as a key barrier to work) which provides limited information on which to base solutions/service improvement.

1.4. Existing research – Local Data

In terms of more specific data, the Countability research team gathered available data from local service providers on service usage and experiences of disabled people. Locally, data relating to disabled people's experiences of public services was quite limited, with no consistent approach to data collection on disabled people and varying levels of cooperation received from different departments within individual service providers.

1.4.1. Reducing Inequality Review

A key piece of research regarding the needs of equality groups was the Brighton and Hove Reducing Inequality Review in 2007. However, most of the focus of this research was on neighbourhood areas, with information gathered on disabled people restricted to numbers of benefit claimants, finding that over 50% of all working age people on benefit claim as a result of incapacity. The review also identified that the city shows very high levels of mental health issues, with relative concentrations of people with mental health conditions in the most deprived areas.

1.4.2. NHS Brighton and Hove Joint Strategic Needs Assessment

Basic data on numbers of disabled people was provided in the Health and Wellbeing Joint Strategic Needs Assessment Summary 2011. This research estimated that approximately 12,200 Brighton and Hove residents aged 18-64 years have a moderate physical disability, and 3,400 have a severe physical disability. Approximately 5,700 local residents aged 18 to 64 years are estimated to have a moderate personal care disability, and 1,300 to have a severe personal care disability. In terms of specific barriers, the research found that residents with a physical disability were more likely to live in a home in disrepair and to be fuel poor. However, increasing numbers of disabled people were being helped to live at home. In terms of learning disability, it was estimated that there could be up to 5000 people in the city with a learning disability, but only 949 were recorded on GP practice registers.

1.4.3. NHS Brighton and Hove 18 Week Patient Experience Survey

This survey was conducted among 361 patients through a self-completion questionnaire to explore issues relating to waiting times and experience of accessing treatment. In general, three quarters of patients rated the care they received as excellent or good. The main differences between disabled and nondisabled people were that patients without a disability expressed less concern about their waiting time than those who have a disability, and that patients without a disability were more positive about the cleanliness of the hospital compared to those with a disability (97% versus 86%).

1.4.4. Brighton and Hove City Council Satisfaction Data (unpublished)

A request was made by the Council's Performance and Analysis team to departmental heads, asking for client satisfaction information, split by disability, as well as any comments and suggestions made by disabled respondents in relation to improving the service. However, due to inconsistencies between departmental approaches to data collection, the response was limited. Only seven service areas responded to the emailed request and only four of these areas were able to provide any information on satisfaction levels, analysed by whether the service user had a disability. In general, satisfaction levels were equal between disabled and nondisabled people, but since data provided did not identify specific departments and only certain departments chose to return data, the results were of limited value and prevented any conclusions from being drawn.

1.4.5. Brighton & Hove City Council 2011 Adult Social Care Survey (unpublished)

This survey covered a sample of respondents who were selected at random to take part because they receive care and support services that are paid for (at least in part) by Brighton & Hove Social Care & Health Services. The survey asked service users about their quality of life and their experiences of the services they receive. 890 surveys went out by post and 46.2% of people responded. 73% had a physical or sensory impairment, 12% a mental health condition and 13.5% a learning disability. 16% of the total respondents were in Residential Care, with 6% in Nursing Care. 78% of people who responded live in the community and receive a range of services including homecare, day care, direct payments and equipment.

Participants identified that services supported them to get out and about, maintain social contacts, access day services and provided assistance with activities of daily living. Common factors identified by participants which would improve their lives included getting out and about more often and having more social contact, improved transport, better communication and information from services, more assistance round the house and with bathing, and greater flexibility of formal support. Users of homecare also identified a need for more consistency of care and more communication from home care providers when carers were unable to attend.

According to the report summary, “There is some positive feedback reported; but all areas leave room for investigation & improvement. The themes that particularly stand out are the amount of control people feel they have over their lives, the amount of social contact people have and how much time people spend doing the things that they value or enjoy”.

1.4.6. Adaptations and Equipment Survey (unpublished)

The 2010 User Experience Survey of People receiving Community Equipment provided a range of information on experiences of community equipment services and also gathered data on barriers faced by equipment users in day-to-day life. The survey was completed by 800 people in Brighton and Hove, 93% of whom had a physical or sensory impairment. Survey data revealed high satisfaction levels with the provision of equipment and information given about the equipment supply process (only 2% were unhappy with the service). 95% of users also reported that the provision of equipment had improved their quality of life to some degree. In terms of barriers to quality of life among equipment users, 30-40% of users had some difficulty getting to the places in their community they wanted to access and were worried about their personal safety. 10-20% of participants felt socially isolated, had a lower standard of hygiene than they wanted, and felt they didn't have enough control over aspects of their lives. Less than 5% of people felt their home was inappropriate for their needs and that they were unable to get the meals they wanted.

1.4.7. Brighton and Hove City Council Tenant Data (unpublished)

The tenant census conducted by Brighton and Hove City Council in 2006 found 3,671 households (52.1%) had a member of their household who has a long-standing disability or infirmity and in a STATUS survey of around 3,000 tenants in 2008 58.8% of respondents indicated they had a member of the household with a limiting long term illness.

1.4.8. 2008 Place survey (unpublished)

The 2008 place survey was analysed and broken down to people under 65 with a long-standing illness, disability or infirmity that affects activity (limiting long-term illness or LLTI). Only 138 respondents fell into this category so the conclusions that could be drawn were not particularly robust, but gave a good indication of areas to pick up on for the Countability research. The data showed that when compared to other residents, people under 65 with an LLTI were less likely to be satisfied with their housing and local area, sports and leisure facilities, and with the police service. They were less likely to feel that they were treated with respect and that people of different backgrounds get on well together, and were also more likely to see antisocial behaviour as a problem and less likely to feel safe after dark. More positively, they were more likely to be satisfied with the Fire and rescue service in the city.

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In summary, the preliminary data search showed that evidence regarding opportunities available to, and barriers faced by disabled people, could be characterised as patchy and of limited practical value to service providers. However there was a general sense from the data of the types of issues which may have a disproportionate effect on disabled people, such as those relating to crime and safety, community participation (or lack thereof), access to employment and education, issues of physical access and the financial impacts of disability. Other areas considered worthy of investigation included how well services meet the needs of people with a learning disability, many of whom may be un-diagnosed, as well as the needs of the large proportion of council tenants with a disability. Many of these themes meshed well with the initial approach of the research project and were therefore easily integrated into the research design. However the limited information on specific barriers suggested that qualitative research methods could be more suitable to meet the research aims.

2 Methodology

2.1. Aims & Objectives

The overall aim of the research was to gather evidence to support service development & monitoring and to support future bids for investment in reducing inequality.

The research question was agreed by the steering group at its first meeting:

What barriers, challenges and opportunities are experienced by disabled adults, aged 18-65, who live in Brighton and Hove?

In more specific terms, the research focused on the following service areas:

Crime and community safety
Housing
Health
Social Care
Transport and the environment
Employment
Services related to community participation

Within each of these areas the research aimed to:

- Explore disabled adults' experiences of service provision in terms of access, usage and how well it meets their needs.
- Identify factors that prevent or facilitate increased independence from the point of view of disabled adults. In particular identifying individual stories about how people have gained greater independence in their lives and the impact this has on service usage and individual well-being.

It was agreed early on by the steering group that the research would focus exclusively on people of working age, aged 18 to 65. With the intention to include people with any type of impairment, whether relating to physical impairments, mental health conditions, learning or cognitive disability, it was considered that the research population was already sufficiently broad and in need of narrowing. In addition, it was felt that services provided to individuals over 65 were often significantly different from those provided to people of working age, and thus created a natural separation which could be used to create a more manageable research target.

2.2. Research Approach

As a user-led Disabled Persons Organization (DPO), the Fed Centre for Independent Living sought to conduct the Countability research project in full accordance with its own ethos and standard practices.

One way in which this has been achieved is in the role played by disabled people, community groups and organisations in influencing the design of the research. Prior to the commencement of the research, an open research design event was held, to which community groups and organisations supporting disabled people were invited from across Brighton and Hove. The invite also went out to individual and group members of the Fed itself. The design event provided the opportunity for individuals and groups to identify barriers individuals might face to participate in the research, and suggest how these could be overcome. In addition, groups shared insights into the common issues faced by their individual members accessing services, in order to identify priority areas for the research to focus on. Finally, the event was also an opportunity for the researchers to identify existing networks of disabled people where research could be promoted.

Secondly, the Fed's ethos has been important in setting the overall approach to the research. From the outset, Countability has been guided by the social model of disability, which conceptualises disability as the product of social rather than individual barriers. As such, the focus of the research has been on the barriers, challenges and opportunities shared by disabled people, rather than seeking to identify the distribution of specific conditions. This sought to move beyond the limitations of the medical model which had often implicitly guided previous research. It was recognized that the value of data on the incidence and prevalence of specific conditions can be limited due to wide variations in many conditions and inaccurate assumptions made by service providers as to the impact this can have on needs and service usage patterns.

2.2.1. Independence, Service Usage and Wellbeing

A key element of the research design for this project was to identify “how people have been able to gain greater independence in their lives and the impact this has had on service usage and well-being”. This was specifically included in order to deliver research of value to commissioners, by exploring factors that could reduce people's levels of service usage while maintaining or enhancing wellbeing.

One potential pitfall of this research aim was that the interpretation of independence can become so entwined with the issue of “service usage”, that independence becomes defined as the ability of a disabled person to manage without support from services or other people. However, such a definition runs contrary to the meaning of independence from a social model of disability perspective. Independence in a social model sense means the ability of an individual to exercise choice and control about how to live their life. In some cases greater independence may indeed mean a decreased use of services, for example provision of a personal assistant may enable people to access work, reducing their dependence on out-of-work benefits. However in other cases greater independence may require an overall increase in service usage, for example where it requires a greater provision of personal care support.

It was not the intention of this research to engage in any discussion of the rights of disabled people to live independently, which has been established in local and central government policy for several years and is enshrined in the work of the Fed. Instead, this research simply aimed to present the data which was collected regarding disabled people's usage and experiences of services, and the barriers and opportunities they face. However, it is important to note that where issues of independence are discussed, the definition used is the social model definition.

Issues of independence, service usage and well-being can often form a complex and complementary relationship. The link between independence and service usage has already been discussed. In relation to well-being, having greater choice and control in one's life (i.e. independence), can often lead to a greater sense of well-being which leads to lower levels of ill-health (either physically or mentally). Where the well-being of individuals is lower, this can in turn have an impact on service usage, for example where people are at risk of abuse or neglect, or lack regular support, this may in some cases result in a higher use of emergency or crisis services.

As these issues are relevant to all service areas and impairment groups, they will be explored throughout the report.

2.3. Method of Analysis

- 50 in-depth, semi-structured interviews
- Five focus groups, each with 4-6 people
- Two “big meetings” facilitated by Brighton and Hove Speak Out, an advocacy group representing people with learning disabilities

The methods chosen were based on extensive consultation with individual disabled people, community groups and service providers which was carried out during the first stages of the project. This involved individual meetings between the research officer and key service providers, organisations working with disabled people, as well as disabled people from the Fed’s Get Involved Group, which acted as an informal reference group for the project. In addition, the aforementioned research design event provided a one-off opportunity for interested parties to influence the choice of research methods and objectives.

Following the consultations and review of existing data, the Countability steering group opted for an in-depth, probing technique using face-to-face semistructured interviews and focus groups, in order to gather detailed information on experiences of service usage, including how barriers might be overcome and opportunities built upon. In-depth interviews were felt to be the optimal method to gather data on pathways to and from independence as they provided greater context to understand participants' individual journeys.

Focus groups were selected as a means to engage with groups who might be underrepresented in interviews due to additional barriers to participation. In particular, it was suggested during the consultation that certain equality or impairment specific groups might be more likely to participate in group activity as opposed to individual interviews, particularly where the research team could run focus groups within settings participants were comfortable with. This was felt to be particularly necessary where participants had similar access requirements, e.g. sign language translators, which they might feel uncomfortable requesting as an individual.

In order to guide the interviews and focus groups to generate data which addressed the research question, a semistructured interview guide was developed by the research team. This was complemented by a separate focus group topic guide tailored to the groups which took part. The guides can be viewed in Appendices 10 & 11 to this report. A key element of the topic guide was the need to allow participants to focus on issues of most importance to them, and determine the direction of the discussion along these lines. This approach sought to incorporate the needs of commissioners who wished to understand disabled people's priorities in regards to service provision.

In addition to people coming forward to participate in interviews, in the course of the research some unsolicited feedback around services was received by post and/or e-mail. In order to ensure data about people's experiences was not lost, these were passed on to the Fed's Get Involved Group for follow-up.

2.4. Recruitment

The research was widely publicised using a variety of media, contacts with existing community groups and through leaflets disseminated across the city. These included:

- An article in The Argus and several smaller community newsletters
- An advert in Friday Ad
- Radio interviews e.g. with juice radio
- Leaflets in community venues, health clinics and leisure facilities
- A mailout to over 4,000 blue badge-holders aged 18-65 in the city
- E-mail and phone contact with community organisations throughout the city

Given the qualitative nature of the research it was not intended to recruit a representative or controlled sample of disabled people. However efforts were made to recruit a diverse range of people, with participants required to complete a screening questionnaire to identify their suitability for the research. The screening questionnaire asked 10 basic questions relating to impairments, demographic and equality characteristics, and can be viewed in Appendix 12. Although the focus of the research was on social barriers rather than individual impairments, it was considered important that people with a range of impairments were included in the research, particularly to make findings credible to providers of impairment-specific services.

One of the questions asked in the screening questionnaire related to how participants had heard about the research. In the majority of cases, this was through the letter sent out to all blue badge holders aged 18-65 in the city. As such, the majority of participants who contacted the research team were blue badge holders and therefore had a physical impairment. This meant that in order to ensure a diverse range of participants, many participants who came forward were not invited to take part in an in-depth interview.

Of the 103 participants that made contact with the research team, 50 were recruited to take part in an in-depth interview.

The recruitment strategy was based on meeting targets to include the following groups, to varying degrees of success:

- Disabled people living in areas identified as within the 10% most deprived areas (five people - target achieved)
- People aged 18-30 (five people - only two were recruited)
- People with a learning disability (five people - only four were recruited)
- People with a physical impairment (five people - target achieved)
- People with a mental health condition (five people - target achieved)
- People with a long-term health condition (five people - target achieved)

Beyond these 30 designated interview slots, 20 additional slots were allocated on a first-come, first served basis. In the final two weeks of the research period, unfilled target slots were opened up to any participants, in order to ensure 50 interviews were completed.

Using this targeted approach to recruitment, a mixed range of participants were recruited for the research, from a range of different backgrounds and with varied impairments, which can be seen in Chapter 3 of the report.

2.4.1. Targeted research

It was recognised by the research team and the reference group for the research that certain groups of disabled people could face additional barriers to taking part in this research. These included barriers to accessing information about the research, as well as to contacting the research team. For some groups (i.e. people who were deaf/hearing-impaired and people with mental health conditions) it was felt that individuals would feel more confident taking part where research was run in conjunction with existing community groups. To address this, the team used a tailored approach to research with these groups as follows:

2.4.1.1. Learning Disability

Prior to commencing the main data collection period, 2 “big meetings” were facilitated by Brighton and Hove Speak Out on health, work and leisure. These meetings were attended by 15-20 representatives with learning disabilities from the 5 self advocacy groups facilitated by Speak Out, and offered an opportunity for the research team to gather preliminary data about experiences of participants with public services. This data informed the subsequent research with people with learning disabilities.

Four participants with a learning disability took part in one-to-one interviews, three of whom were supported by a Brighton and Hove Speak Out advocate. A focus group was also held at City College for young adults with a learning disability 18-25. This was attended by seven participants.

2.4.1.2. Mental Health

Two focus groups were facilitated by Mind aimed specifically at users of mental health services. These were attended by a total of 10 participants.

2.4.1.3. Deaf/hearing impairments

One focus group was facilitated by a sign language translator from the Sussex Deaf Association aimed specifically at people who are deaf/hearing impaired. This was attended by seven participants

2.5. Ethical Considerations

As part of the research process all participants were given an information sheet outlining the purpose of the research and how their data would be used. Participants were also required to sign a consent form before participating in the project. Information sheets and consent forms can be seen in Appendices 13 & 14.

The ethical concerns raised by this project were discussed from the early stages by the Research Officer and consultants from the University of Brighton. A key issue to emerge related to participants’ capacity to consent, particularly for participants with a learning disability or severe cognitive impairment. To address this, the research team worked with Brighton and Hove Speak Out, an organisation with extensive experience of working in an advocacy role with individuals with a learning disability. Care was taken to select participants with the capacity to consent from existing groups facilitated by Speak Out. Consent forms and information sheets were produced in easy read format and time taken to ensure participants were fully aware of the nature of the research and their involvement.

Another area where the issue of consent emerged related to families and carers of disabled people who lacked capacity to consent. Some family members contacted the research team to get involved in the research on the behalf of the disabled person. However, the researchers chose to focus exclusively on capturing experiences of disabled people themselves rather than the perspectives of carers, due to the complex relationship that can exist between carers and disabled person which might influence the validity of data. Researchers instead made any adjustments which could be made to allow disabled people to take part by themselves (in some cases through the use of an independent advocate, in one case through a text-based interview).

The other main issue that arose in the particular context of this project, but which is common to research of this type, concerned participants who become distressed as a result of taking part in the research. To deal with this possibility the research team were briefed on appropriate signposting procedures and provided with information which could support participants post-interview.

2.6. Research Limitations

As with any piece of research, limitations can be identified in the approach taken by the Countability project, which determine how well the findings reflect the experiences of certain groups of disabled people.

The approach taken to categorising participants, for example, whereby participants self-identified their impairments, made it more difficult in some cases to distinguish the experiences of these groups. There was some confusion among participants regarding which category their impairment fell into, particularly when attempting to distinguish between long-term health conditions and physical impairments. As a result, the analysis of data was sometimes limited when attempting to draw out common themes according to these less distinctive impairment groupings

It was recognised that the decision to incorporate a whole spectrum of impairments naturally limited the depth of investigation we were able to achieve with any given group. However, it was felt that the research provided a rare opportunity to gather data on disabled people, and any restriction on scope of research could have a detrimental effect on service providers' understanding of people in excluded impairment groupings. It was considered a broader approach would allow providers to identify further targeted research in the future, should evidence suggest this might be worthwhile.

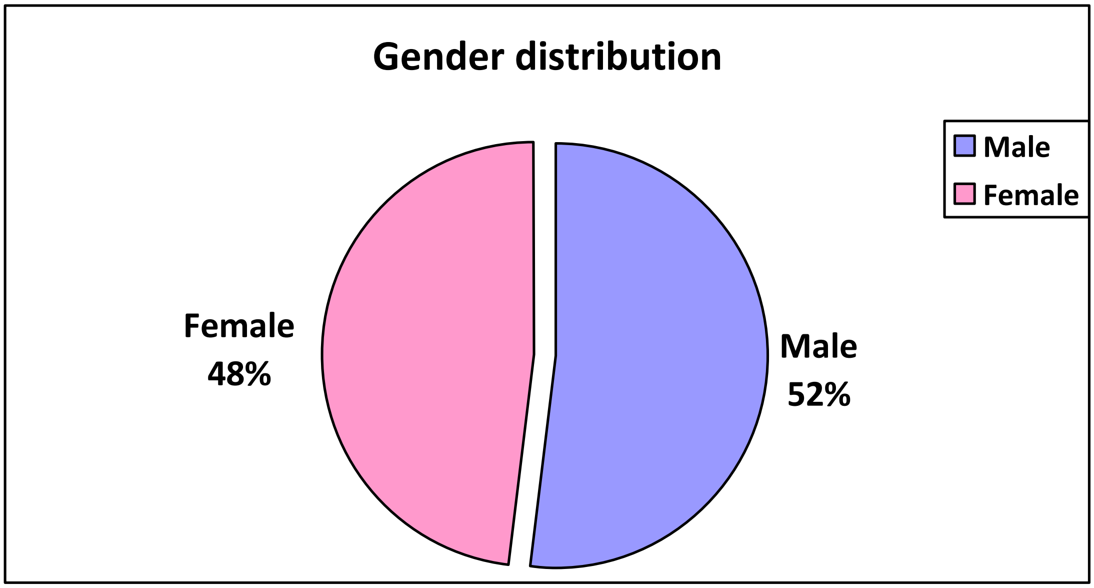
Another limitation in the research design was the approach taken to people with a learning disability. In particular, the fact that interviews were one-off interactions which typically lasted only an hour, meant that responses from participants with a learning disability could not be effectively explored. Often questions put to participants with a learning disability received short answers with little detail, and some participants appeared reluctant to discuss problems they had experienced, particularly in relation to their home environment and interactions with staff. On speaking with staff who assisted with facilitation of these groups, it was felt that obtaining more detailed and informative data required lengthier interactions with participants over several visits, in order to build up trust and confidence of participants to talk with the interviewer. As such interaction was beyond the scope of this project, it was felt that instead greater use could be made of data already collected by Brighton and Hove Speak Out to identify experiences of people with learning disabilities. A report was commissioned on this data which is included as an appendix to this report.

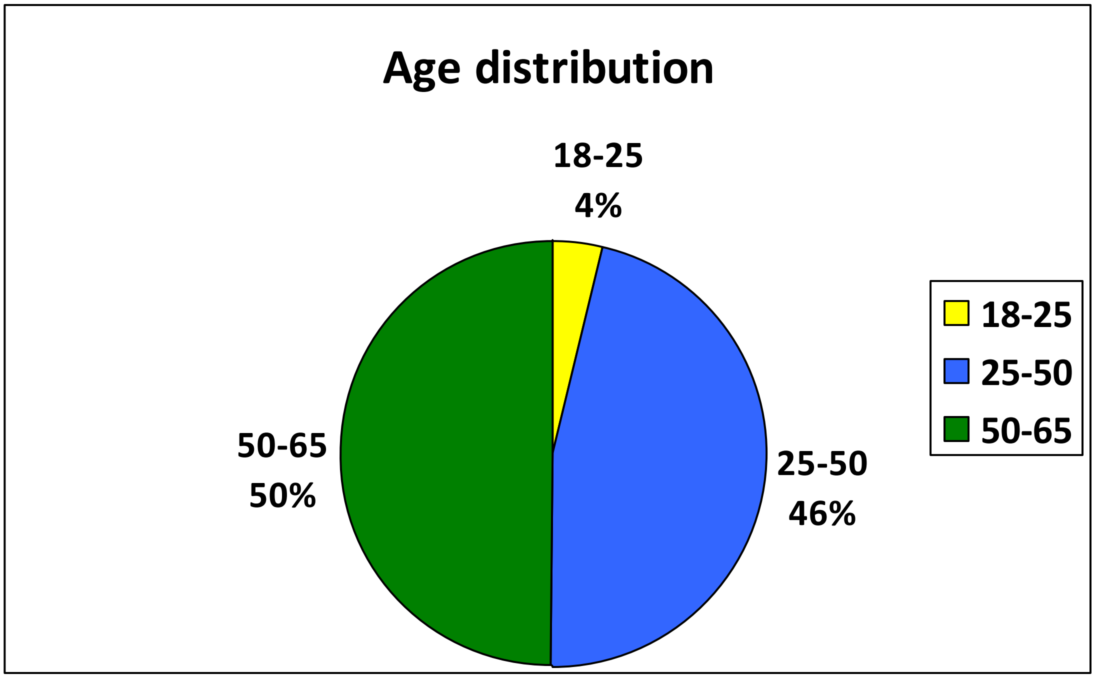
Due to the decision to focus on the perspectives of disabled people rather than families or carers, another limitation of the research is that it does not effectively capture the perspectives of disabled people who lacked capacity to consent. In this research, therefore, we can only report and comment on disabled people's own descriptions of their perceived experiences, where they were able to express themselves and make an active decision to participate.

Chapter 3 of this report looks at the characteristics of research participants in more detail, and identifies specific gaps in terms of impairment, age and equality characteristics

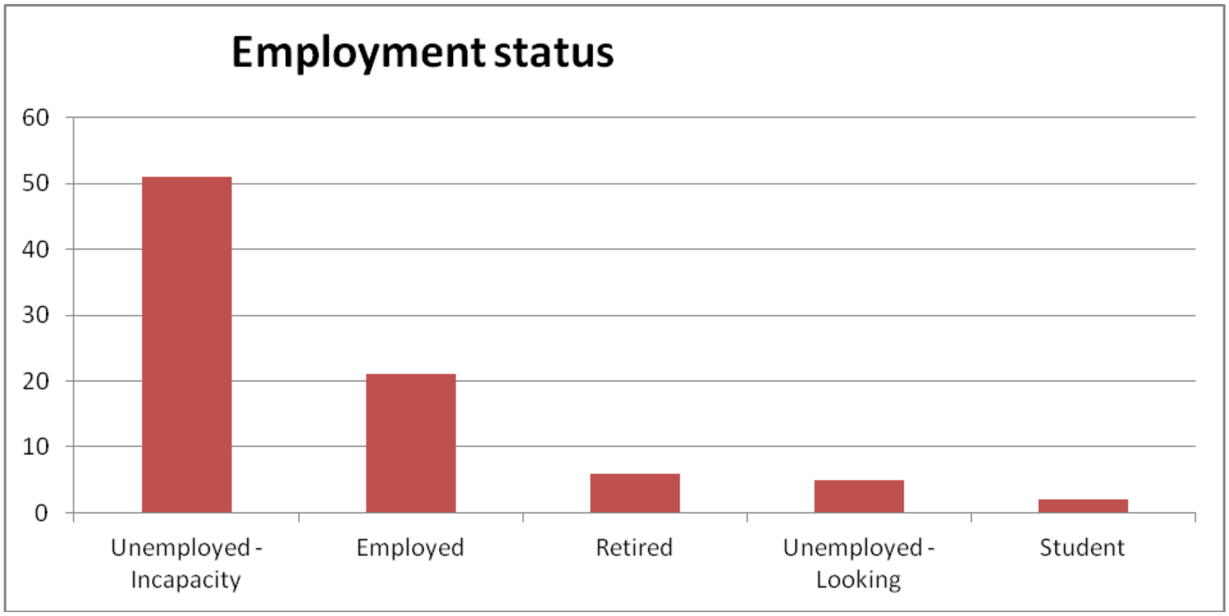
3 Participant Characteristics

A basic demographic breakdown of all participants (50 interviewees and 34 focus group participants) is provided below:





Participants were split 48% (40 participants) female to 52% (44 participants) male. Three participants (4%) were aged 18 to 25, 39 participants (46%) were aged 25 to 50, and 42 participants (50%) were aged 50 to 65.



Another basic demographic question asked related to employment status. 51 participants were unemployed due to incapacity, 5 were unemployed but looking for work, 6 participants had taken early retirement on the grounds of disability/incapacity, 21 participants were employed in a full-time or part-time capacity, and 2 were in full-time higher education.

3.1. Impairment Groupings used in this report:

It is recognised that many different categories and subcategories can be used to distinguish disabled people, and this applies equally to the research participants. However, efforts have been made to identify the most significant distinctions, based on the types of barriers and opportunities that participants identified. These distinctions tend to be of varying importance depending on the subject area being discussed, and have only been referenced where differences have emerged.

The following non-exclusive categories are used at various stages in this report. Participants often fell into more than one group.

Mobility impairments
This group includes participants with an impairment which reduces mobility. Participants in this group could use wheelchairs and scooters to varying degrees, with some participants not using them at all.

Visual impairments
This group includes participants with partial or limited vision, and those who were completely blind. Participants in this group used a range of access aids including white canes, guide dogs and personal assistants.

Mental health impairments
This group includes participants with a mental health condition such as bipolar, depression and social anxiety conditions.

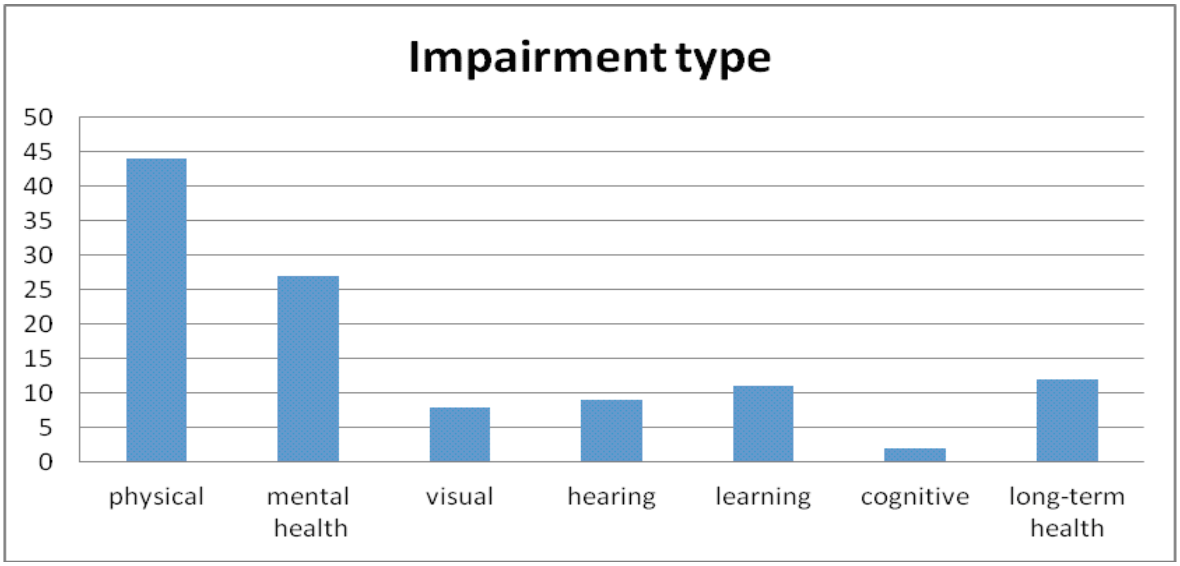
Cognitive and behavioural impairments
This group includes participants with cognitive impairments such as dyslexia, and also autistic spectrum conditions.

Deaf/hearing-impaired
This group includes participants who identified as deaf or hearing-impaired, including participants who had been deaf from birth and those who had developed impairments later in life. Participants used a range of communication methods including lip reading and sign language.

Learning disability
This group includes participants who identified as having a learning disability

Long-term health condition
This group includes participants who identified as having a long-term health condition, such as COPD, Asthma, Diabetes and a wide range of other conditions.

Distribution of impairments among participants:



Participants identified as having a wide range of impairments, with several participants having multiple impairments. 44 participants identified as having a physical impairment, 27 participants identified as having a mental health impairment, 8 participants had a visual impairment, 9 had a hearing impairment, 11 had a learning disability, 2 had a cognitive impairment, and 12 had a long-term health condition.

3.2. Categorising Participants: A note of caution

As noted previously, this report is based on the social model of disability, which focuses on social barriers to equality for disabled people as opposed to individual impairments of participants. There is a risk that categorising issues of service usage according to the impairments of participants focuses too much on impairments and further institutionalises the medical model, by casting impairment as the locus of the problem.

However, it is also recognised that services are often organised along impairment-specific lines and examining themes raised by individuals from different impairment groupings can enable a targeted response by commissioners. It was felt that if done cautiously, such an approach could both be useful for service providers and also build on the strengths of the social model.

The social model of disability does not state that all disabled people are the same, but rather that the barriers to participating in society stem from society itself rather than the impairment. It still allows for the fact that, for example, people with physical impairments are more likely to face social barriers to access than people with mental health problems. This is not because of any inherent functional ability of people with physical impairments, but because access barriers to people with physical impairments (e.g. stairs) are more prevalent in society than other access barriers.

Although this may be a subtle difference, the focus on correlation rather than causation has important implications for how service providers can respond most effectively. For example, the correlation between physical impairment and access barriers does not mean that everyone with a physical impairment will face these issues, or that no one with a mental health condition will face them. By recognizing these similarities and differences both within and across impairment groups, and the need to explore them in more detail, it is possible to develop a more sophisticated approach to the provision of services to disabled people.

In this research, many opportunities and barriers are shared between participants from different impairment groups. In addition, many participants also fall within several impairment groups, particularly those with both physical and mental health impairments. Nevertheless, in relation to their experiences of services, participants from some impairment groups were more likely to identify certain barriers than people from other impairment groups.

In each of the detailed analyses, common issues for all participants are explored first, before proceeding to explore differences between participants with different impairments where these emerged.

3.3. Recruitment Gaps

Representation of equality groups in the research was mixed:

There was unfortunately considerable underrepresentation of younger disabled people, with only two interview participants aged 18-25. A focus group was planned and advertised among a range of community groups working with younger people as well as in colleges and universities, but received no interest. A key issue was the lack of existing groups for young disabled people from which to recruit participants. This suggests a more innovative and dynamic approach might be required to properly engage with younger disabled people.

While a focus group for the LGBT community was planned, the research team was unable to identify a community organisation prepared to assist with recruitment and publicity for the group. Given that representation of the LGBT community was fairly high in the one-to-one interviews, this was not considered to be a major gap in the research.

Representation of black and minority ethnic groups was somewhat more limited, with a modest 4/50 interview participants and 3/34 focus group participants who identified as BME. Two attempts were made to run a BME focus group with assistance from the Black and Minority Ethnic Community Partnership, resulting in only two participants registering, both of whom did not attend.

Another recruitment gap in this project has been participants living in residential or nursing care. Despite widespread recruitment, on reflection it was considered that particular barriers faced by this group in accessing information and arranging their own lives might have inhibited their participation in this research. The lack of targeted recruitment of this group thus meant they were not well represented in the research beyond 2 participants with a learning disability.

Another important point to note is that as the recruitment methods were based on self-selection, this was more likely to exclude participants in periods of crisis. Participants we spoke to were often at stages of their lives where they had adapted to their impairments, which could have a consequent impact on how they characterised their lives and experiences. As one participant commented:

> *I'm in a position now where I probably wouldn't have done this interview two months ago because I'm still getting back into life but now everything's ok and that's why I'm here (Male,25-50, mental health condition)*

Although the research is not intended to provide a representative picture of disabled people, this factor serves as a useful reminder that experiences may not fully capture current information from people in crisis.

*

In summary, the spread of participants in the research is considered to be fairly diverse, and includes most of the major impairment groupings. However, some key gaps remain despite extensive efforts at recruitment. As this is qualitative research which does not seek to be representative of all disabled people in the city, caution should be taken in interpreting research results in relation to any group of disabled people. However particular caution needs to be exercised in relation to any findings relating to young or BME disabled people, and those in residential or nursing care.

4 Findings

4.1. Structure of the report

Detailed reports of the information gathered from participants in relation to major areas of public service provision are included in this report in Appendices 1-8. These individual reports include in-depth quotes from participants relating to their experiences of services. Appendix 9 examines data gathered by Brighton & Hove Speak Out on experiences of services of people with a learning disability.

This findings section attempts to summarise the key themes emerging from the data in each subject area. This is followed by a discussion section which explores crosscutting themes and seeks to develop learning points for service providers and the Fed.

4.2. Summary of Key Themes

4.2.1. Community Participation

4.2.1.1. Barriers and opportunities for social activity and community engagement

In terms of involvement with social activities, whether through formal or informal groups, two main patterns were evident among participants. In some cases, participants reported low levels of involvement in social activity and consequently felt very isolated, which they attributed to barriers to community participation including a lack of information about community activities available, financial limitations, or a lack of support from personal assistants to access these groups. Although these factors could impact on all participants, it was those participants not accessing education, employment or volunteering who felt most significantly affected as they had been unable to build up other social contacts.

> “I would just love something where you can get together with people… in a social setting where you can chat to people because I think that’s half the problem just feeling so isolated.”
> *(Male, 50-65, mobility impairment)*

Some participants also perceived a limited range of social activities available, which prevented them participating in the community. Participants reported a lack of variation in location and timing of events, lack of accessibility of non-disability specific groups, and condition-specific groups which were seen as outdated or in some cases not inclusive enough.

Several participants felt there was insufficient information available on community activity. Notably, participants reported accessing and responding to information in very different ways, for example in the extent to which participants used the Internet, which some felt was a social lifeline and important information tool, while others faced barriers to its use.

Conversely, other participants were far more engaged in their community, with involvement in many different groups and others with large networks of friends and family who they could engage with socially. For many of these participants involvement in social networks came from employment, volunteering and networks of identity based on health conditions, sexuality, religion or faith.

4.2.1.2. Peer support groups

In terms of the groups and organisations that participants accessed, many participants participated in peer support groups which provided them with opportunities for social contacts, information about services, and enabled them to better manage their health conditions. Peer support groups were felt to enhance participants' quality-of-life and mental health and improve their access to services they needed. Participants also used religious, sexuality and impairment-related groups, while others accessed one-to-one befriending schemes.

> “ When you talk to people that understand because they have it – straight away, it's amazing and it doesn‘t cost the council anything. ”
>
> *(Male,25-50, mental health condition)*

4.2.1.3. Impairment-specific issues

Participants with physical and visual impairments often faced significant access barriers to using community venues and therefore accessing certain community groups. This included barriers caused by a lack of physical access, as well as policies and attitudes of service providers. For participants who were deaf and hearing impaired, the lack of provision of sign language interpretation and lack of inclusion of deaf people in community groups created a barrier to participation. For participants with a mental health condition, it was felt that more encouragement of existing groups and provision of information through trusted sources could enhance opportunities for community participation, which could have a significant impact on participants’ usage of services.

Data gathered by Brighton and Hove Speak Out demonstrates that community participation is a very significant issue for people with learning disabilities, who often lack the support to participate in non-disability-specific services, as well as accessible information about events and leisure facilities. This is true both for people with mild learning disabilities and those with moderate or severe learning disabilities in larger care homes which do not support community participation beyond day centres and occasional events. This has a significant negative impact on people's quality of life and their mental health. However, there were also reports of some people with learning disabilities who were well supported to live Person-centred lives and able to access the community in the way they wanted.

4.2.2. Health

Experiences in regards to NHS health services were mixed between participants, and even despite some clearly identified problems, many were overwhelmingly positive about the importance of the NHS in managing their own health conditions.

4.2.2.1. GPs and Primary Care

In relation to accessing primary care, a key theme to emerge from the data was the barrier created for some disabled people by inflexible appointment booking processes, which required people to ring or visit the surgery early in the morning. Participants also reported mixed experiences of the care they received from GPs. Factors of importance to participants in whether they characterised their experiences of GPs as positive or negative included the care and time taken by GPs when seeing patients, their general bedside manner, their willingness to proactively treat problems, and the extent to which they involved the patient in treatment decisions. The level of continuity of care was also an important factor, with participants who were able to build up a personal relationship with their GP generally more satisfied than those who saw many different GPs in larger practices. Some participants had particularly negative experiences of GPs and experienced barriers from practice staff to changing GPs.

> “ My surgery is brilliant. All the staff know me, I fall asleep sometimes waiting for my doctor because she takes so long, because when you get there she doesn’t chuck you out, she does find things out for me… ”
>
> *(Female,25-50, mobility impairment & mental health condition)*

4.2.2.2. Inpatient Services

Inpatient services at the Royal Sussex and Princess Royal hospitals received considerable negative feedback from participants. Participants who had been admitted to or were visiting wards perceived poor standards of care from nursing staff. This was attributed by participants to a lack of continuity of care due to high numbers of agency nursing staff, and the lack of adequate personal care provided by nursing staff with toileting and feeding, which they felt compromised patient dignity. Participants also reported problems with availability of beds and knowledge among A&E staff of rare conditions, but one perceived improvements in waiting times for A&E consultations. Participants who had experienced hospital stays on specialist wards were far more positive about their experiences, with one ward being particularly commended for demonstrating a high standard of care and working with a health charity to enhance the support provided to patients. Specialist units also received positive reports from participants.

4.2.2.3. Outpatients & Community Services

Participants had generally positive experiences of accessing outpatients and community services. A major concern for participants using these services were the long waiting times for appointments. A key factor in the quality of participants' experiences was the extent to which clinics were able to provide flexible and tailored treatment which took into account participants' impairments. Some services performed well in this regard while others were felt to demonstrate a lack of disability awareness. Participants emphasised the importance of specialist nursing teams and condition-specific nurses who provided specialist knowledge and advice which enabled participants to better manage their impairments or health conditions and prevented hospital admissions. However, concerns were raised over the continuity of this support.

> “ There's a general take drugs and get on with it attitude and you need to push for the counseling ”
> *(Female, 25-50, mental health condition)*

4.2.2.4. Mental Health Services

Participants accessing mental health services were overall very positive about counselling services they had accessed, but expressed concerns with the limited availability of these services and what was seen as the tendency of GPs to rely on medication rather than talking therapies. Participants also felt there was inadequate support to prevent people reaching periods of crisis, and found that more one-to-one support would be helpful in this regard. Some participants made use of educational and alternative therapies which they found beneficial in promoting good mental health. Participants using multiple mental health services also reported poor coordination between services and felt that the division between crisis, recovery and transition services could often be confusing and was undermined by poor handover procedures and long waiting times. Many participants with a mental health condition also felt that mental health professionals did not adequately involve them in treatment.

4.2.2.5. Cross-cutting health issues

Participants also identified issues which cut across multiple health services, including poor provision of information on treatments and support available, and difficulties with funding for specialist treatment.

4.2.2.6. Impairment-specific issues

Participants also identified certain impairment specific barriers. Participants with physical impairments experienced problems travelling to and accessing health service buildings, but stressed the importance of hospital transport which in some cases improved participants' overall experience of treatment. Participants who were deaf or hearing impaired experienced particular problems with communication across health services, including lack of sign language interpreters when needed and limited understanding of participants' communication needs by health professionals.

Issues raised in regards to health in the work done by Brighton and Hove Speak Out include a lack of involvement of people with learning disabilities in their own health care, and a lack of awareness of accessible health tools. Many people with learning disabilities expressed fears of accessing health services and have limited awareness of how to maintain a healthy lifestyle. Some people did however have more positive experiences of accessing health professionals and understood what was going on during their visits.

4.2.3. Social Care

Participants in the research accessed support with aspects of daily living from a wide range of formal and informal sources.

4.2.3.1. Direct Payments

Several participants were users of Direct Payments, and spoke positively about its importance in improving the level of choice and control they have over their lives, and enabling them to participate equally in society, with a consequent improvement in their mental health. Direct Payments were felt to meet participants needs better than other forms of care due to greater flexibility and consistency of carers. The main criticism related to Direct Payments were that some participants felt there were insufficient hours of support to enable them to participate in social and community activity.

> “I have carers provided to me through the Council, through Social Services…I have PAs with me twenty-four hours a day. I employ them myself through Direct Payments. It works really well.”
>
> *(Female,25-50, mobility impairment, visual impairment and long-term health condition)*

Participants on the Direct Payments scheme felt that support for recruiting and employing PAs was good and long term users of the scheme felt it had improved in recent years. Some participants experienced problems being signposted to the Direct Payments scheme in the first place, and one had a particularly negative experience of accessing sufficient support for 24-hour care using the scheme.

4.2.3.2. Other formal sources of care

Some participants chose to use other formal sources of care. In these cases, participants had avoided Direct Payments due to concerns with the amount of administration involved and felt that the amount of support they received on Direct Payments would be lower than using other sources. Participants choosing to use care agencies or home help schemes instead of Direct Payments often experienced problems with the inflexibility of this kind of support. One participant who had been assessed as ineligible for Direct Payments had used carers in a rehabilitation role which was inappropriate to her long-term needs.

4.2.3.3. Informal sources of support

Some participants used Disability Living Allowance to pay for help around the house. However increasing costs elsewhere has impacted on the amount of support some participants can afford. Similarly, concerns over the financial costs of care had also been raised by participants in receipt of formal sources of care. Participants also received extensive support from friends, family and carers. In some cases this involved occasional help for example with shopping or heavy lifting, and in others extensive help with all tasks including personal care. Some participants were content with this type of support, while others felt it was inconsistent and unreliable and negatively impacted on their independence, dignity and relationships with carers.

> “The only thing I would say on the downside of the adaption is the length of time you have to wait for them to be done. And it seems an awful long time. Like nearly two years.”
> *(Male, 50-65, mobility impairment & long term health condition)*

4.2.3.4. Equipment & Adaptations

Equipment and adaptations were often very important in participants’ quality of life and was reported to decrease the support needs of some participants. Participants were generally happy with the advice and information provided at occupational therapy assessments although some felt that it was overly standardised and did not reflect the true range of equipment available due to budget limitations. Participants experienced long waiting times for major adaptations but smaller pieces of equipment were generally easier and quicker to obtain. Where participants had to wait, this could have a significant impact on their quality of life and increased their need for support. Participants felt that often not enough information was provided about waiting times and the adaptation process. Some participants noted increased restrictions on what adaptations and equipment could be funded, such as kitchen adaptations, while one experienced problems funding maintenance and repairs of adaptations.

4.2.3.5. Impairment-specific issues

For participants with mental health conditions, reliance on friends, family and neighbours for support often created problems due to the stigma associated with mental health conditions which prevented participants seeking support when needed. It was felt by many of these participants that support workers could play an important role in averting periods of mental health crisis.

Based on the supplementary research by Speak Out, key issues for people with a learning disability in relation to social care revolved around the limited level of support for some people to get out and about in the community, meet friends and pursue relationships. Even where people were involved in activities, they appeared to have little choice over the activities they took part in. An important issue for many people was the need for staff who were friendly, kind and fun, which enhanced their lives.

Speak Out’s work also highlighted that people with learning difficulties living in registered care homes were positive about their experiences where they had more control over domestic duties and where they had friends in the home. Some people in care homes wanted more choice over how they lived their lives including basic issues such as when they went to bed, the clothes they wore and the food they ate. People living in shared houses also found the level of choice they had was very important, e.g. choosing furniture, etc. Most people living in independent setups with some staff support were happy with the level of independence they had, but had some difficulties where there were conflicts with other neighbours or residents. People with mild learning disabilities also often had problems with a lack of support in their own homes.

4.2.4. Housing

4.2.4.1. Satisfaction with homes

Factors that influenced whether participants were satisfied with their current housing arrangements included characteristics of the area (e.g. safety, noise, busyness, local amenities), attractiveness of properties, accessibility of properties, and relationships with neighbours. The extent to which housing met participants needs was varied, with many satisfied with their accommodation while others were living in unsuitable homes and waiting for adaptations or to be allocated social housing. Several participants were stuck in unsuitable homes where they faced barriers which prevented them getting out and about, or where they feared for their safety due to neighbourhood disputes or harassment. Some participants felt that moving home was more difficult as a disabled person.

> “I can't get out. Trying to get it into their head that this property is actually totally unsuitable for me and actually dangerous for me...they just seem to think well you’ve got a house – go away.”
> *(Female, 25-50, mobility impairment)*

4.2.4.2. Social housing: waiting times, allocations and tenancy

Participants accessing or waiting for council housing had all experienced long waiting times, in some cases up to and beyond 4 years. Many participants felt that the allocation process for council housing did not adequately take into account their needs, particularly where participants' needs had changed due to progressive impairments or health conditions. Participants with mental health conditions and those with mobility impairments who were non-wheelchair users also felt that their needs were not adequately take into account. As a result, some participants had been recommended unsuitable properties, while others were trapped in their own homes while they waited on the housing list. Some participants had received or inherited permanent tenancies which reduced their anxiety regarding housing and allowed them to continue living with family carers, reducing their dependence on external sources of care.

4.2.4.3. Emergency housing

A participant accessing emergency housing found his immediate needs were met but permanent housing did not take into account his mental health needs, forcing him to move abroad to live with family until his health improved.

4.2.4.4. Shared ownership

One participant had experienced considerable difficulties making adaptations to a shared ownership flat, and found it was poorly served for disabled access relative to Council owned properties.

4.2.4.5. Private rentals

Participants who were privately renting from landlords have experienced problems due to rent increases and cuts to housing benefit, but faced barriers to moving to cheaper properties due to their support or access needs. Many participants also found it difficult to find rental properties due to discrimination from landlords towards benefit claimants.

> “They don’t seem to look after these properties that well…we’re a forgotten area as far as the council are concerned, everywhere else they’ve got new doors and everything else done… I’ve been waiting for a new front door for the past three years. I’ve got a gap an inch and a half wide top and bottom”
>
> *(Male,50-65, mobility impairment & long-term health condition).*

4.2.4.6. Housing services

Participants living in council housing often felt that properties were poorly maintained and were waiting on basic improvements. Participants accessing services from the Council in relation to housing benefit and residential disabled parking had mixed reviews of the service they received, with some participants being subject to administrative errors and bureaucratic delays which had a negative impact on their quality of life. Others spoke positively about supportive housing staff.

4.2.4.7. Learning Disability Issues

Based on Countability and data gathered by Speak Out, people with learning difficulties reported facing barriers to moving home due to the complexity of the allocation process for social housing, and in some cases lack of understanding from housing staff.

4.2.5. Transport & Environment

Participants used a variety of modes of transport, each presenting its own barriers and opportunities to getting around the city.

4.2.5.1. Buses

Participants using buses noted the positive trend of improvements in the accessibility of buses in recent years. Most participants felt that buses served central areas well although it was felt that some routes required too many changes e.g. from Brighton to Hove polyclinic, and that getting across the city took too long. In more peripheral areas of the city participants experienced longer waiting times and inconsistent bus services which often meant buses were too crowded to use. Many participants felt that bus drivers were sometimes rude and unhelpful to people with access needs and remembered these experiences the most. Participants stressed the importance of concessionary schemes such as the disabled bus pass in giving them more opportunities to get out and about, although it was felt that the lack of concessions for carer escorts and limited times when bus passes could be used were too restrictive.

> “Buses are a bit of a nightmare. Although I’m not actually in a wheelchair they’re just really impatient to get off and they drive off while I’m still standing so I’ve just given up using them.”
> *(Male, 50-65, mobility impairment & long-term health condition)*

Many participants reported problems with bus drivers driving away from bus stops before people were seated which prevented some participants from using buses altogether and in two cases resulted in participants being taken to the hospital. Participants with invisible disabilities often experienced attitudinal barriers from fellow passengers who objected to their use of priority seats, in some cases verbally abusing the participants. Participants with visual impairments faced barriers due to problems identifying bus numbers at busy bus stops.

Several participants were unable to use buses due to problems walking to bus stops and transferring to other buses mid-journey, managing with crowds, and fitting larger wheelchairs and scooters onto the bus. Participants with physical or mobility impairments faced particular barriers to using buses, including poor accessibility at some bus stops, malfunctioning ramps, and limited availability of wheelchair spaces on busy bus routes. However some participants felt more buses now had functioning ramps. Others spoke positively of the opportunity provided by the bus company for "test-runs" for individuals worried about using buses, which helped them to gain confidence.

4.2.5.2. Taxis

Most participants were satisfied with taxi services where they had used them. The main barrier to participants using taxis was the cost. Some participants received taxi vouchers but felt these did not go far enough. Participants who were powered wheelchair users experienced problems accessing taxis due to steep ramps and insufficient space, although one spoke positively of the new rear-entry style vehicles which provided better access and security for wheelchair users. Participants who used guide dogs felt there had been increased awareness among taxi drivers of legal duties to take guide dogs but that some taxi drivers were still reluctant to take them.

4.2.5.3. Cars

Many participants relied extensively on private cars to get around, which were critical where participants faced barriers to other means of transport. In several cases these cars were obtained through the motability scheme, either for the participants themselves or their carers to drive. The majority of participants also had disabled parking badges which were felt to be essential to make the car a viable option for travel. The largest barrier to using private cars was the lack of disabled parking, which participants attributed to both insufficient spaces and disabled parking badge abuse.

> “ The main difficulties I find are these dropped kerbs…there’s one right at the end of your road...it goes down and up steeply, and my wheels spin ‘cause they can’t get a grip. And there’s lots of those around Brighton ”
> *(Male, 50-65, mobility impairment & long term health condition)*

4.2.5.4. Walking/scooting

Participants with mobility and visual impairments faced some barriers to getting around the city on foot or wheelchair/scooter. Many wheelchair and scooter users experienced problems due to the poor quality of streets, which could be cracked and uneven, and dropped curbs which could be either absent or too steep. In some cases, these barriers caused inconvenience for participants getting around, but in other cases caused participants pain and put them at risk of falling into busy roads. Other barriers to getting around on foot or wheelchair/scooter included the placement of street furniture such as advertising boards, and vehicles parked on pavements. Several participants also avoided walking round the city in central areas because of crowds.

4.2.5.5. Trains

Several participants used train services to travel out of the city, and made use of assisted travel schemes for assistance with boarding and disembarking trains. In some cases this service worked well while in other cases participants did not receive the assistance they had requested and were unable to disembark at the correct station.

4.2.6. Employment & Volunteering

4.2.6.1. Working status of participants

Participants who were employed tended to have long-term impairments or health conditions they had had for some time or conditions which were now being managed with medication. Participants who identified as unemployed and unable to work due to incapacity typically had conditions which caused pain and fatigue, or fluctuated on a day-to-day basis. Some participants in both groups held volunteering posts although those with fluctuating conditions tended to volunteer only on an ad hoc basis or from home.

4.2.6.2. Significance of work/volunteering

Most participants saw employment as an ideal to which they aspired if they felt capable to work. Participants also emphasised the importance of volunteering for providing a route into employment and a source of employment opportunities, as well as its importance in providing social contact and indirect emotional support which could help them to manage health conditions and avoid depression.

4.2.6.3. Barriers to accessing employment

Most participants not in employment saw their impairments and health conditions to be the main factor which prevented them from working, particularly where these caused pain, fatigue and fluctuating symptoms. Participants felt that employers would not want to employ them where their conditions were unpredictable. Some participants seeking work felt that the benefits process did not provide sufficient support for a gradual return to work and this could sometimes act as a disincentive to seeking employment. Many participants simply felt the main barrier to employment were the lack of suitable jobs available in the current financial climate.

4.2.6.4. Support needed to help people work

When asked what support was needed to help people work where they wanted to work, participants emphasised the need for effective support to help find employment, including advice on self employment where appropriate, and for this support to continue once they were employed to support them in remaining in employment. It was felt that effective return to work and occupational health programmes could be an important tool to help participants remain in employment where they became ill. Some participants felt that greater availability of volunteer and job opportunities requiring low hours (i.e. less than five hours a week) would also enable them to access employment. Many participants felt that reasonable adjustments such as support workers, assistive technology, support to make working environments accessible, differential treatment of disability related sick days and other adjustments were important in making employment accessible.

> “I don’t want to be on these benefits, I want to get back to work and I’d like to just talk to somebody who has an understanding of the particular issues rather than just going to a job centre, somebody with specific knowledge to help and support.”
> *(Female, 25-50, mental health condition)*

4.2.6.5. Bad practice of employers

Several participants had experienced bad practice from employers which had created a barrier to accessing or retaining employment. In some cases participants had lost employment when employers found out they had an impairment or mental health condition. In other cases employers did not provide reasonable adjustments or did not consult with the participant resulting in inappropriate adjustments being made.

4.2.6.6. Learning Disability Issues

Many people with learning disabilities expressed a desire to do some work, typically 4 hours a day, 2-3 days per week. However it was felt there was limited choice of job opportunities and in some cases a lack of support to find an appropriate job. This was particularly the case for people with a mild learning disability who had no support from social services and relied on general employment support services which people felt did not give them the kind of support which was needed.

4.2.7. Crime & Safety

4.2.7.1. Perceptions/experiences of crime and safety

For some participants, perceptions of safety were more to do with personal feelings of vulnerability than aspects of the area itself. In general, however, perceptions of safety typically depended on whether participants had witnessed or experienced crime. Most participants felt safe in the area in which they lived with several perceiving improvements in recent years.

For some participants, there were real safety concerns about the area in which they lived, with some participants having been the victim of crime, particularly vandalism.

Areas of particular concern were parts of Whitehawk and areas around St Peter's Church. Some participants also had experienced problems with drinkers in central Brighton and Hove, with several participants choosing to avoid the centre of Brighton at weekends due to fear of groups of drunken people.

A few participants appeared to have been the subject of one-off disability hate incidents in different areas of the city. These included incidents where the participant was subject to verbal abuse and one particularly serious example where the participant was sexually abused. However in both cases these incidents were reported to the police and participants were happy with the response they had received.

> “Faith in the police services in this particular area is not particularly high. In Hove if there was a problem, the police seemed a lot more interested. It’s like they’ve just written off this area as trouble.”
> *(Male, 50-65, mobility impairment & long-term health condition)*

4.2.7.2. Police service

Participants had mixed experiences of using police services. Some participants felt that there had been an inadequate response where crime had been reported in their area. Participants who had been involved as witnesses or victims of criminal cases were generally more positive about their involvement with the police. However, two participants with mental health conditions felt they had not received an appropriate standard of care from police when in crisis. Participants who were deaf and hearing impaired felt there was inadequate communication where they had been involved with the police.

4.2.7.3. Other services

Other services participants had used included the Antisocial Behaviour Team and Fire and Rescue service, but involvement was limited and feedback generally positive.

4.2.7.4. Learning Disability Issues

Based on the work of Brighton and Hove Speak Out, people with learning disabilities did not tend to have that much experience of crime. However there were concerns about feeling safe and some people had experienced verbal abuse or disability hate incidents. People with learning disabilities had limited awareness of the Community Safety team and some were fearful of the police which suggests there were some issues regarding how easy it was for people to report problems.

4.2.8. Finances & Benefits

4.2.8.1. Benefit application/appeal process

Participants reported quite negative experiences of applying for various benefits, particularly Disability Living Allowance and Employment and Support Allowance. Participants felt that benefits forms were too complex, and where face-to-face assessments or tribunals were used, felt that these often misrepresented the participants' impairments, and were a stressful and in some cases painful process.

Many participants had successfully appealed against negative decisions on Disability Living Allowance. Participants experienced various appeal processes, with some attending a tribunal, others answering questions over the telephone, and others submitting appeal letters. There were several reports of assessments and tribunals being cancelled at the last minute, and the appeal process caused considerable stress and anxiety for participants.

> “You really really need an advocate. Which should be a floating advocate, would be like perfect for people like me. Who could just come and see me through say my ESA thing when it comes or DLA
> *(Male,50-65, mobility impairment, mental health condition & long-term health condition)*”

4.2.8.2. Support with accessing benefits

Most participants had accessed some form of support relating to benefits, which most felt was invaluable in enabling them to access the support they needed. In some cases participants accessed information on benefit entitlements from GPs or advice organisations. However several participants felt there was insufficient signposting in relation to benefits. Participants also accessed support with making applications and appeals, including assistance with form filling and in a few cases support from advocates at tribunal. Participants were generally positive about the quality of support that had been provided, although some participants felt that mainstream advice services did not always meet their access needs.

4.2.8.3. Managing money/costs

Most participants felt that they had enough money to live on, with some participants using a combination of benefits, savings and insurance/retirement schemes. However some participants were experiencing problems meeting their everyday costs due to disability related expenditure, with one participant struggling to access support due to cuts to housing benefit which required her Disability Living Allowance to be spent on rent.

4.2.8.4. Concerns for the future

Many participants were seriously concerned about their financial future, due to proposed changes to Disability Living Allowance and ongoing reviews to Employment and Support Allowance. Participants with fluctuating conditions and those causing chronic pain or fatigue were particularly concerned as it was felt that benefits assessments did not accurately represent their level of ability and could result in them being considered ineligible for support they needed. Participants in employment were also concerned that cuts to benefits and other services could mean that support was not available if they lost employment in the future.

4.2.8.5. Attitudes towards benefit claimants

Finally, some participants were concerned about deteriorating attitudes toward benefits claimants among the media and general public.

5 Discussion

This section of the report provides further analysis of the specific services explored in the Countability research, exploring the most significant issues raised by participants in terms of barriers and opportunities for participants' to use services, and their impact on participants' level of independence and quality of life. This section also draws out potential learning points from the evidence gathered by this research. Specific services are first explored before moving on to analyse crosscutting issues for all services.

5.1. Community Participation

5.1.2. Social isolation

The interviews and focus group data suggest that the issue of social isolation is particularly significant for some participants in all impairment groupings and can have a negative impact on their quality of life and mental health. This is largely supported by data gathered in the 2011 Brighton & Hove Adult Social Care survey which also found many participants wanted to get out and about more often. Participants in Countability who reported being more engaged in the community often felt reassured that support could be available from these networks if needed.

This research indicated that greater engagement in employment, volunteering or education could be particularly important in providing opportunities for participants to develop social contacts. In addition, networks of identity, including impairment-specific peer support groups, could also provide a social function which alleviated feelings of social isolation among participants. These findings suggest that greater support of community groups and activities as well as support for disabled people to participate in such networks (such as through direct payments for individuals and greater provision of reasonable adjustments within groups), could help to address issues of social isolation. The experiences of some participants suggests social isolation can have a negative impact on mental health and increase people's need for crisis services or other mental health support.

5.1.3. Choice & Control

Many of the barriers to community participation which emerged from the data (such as inaccessible venues and a limited range of times and locations for community activity) could be seen to limit the choice and control participants had over the community activity they engaged in. In addition, many participants were primarily involved in disability specific groups, suggesting that mainstream groups did not necessarily meet people's needs effectively. This suggests that improved access in existing mainstream groups and greater flexibility of disability specific groups could go some way to providing more options for community engagement which could address issues of social isolation and ensure disabled people could choose community activities which met their needs. In addition, improved information provision would also ensure existing services are utilized effectively.

5.1.4. Peer Support Groups

Peer support groups appear to play an important role for many participants both in terms of social contacts and provision of information. This suggests that greater access to peer support groups could alleviate social isolation while also enabling disabled people to better access services they need.

5.2. Health

5.2.1. Resource Availability

Some of the issues raised by participants regarding their (poor) satisfaction with services focused on issues of resource availability, such as waiting times for appointments and bed availability. This was also true of issues raised around funding specialist treatments where insufficient resources meant participants were unable to access certain health treatments.

5.2.2. Treatment style – care, involvement, disability awareness

The data also highlighted many factors which influenced participants' satisfaction of health services which were not directly tied to resource availability. For example participants appeared to be most satisfied with medical professionals where they felt fully involved in treatment decisions, and felt that medical staff took care and time to ensure patients were treated appropriately. This appeared to be the case whether referring to a GP surgery, consultants or specialist nursing teams. Greater involvement of patients was particularly important where GPs lacked the specialist knowledge which participants with rarer and long term conditions often had themselves.

Ensuring patients' needs were met often required tailoring specialist treatment to individual needs (as with participants experience of neurophysios), and in other cases (particularly among GPs) simply meant listening to the participant and acting proactively to address health problems. Where treatments did not accommodate patients needs they could not be followed effectively. Lack of involvement, care and respect for patients were reported by some participants in relation to most areas of health care, but to an even greater extent among participants accessing mental health services. Data suggests a more caring, involving approach from health professionals which listens to patients needs and adapts accordingly would be well supported and could lead to more effective outcomes.

5.2.3. Continuity of care

Participants often felt satisfied where they received care from medical professionals who knew their patients. Participants in smaller GP surgeries emphasised the benefits of this where they saw a single doctor, however consistent care could also be experienced in larger GP surgeries where doctors followed an agreed care plan. This suggests the key factor is the consistency of treatment and approach rather than the need to see the same individual health professional. In inpatient settings, continuity of care depended on nurses who knew the needs of their patients and ensured treatment could be effective. Most participants did not feel this was delivered by agency staff who could change from day to day. Consistency of care was felt to be particularly important in the quality of health outcomes that resulted from such treatment, and data suggests that approaches focused on delivering consistency could significantly improve participants' satisfaction with health services.

5.2.4. Meeting patients' access and support needs

Several participants felt their needs were simply not met adequately across health services. This could be the case where participants required personal care such as assistance with toileting, dressing and feeding, which was often not adequately met in busy inpatient facilities. Needs were also not being effectively met by some services where participants required communication support (e.g. sign language translators), or where they had access needs such as need for parking or level access. In inpatient services participants had no choice but to accept services which they felt did not adequately meet their needs. In other areas, alternative choices were available (such as using a more accessible GP surgery or hospital transport where access was limited) but these were not always convenient and did not address the fact that disabled people often did not have the same level of choice as their non-disabled counterparts. This suggests improvements may be needed throughout health services in how disabled people's needs are met.

5.2.5. Choice and control

Despite some participants seeking to choose their treatment provider, administrative barriers were often experienced to change or selection of non-default options. This could include unhelpful staff who discouraged patients from changing providers (e.g. switching GPs within a single practice), lack of availability of alternative services (e.g.

physiotherapy services), or reliance on area-specific services such as district nurses which could be tied to a specific GP surgery. Often the participant was unclear what the barrier was to exercising choice of treatment provider but felt they simply had no alternative options available. This suggests that the culture that exists among health professionals may not always be supportive and empowering for patient choice.

Similarly, patient choice was also limited by the provision of information on treatments and support available, which many participants felt was often lacking from GPs who they looked to for such information. Participants were very positive about services where information provision was considered in treatment pathways. One example of this was the specialist Digestive Diseases ward where health professionals worked in partnership with community organisations to provide information. Similarly, specialist nursing teams and condition-specific nurses also provided specialist knowledge and advice which enabled participants to better manage their impairments. From nursing teams, emergency advice was also available which in some cases was reported to prevent hospital admissions. Greater information thus appeared to enhance patient understanding and treatment outcomes.

5.2.6. Preventative approaches to mental health

A major issue for participants in mental health services was perceived to be the lack of preventative support to avoid periods of mental health crisis. Services such as counselling and talking therapies were felt to be important in this regard but several participants felt there was inadequate availability. Some participants also felt that low levels of one-to-one support could avoid costly periods of mental health crisis, and could result in a better allocation of resources. Some participants made use of educational and alternative therapies which they found beneficial in promoting good mental health. Many participants were critical of the current division of services which they felt could be confusing and did not work in a coordinated way. The data thus suggests there is considerable support for a more preventative approach focused on talking or alternative therapies and personal support.

5.2.7. Learning disability

Evidence suggests people with learning disability often lack awareness of tools available for supporting them with accessing health services and do not receive support from service providers. Providing more choice and control in this area and improving education and support for people with a learning disability would likely improve health outcomes and the effectiveness of treatment.

5.3. Social Care

5.3.1. Direct Payments

Effective Direct Payments support provided several participants with more flexible (in terms of types and timing of support) and consistent (in terms of care staff) support with day-to-day living, which many participants felt more effectively met their needs than formal sources of care and thus enhanced their quality of life. Direct Payments provided participants with choice and control over their lives as they provided flexible support which could enable participants to engage in the community. However, several participants felt they had insufficient care hours to participate equally in the community, as their Direct Payments reportedly only provided enough support for assistance with essential tasks. This suggests that while the expansion of the Direct Payments scheme can bring considerable benefits to participants, this cannot simply be achieved by increasing numbers of people accessing direct payments, but is dependent on sufficient resources within the scheme being allocated to a full range of outcomes including community participation.

In terms of how the Direct Payments scheme could be expanded, the data shows that some participants not accessing the scheme were concerned over the administrative burden of the scheme and the level of support they would receive. This suggests that efforts to promote the scheme could be most effective where they emphasised the support available to people on the scheme and provided reassurances that support would not be less than that provided from formal sources.

In addition, evidence suggests that council staff were not always seen as providing effective signposting toward Direct Payments. In some cases the process of referral appeared to participants to be unclear, with some participants aware of the Direct Payments scheme but unable to access an assessment. Where participants had accessed a social worker, experiences varied. In one case, a participant on extensive Direct Payments support reported being given inaccurate advice and felt his social worker discouraged him from accessing adequate social care support. However, this was contrasted with the experience of one participant who found her social worker to be very supportive in helping her to access Direct Payments. This suggests that further investigation of awareness of the Direct Payment scheme among general council staff and of the consistency of advice provided by social workers themselves could be useful, particularly for individuals who require 24 hour care support.

5.3.2. Unpaid carers

Where participants didn't receive formal support with daily living, they often turned to friends and family for support. In some cases participants reported being content with this support and that unpaid carers were willing to provide it. However, for other participants this kind of support was felt to be inconsistent and unreliable, and participants' dependence on others could negatively affect relationships with these unpaid carers and impact on participants' mental health. The data thus suggests that over-reliance on unpaid sources of support risks impairing the physical and mental health of disabled people and unpaid carers, and can limit the level of choice and control disabled people can exercise over their lives. This is a key area for some disabled people where independent living could be most at risk and warrants further investigation given future restrictions on social care eligibility.

5.3.3. Privately-funded care support

Participants often used their own resources to pay for support in their day-to-day lives, in some cases privately funding support using the Disability Living Allowance. In other cases participants contributed to costs of care provided by Social Services. Concerns were expressed by some participants regarding the affordability of this support, particularly given increasing costs in other areas of their lives and forthcoming national changes to benefits. This suggests that the changing financial climate over the next few years could impact on participants' ability to meet their support needs, presenting potential risks to these participants.

5.3.4. Equipment and adaptations

Another key issue to emerge was the important role that equipment and adaptations played in enhancing participants' quality-of-life. When these were provided they allowed participants to carry out basic tasks and in some cases reduced risks they faced their own home (e.g. falls).

Issues around equipment and adaptations raised in the research often focused on waiting times, and the level of information and advice available. Data suggests that any efforts to streamline the process for providing large-scale adaptations which reduced waiting times could improve participants' quality of life, independence and in some cases safety of participants and carers and would be well supported. In many cases, participants were prepared to wait but indicated simply that better information about the adaptation process and likely wait could improve their experience. This suggests that a review of information provided to ensure it is comprehensive, consistent and clear to service users could be a cost-effective way to improve service provision.   Some concerns were also expressed about perceived restrictions on what adaptations and equipment could be funded. This suggests that resource limitations were having a negative impact on participants quality of life and ability to use areas of their own homes (e.g. due to lack of accessible kitchen equipment).

5.3.5. Support for people with learning disabilities

Issues around choice and control and social isolation faced by people with a learning disability appeared to have a significant impact on quality of life and wellbeing. Support to access the community and meet friends could be done in innovative ways for groups of friends. In other areas, greater levels of choice and control (e.g. choosing when to go to bed or what clothes to wear) would cost almost nothing but could lead to significant improvements in people's quality of life.

5.4. Housing

5.4.1. Suitability of existing homes

Comments from participants regarding satisfaction with their homes showed that as would be expected, basic factors such as location, attractiveness and safety were important. As disabled people however, it was also important to participants that their support or access needs were also met. This was clearly not felt to be the case by some participants, with seemingly severe impacts on these individuals, as they reported being trapped in their own homes or fearing for their own safety.

Participants with secure tenancies or those who owned their own homes did not report experiencing the same level of anxiety about housing issues as participants with insecure housing arrangements. The evidence further suggests that concerns over housing could have a significant impact on participants' mental health. This finding, combined with the potential impact of unsuitable housing on participants' independence, highlights the importance of supporting disabled people to find suitable housing. Many participants felt more such support was needed, whether in relation to social housing, private purchase, shared ownership or rental properties.

5.4.2. Accessing social housing

For participants seeking to move into social housing, waiting times could be particularly lengthy, which is perhaps unsurprising given the high level of housing need in the city. Given the significance of the issue for disabled people, however, it is particularly important to ensure priority of need is considered adequately. The fact that some participants felt their housing needs had not been adequately assessed, particularly where conditions were progressive or for people with mental health conditions or physical impairments who did not use a wheelchair, suggests further investigation would be warranted into how individual needs are assessed. In particular, the report from one participant that a disability liaison officer was not assigned until seven months into her wait suggests the process for providing such specialised advice and support should be examined further.

5.4.3. Accessing the private rental market

Barriers in the rental market such as a lack of accessible properties to rent made it difficult for many participants to find properties in the first place, and made it harder for participants to relocate than non-disabled counterparts. As noted, discrimination by landlords against benefits claimants also made it hard for many participants to find suitable rental properties. The difficulty many participants had in relocating suggests that financial changes such as cuts to housing benefit and increasing rental costs could have a devastating impact on disabled people. Those participants already facing such issues reported using Disability Living Allowance to make up the shortfall in rent, or turned to the council for assistance with rehousing. This evidence suggests financial changes pose a potential risk of disabled people being unable to meet their support needs, and is likely to increase demand on housing services. If adequate support is not available either to allow disabled people to remain in existing properties or find suitable alternatives, levels of poverty and/or homelessness could increase.

5.4.4. Accessing shared ownership schemes

The example of one participant living in a shared ownership flat suggests that further investigation could be warranted into the support available for people in this situation, and whether financial restrictions and other criteria for support with housing and adaptations are applied fairly and avoid creating unnecessary barriers.

5.4.5. Services provided by Council Housing staff

Participants living in social housing often felt that properties were poorly maintained which put their safety at risk and were waiting on basic improvements. This somewhat supported the finding from the Joint Strategic Needs Assessment that people with physical impairments were more likely to live in a home in disrepair. This indicates a need to ensure sufficient resources are invested in basic maintenance of social housing.

In regards to other services provided by council housing staff, mixed reviews regarding staff attitude and disability awareness suggests further training could be warranted in certain areas. In regards to the provision of disabled parking, which was an issue for some participants outside their own homes, evidence suggests reserved spaces for disabled residents could improve the suitability of some housing. Similarly, the experience of one participant with extensive delays seeking a new parking space suggests that streamlining of the allocation process for residential disabled parking might also be beneficial in this regard. Given the potential increase in demand for affordable, suitable housing where people are forced to move, the removal of such administrative barriers could be a relatively cost-effective means of increasing housing suitability for some disabled people.

5.4.5. Learning disability

Evidence suggests greater support for people with learning disabilities could enhance their experiences of housing services and improve satisfaction with where they lived. In some cases this could significantly improve participants' mental health.

5.5. Transport & Environment

5.5.1. Physical Access

It is worth noting that several participants identified significant improvements in the accessibility of buses in recent years. However, the barriers faced by participants with mobility impairments indicate that access issues remain significant. Issues such as poor accessibility at some bus stops and malfunctioning ramps meant that some participants did not see buses as a reliable means of transport. This suggests that unless accessibility is delivered on a consistent, widespread scale which allows participants to travel without restriction, many participants will still be effectively excluded from bus travel. In addition, some participants with visual impairments felt that further adjustments were necessary to improve accessibility. These findings regarding accessibility indicates there is a clear need for continued investment in accessibility of buses, which involves disabled people to ensure effectiveness.

As with buses, some key access barriers remained for some participants in using taxis. Evidence suggests that not only do "wheelchair accessible vehicles" pose problems for several participants with mobility or visual impairments, but could also be inaccessible to considerable numbers of wheelchair users. This suggests that any efforts to improve the accessibility of taxi services must take a comprehensive approach to meeting the needs of disabled people which moves beyond assumptions around existing provision and involves disabled people at its core.

5.5.2. Scheduling & Availability

The experiences of some participants in relation to difficulties accessing crowded bus services indicates that busy buses can have a disproportionate impact on disabled people's ability to use bus services. In many cases, this was worse in peripheral areas or at certain times of day. Similarly, participants' experiences suggest that the scheduling of bus routes can impact on some disabled people's ability to use bus services where certain routes require changeover of buses and necessitate walking between bus stops. This suggests that in order to deliver accessible services, the scheduling of bus services should take into account the needs of disabled people by seeking where possible to avoid overcrowding and minimise walking required to access certain areas of the city.

5.5.3. Attitudes of service providers

Positive experiences reported by participants in dealings with the Brighton and Hove bus company, when raising complaints and in regards to assistance provided with "test-runs" for wheelchair or scooter users, indicates that good customer service at the company is important to participants and appears to be rated well.

Although many participants reported positive experiences of using buses, issues regarding attitudes of some bus drivers appear to be an area where there is significant room for improvement. In some cases, where bus drivers were perceived as unpleasant or rude, this had a negative impact on participants' satisfaction with their journey. In other cases, where bus drivers were felt to be unhelpful to participants with additional access for support needs (whether in relation to communication with participants with sensory impairments, or support with access features e.g. ramps), this made people feel as if they were an inconvenience which left them upset or humiliated by their journey. Finally, there were cases where bus drivers were reported to lack care and concern for passengers, particularly in ensuring they were seated before departure. Based on the reports of several participants of injuries sustained from falls in buses, this could present a very serious safety risk. These attitudinal issues which emerged repeatedly from the evidence thus suggest the need for retraining of drivers with a key focus on customer care, disability awareness and equality. For some participants it was felt that attitudinal problems from some drivers were linked to pressure to keep buses to schedule. This suggests further investigation may be needed to ensure bus scheduling does not put customer safety at risk.

Similar experiences have been reported with attitudes of taxi drivers, particularly in relation to assisting participants who were guide dog users. This suggests awareness training might also be important for this group of service providers.

5.5.4. Attitudes of public

Evidence suggests that attitudinal barriers with transport extended beyond bus drivers to include members of the public themselves. In particular, the reports of many participants with hidden impairments, suggest that there could be poor understanding among the public of how impairments can be presented, specifically in terms of the need for individuals to use priority seats on buses. A similar lack of understanding was reported in regards to people with less obvious impairments using disabled parking badges. In both examples members of the public were reported to have subjected participants to verbal abuse. Several participants felt that these issues were part of a general trend of increasingly hostile attitudes towards disabled people. This suggests that not only is greater awareness needed among the general public of hidden impairments, but sensitivity should be shown by service providers when addressing any issues such as parking abuse or benefits fraud to avoid worsening public attitudes. Such a finding might be taken further to suggest that efforts such as awareness-raising campaigns about hidden impairments might be needed to counter what is seen as a national trend of increasing hostility towards disabled people.

5.5.5. Transport costs

A key issue which crossed over several means of transport was the issue of cost, which for many participants could be a barrier to getting around the city. As evidenced, concessionary passes for buses and trains and taxi vouchers were of considerable support to some participants, yet lack of provision for carers and time restrictions meant some participants remained unable to use buses. Taxi vouchers were also felt to be inadequate in value. This suggests further investigation could be useful into the various concessionary schemes and restrictions to ensure options are available for participants on limited incomes to travel around the city. This could help to prevent increasing financial pressures leading to greater social isolation of disabled people and a consequent impact on physical and mental health.

5.5.6. Street Access

The major barriers identified in regards to travelling around the city on foot or wheelchair/scooter were poor or non-existent dropped curbs, broken streets and street furniture. Participants' experiences indicated that certain localised areas were a particular problem, such as the Lanes and areas around Kemptown. Investment in improving these areas would allow wheelchair and scooter users to travel freely around the city without risk to their safety. By focusing on specific problem areas, creating a core safe route to key locations in the city might also be achieved in a cost-effective manner. However, although some recent changes to street design were welcomed by participants, an important point to note is that other changes created additional barriers to some participants, particularly for those with visual impairments. This indicates that any future street design seeking to maximise accessibility would benefit from extensive involvement of disabled people throughout the process.

5.6. Employment and Volunteering

5.6.1. Potential to support disabled people into employment

Only 5 participants involved in the research identified themselves as unemployed and capable of working. A high proportion of participants felt that their impairments or health conditions meant they would be unsuitable for work. As noted previously, this research does not constitute a representative sample of disabled people. However it suggests that many disabled people on incapacity benefits or Employment and Support Allowance could be unable to work, and unlikely to be seen as attractive candidates to employers. This raises potential concerns should large proportions of people on Employment and Support Allowance be assessed to be fit for work in the future, which has been observed in other areas of the country where recent reviews have been conducted. In such cases, failure to find work within a year could lead to cuts in benefits which would have a devastating financial impact and a negative impact on claimants' physical and mental health.

The fact that the majority of participants saw employment as an ideal to which they aspired (if or when they felt capable to work) indicates that should suitable jobs be available which allow participants to continue to meet their health and support needs, there would be a definite willingness among participants to move into employment. However, for the large proportion of participants with pain, fatigue or fluctuating conditions, the evidence suggests there are few reasonable adjustments that can be made to enable participants to work. In some cases low-hours jobs or work from home might be appropriate, however often participants spoke of being unable to maintain any regular commitments. This suggests major challenges could exist to finding suitable jobs which would allow participants in this group to move into employment.

Often participants who were employed tended to have long-term impairments or health conditions they had had for some time or conditions which were now being managed with medication (but notably these did not tend to involve pain, fatigue or fluctuating symptoms). This suggests that experience and skills gained by these participants in managing impairments or health conditions were important in enabling them to function in employment. This suggests rehabilitation schemes could be useful in some cases to support participants to develop these skills and maintain or enter employment.

5.6.2. Volunteering opportunities

The significance many participants attached to volunteering indicate that it can play a critical role in people's lives. It can act as a route into employment and a means for some participants to develop skills for work. It also has a role to play in alleviating social isolation which was identified to be a potential issue in the research on community participation, and could thus be important in promoting physical and mental health and well-being. This highlights the importance of ensuring accessible volunteering opportunities are available in the city. However, one participant’s fears of volunteering leading to judgements being made too quickly about her capability to work suggests that benefits assessments may work against volunteering acting as a "test-drive" of employment.

5.6.3. Making employment accessible

For participants who felt capable of work but were unemployed, the fact that the main barrier to employment was seen to be the lack of suitable jobs indicates that actions to increase accessible jobs would be welcomed by participants. This might include support for employers to make employment more accessible, or greater efforts to promote jobs for disabled people.

This research provides a wealth of information of reasonable adjustments that participants felt increased the accessibility of employment where adopted by employers. However, based on some participants' reports of bad practice among employers, the provision of reasonable adjustments was felt to be inconsistent, and the participant was not always fully involved in discussing how to make their employment more accessible. This indicates further work could be warranted to improve employers' knowledge and practice of making reasonable adjustments and supporting disabled people in employment. This could be achieved through direct work with employers as well as support for disabled people themselves to understand the types of adjustments are available and their rights to request these adjustments from employers.

5.6.4. Support available to return to work

Another key area where the evidence suggests more support could be useful was in relation to support to help participants find and remain in employment. Some participants felt existing support was unhelpful and focused on proving illness as opposed to providing effective support to move into employment. In addition, it was felt by some participants that support was ended too quickly after entering employment. This suggests there are considerable areas for improvement to ensure support organisations are fully aware of issues faced by disabled people in employment, the importance of reasonable adjustments, and how to provide effective support to allow participants to maintain employment. This research indicates that further investigation of the quality of support provided and how it might be improved would be useful to address these issues.

5.7. Crime and Safety

5.7.1. Perceptions and Experiences of Crime & Safety

Participants' perceptions of safety suggests that although crime is not of concern to many participants, there are key areas which participants saw as unsafe or felt had high crime rates. Some participants living in these areas have experienced crime, others felt scared to go out at night and were often fearful that they could be targeted as they felt their impairments made them vulnerable. Other participants who did not live in areas they felt were unsafe tended to avoid these areas, such as areas of central Hove and Brighton where there were groups of drinkers.

This evidence suggests that perceived crime and safety in the city can have an important impact on disabled people in terms of where and when they choose to go out in the city. In addition, the fear expressed by participants indicates that the perceived safety of the area in which they live could also have a serious negative impact on disabled people's quality of life.

This suggests that increased efforts to improve perceived safety and tackling crime rates would be welcomed by participants in key problem areas. Where such measures improved peoples' confidence in safety this could potentially have an impact on the extent to which participants can get out and about, engage in their community, and feel satisfied with their housing (which could influence demand for alternative housing for people living in problem areas). However, the experiences of some participants suggest that certain areas are felt to have been "written off" which indicates intensive efforts might be needed to improve perceptions and address ongoing problems.

5.7.2. Disability hate incidents

Most of our participants did not report experiencing disability hate incidents, although it is still possible that incidents perceived as minor might not have been reported in interviews. The few serious experiences that were reported by participants had been dealt with to their satisfaction which is a positive finding. However, as with other findings in this research, it is important to recognise that the participants do not necessarily present a representative picture of disabled people in the city. Given the pattern of localised problems with crime and safety, it is suggested that further efforts to explore the extent of disability hate incidents in the city should focus on disabled people living in specific problem areas.

Evidence from the learning disability research suggests work may be warranted to improve awareness of reporting mechanisms for hate incidents amongst people in this impairment group.

5.7.3. Police Services

Participants' experiences of the police have tended to be positive where participants were victims or witnesses and had a visible impairment which police were aware of. However, the concerns raised both by participants who had mental health conditions and those who were deaf or hearing-impaired about the treatment they received from the police suggests further investigation could be warranted into how the police identify and treat people in these impairment groupings. The evidence for this research suggests there may be a lack of disability awareness among the police which needs to be addressed.

5.8. Finances and Benefits

5.8.1. Benefits assessments/appeals

Most participants' experiences of benefits services related to claims for Disability Living Allowance and incapacity benefit/Employment and Support Allowance, for which assessment and eligibility criteria are set nationally. Nevertheless, they do raise concerns for local services, which are likely to be placed under increasing demand should people be assessed as ineligible for support which they need. Given the high level of participants reporting having benefits decisions overturned on appeal in other areas of the country, it appears that the potential level of error could be quite high. This indicates a need for a consistent citywide approach to promoting fair and high-quality assessment criteria for benefits.

The evidence also suggests that where benefits claims are administered at the local level, it is necessary to ensure that a fair assessment process is followed within national guidelines. This applies particularly to how appeals are administered, which could cause considerable stress and anxiety for participants. In some cases this appeared to be unnecessary as appeal hearings were cancelled at the last minute in favour of a desk-based review, indicating that greater preparation could improve the experience for claimants.

5.8.2. Support to access/appeal benefits

In addition, evidence from this research suggests that support for disabled people to apply for benefits and appeal decisions perceived to be unfair, is critical to enabling people to access the support they need. This includes both support for form filling and in particular for advocacy for participants at benefits appeals/tribunals. Where this allows people to access support from national benefits they are entitled to, this is likely to decrease the financial pressure on local services.

Participants' experiences with inaccessibility of mainstream services indicate that all providers of advice and advocacy support need to be cognisant of disabled people's access and support needs. In addition, issues raised by some participants around provision of advice and signposting suggest that improvements in advice provision may be necessary among providers who may be the first contacts for disabled people (e.g. GPs, job centres).

5.8.3. Financial problems for disabled people

Among the participants in the research, a relatively small number felt they didn't have enough money to live on, although again it is worth noting that the sample was not representative. Problems which were reported appeared nevertheless to be very significant for these participants who were unable to meet basic costs or fund private support. This suggests there could be potential future impacts on these participants independence, support needs, physical and mental health and well-being which cannot be predicted. It is also clear that a far larger number of participants were concerned about their financial future as many depended on benefits to survive and were concerned that they would be assessed as ineligible despite having no other means to meet costs of living. This suggests that issues around financial resources are a potential area of future concern and should be monitored closely during the current period of welfare reform to ensure disabled people's needs continue to be met.

5.8.4. Attitudes toward benefits claimants

Reports by some participants regarding deteriorating attitudes toward benefits claimants indicates another area where monitoring is required, and continued efforts to ensure hate incidents can be reported. It also suggests that additional work may be required on countering negative perceptions of disabled people and promoting equality.

5.8.5. Learning disability

As noted above, many people with learning disabilities faced barriers to accessing and managing their own money. This indicates improved awareness and greater control over managing money would increase their level of independence, with only a negligible impact on service usage.

5.9. Cross-cutting Issues

By examining service provision as a whole, a number of themes can be identified which cut across multiple service areas.

5.9.1. Provision of accessible information

A recurring theme in the research is the lack of information provided to participants in regards to accessing services. This was reported in relation to the availability of accessible community activities in the city, availability of different health services and treatments, information on procedures for funding and fitting large-scale adaptations, and information on waiting times for social housing. In addition, many participants experienced a clear lack of appropriate signposting toward Direct Payments support and benefit entitlements.

The consequence of poor provision of information is a lack of uptake of necessary support by disabled people, which impacts on participants’ quality of life and choices they are able to make. Failure to access appropriate support when it is most needed can lead to greater use of crisis services and prevent participants taking an equal part in society. In some cases, greater clarity over waiting times and where to source private treatment or support could enable some participants to choose instead to use private services and reduce demand on public services.

In many cases, although information is available, participants evidently do not know how to access it, particularly those who have recently become disabled. In other cases, information is not provided in an accessible format - such as Easy-Read or documents accessible for visually impaired computer users (e.g. Word documents as opposed to PDFs). Participants' responses suggest information is needed both online and in traditional paper-based formats. Some participants also do not access text-based formats and need information provided from service providers they interact with on a face-to-face basis. Effective communication is also needed for participants who are deaf and hearing impaired, who may not access text based formats and require sign language interpretation.

Evidence suggests that further work is required on reviewing how all services communicate with disabled people and increase awareness of the services they provide. The Digestive Diseases ward at the County Hospital provided a good example of quality information provision to disabled people at an early stage, which appears to be a model worth further investigation.

5.9.2. Disability Awareness among service providers and the general public

Another theme to emerge across multiple services is a general lack of disability awareness among public and private service providers and members of the general public. A key area in which awareness was felt to be lacking was awareness of the full spectrum of impairments and varied needs that people in different impairment groupings might have. In some cases this translated into a lack of anticipatory reasonable adjustments among providers of non-disability specific community activities and employers, which prevented participants using these services. Poor awareness of disability, particularly invisible disabilities among the general public, also led in some cases to disability hate incidents. Participants also felt that public service providers often did not understand their support needs, particularly in relation to the allocation of social housing and benefits such as Employment and Support Allowance and particularly for those participants with mental health conditions and participants with mobility impairments who were not necessarily wheelchair users.

Awareness was also felt to be lacking in regards to the contributions that disabled people can make to society. This was felt to result in issues such as the reluctance of employers to employ disabled people and in some more extreme cases resentment of disabled people, which was felt to be exacerbated by recent media coverage of the cost of benefits and support for disabled people.

According to participants' experiences, lack of disability awareness could thus lead to incidences of disability hate, could limit the opportunities for participants to participate in the community and in employment, and could undermine the effectiveness of health treatment where participants' needs were not taken into account. In contrast, there were many examples of good practice among service providers in relation to disability awareness, where providers worked with disabled people to better meet their needs and sought to provide more personalised support. This led to more effective service provision and a better quality of life for participants. This suggests that the provision of disability awareness training to service providers throughout the city could improve experiences and effectiveness of services for disabled people

5.9.3. Availability of preventative support

Another major theme to emerge was the experiences of participants that various sources of support could not be accessed until participants were in crisis or perceived as being "the most disabled/most vulnerable". This was particularly felt to be the case in regards to the lack of preventative services, such as one-to-one support and talking therapies, which could help participants to avoid periods of mental health crisis. In relation to social care it was felt that only "the most disabled" received support, while in terms of housing it was felt that wheelchair users were prioritised over participants with severe mobility impairments who chose not to use a wheelchair but still had very limited mobility. In addition, there were several cases where participants felt service providers offered more support when they perceived participants to be in crisis or severely disabled.

Where support was only provided in periods of crisis, this could be more intense and costly than low levels of preventative support such as support workers, peer support groups, support to rent privately rather than accessing emergency housing. In addition, support targeted at the most disabled or most vulnerable is typically based on the perceptions of service providers who as noted above were perceived to lack disability awareness, meaning support might not always be targeted where it is most needed. Such an approach could also result in missed opportunities to provide low-cost support to prevent participants becoming more disabled and consequently more in need of support and services. This suggests a culture shift may be required in how support is regarded, to recognize that in many cases early provision can not only improve quality of life and independence but also save resources in the long term. Further investigation could also be warranted to explore the potential benefits of preventative support in relation to all services in the city.

5.9.4. Physical accessibility across the city

One major theme which affects all services explored in this research is the lack of accessibility throughout the city. This results from lack of adjustments made to buildings throughout the city to make them accessible, which are often more costly to provide due to the naturally hilly environment and the number of older buildings. Many community and private venues have simply not implemented reasonable adjustments while for others there are no reasonable adjustments that can be made. In many cases access is limited by insufficient provision of disabled parking.

Participants experienced problems accessing a range of services due to these accessibility issues, including community activities, health clinics (GPs and hospital where access or parking were an issue), places of employment and housing (both due to a lack of accessible housing and inaccessibility of housing services). Participants also experienced difficulty getting out and about in the city due to access barriers such as broken streets and poor dropped curbs. Poor accessibility in the city can have a significant impact on participants' level of choice and control and their ability to participate equally in society.

An important point to note in regards to accessibility in the city is that significant improvements have been made, particularly to major venues and public buildings, as well as to public transport such as buses and taxis. These improvements have had a positive impact on participants' lives and engagement in society, and demonstrate that the natural characteristics of the area and the prevalence of older buildings do not necessarily prevent accessibility improvements. Nevertheless, despite these improvements significant access barriers remain throughout the city. Experiences of some participants where access features have been removed or not improved during redevelopments also suggest that private service providers may have become complacent about their duties to provide reasonable adjustments. This suggests further work may be warranted to ensure accessibility continues to be treated as a priority and improvements continue to be made.

5.9.5. Involvement of disabled people

A final theme to emerge from the data was the importance of involving disabled people in the commissioning, delivery and review of public services. One example of this was participants who felt they were not involved in decisions on their own health treatment, which they felt led to poor health outcomes. Similarly, the involvement of disabled people in designing public services was felt by participants to be important in order to create services which effectively met the needs of disabled people. This was supported by the fact that where disabled people had not been involved in the design of services targeted specifically at disabled people, participants reported dissatisfaction with services which they did not feel effectively met their needs. Examples included day services which did not appeal to many disabled people, and the provision of "accessible" transport (e.g. wheelchair accessible taxis) which several participants were unable to access. Another area in which participants did not feel involved was in benefits decisions which they felt did not take into account their experiences.

Some participants felt that engaging and involving disabled people in service design could lead to improved services which better met disabled people's needs. Evidence suggests this could lead to improved outcomes in relation to participants' engagement in the community and overall health and well-being. Participants would also be more likely to be satisfied with services where they felt they had been heard and engaged, and less likely to challenge benefits decisions which they feel accurately represented their impairments or health conditions.

6

Concluding Remarks

The Countability research has gathered a wealth of data from participants regarding their experiences of public services and the barriers and opportunities which they face. Participants have shared many examples of both positive and negative practices which should allow service providers to identify key areas for improvement and examples of how needs of disabled people might be met most effectively.

As a non-representative sample of disabled people, it cannot be claimed that this report reflects the full range of views of disabled people in the city or that it provides an exhaustive list of all issues disabled people may identify in relation to service provision. However, the diverse range of participants interviewed for this research, from different backgrounds, different age groups and different impairment groupings, has identified many significant issues and touched on a huge range of themes, which gives an insight into the experiences of disabled people in Brighton and Hove.

The key point on which to conclude is therefore that disabled people are a particularly diverse group whose experiences and opinions cannot be captured in a few short paragraphs, or even in an extensive research report. While this research can be used as a starting point for public and private service providers seeking to improve services, it can provide no substitute for extensive and ongoing involvement of disabled people in service commissioning and design. Empowering disabled people in this way is essential to provide effective, fair and evidence-based services, and brings society one step closer to achieving full and equal participation of disabled people.

Following the publication of this research, the Fed Centre for Independent Living and providers of public services will continue to work together to improve services and ensure findings are acted on. The Fed will continue to promote independent living for disabled people and strive to ensure that disabled people are involved in future design and commissioning of public services

Concluding Remarks

7 References

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Unpublished Data

Brighton & Hove City Council 2011 Adult Social Care Survey

Brighton & Hove City Council 2010 Adaptations and Equipment Survey

Brighton and Hove City Council Tenant Data (Raw Data)

Brighton & Hove Strategic Partnership 2008 Place survey (Raw Data)

A1 Appendix 1: Community Participation

A1.1. What is community participation?

For the purposes of this research, community participation was defined as involvement participants have had with both formal and informal groups, organisations and social networks operating in the community. The research team wanted to know how involved participants were in these networks, and why, and in particular the opportunities and barriers they were presented with when engaging in community activity.

A key point of interest in this section of the report is the general benefit participants have derived from community networks, groups and organizations, in terms of social activity, provision of information about community activity and other general services. Although it may be touched upon here, data in regards to how organisations have been involved with participants in relation to specific issues such as health, housing or social care, are included in the relevant services section of the report. Information about participants' volunteering activity within these organisations can also be found in the employment and volunteering section of the report.

A1.2. Approaching the Topic

During the interviews the research team began by asking general questions about what participants got up to in a typical week and how they occupied their time. As well as employment and volunteering activities, and individual hobbies, respondents mentioned community and voluntary groups and social networks, both formal and informal.

Later in the interview, researchers returned to the following questions of community participation:

> *What kind of activities do you like to participate in when you have time available?*
> - *We want to know about any clubs, groups or organisations you are involved in*
> - *We want to know about social activities with friends, families and partners*
> - *We want to know about any Sports, leisure and hobbies you do*
> - *We also want to know about any Online groups/activities*
>
> *What kind of activities exist in your neighbourhood? Do you get involved in these? Is there anything that stops you getting involved?*
> *Is there anything you would like to do more of?*

In the varied discussions on the topic, researchers probed for further information on any challenges and barriers participants faced engaging in their community, as well as how they had become involved in any groups they regularly attended. Researchers also explored how participants felt about their level of involvement in their community in general , and in specific groups, the benefits they provided and if there were any ways in which services could be improved.

A1.3. Detailed analysis

In terms of involvement with social activities, whether through formal or informal groups, two main patterns were evident among participants. In some cases, participants reported low levels of involvement in social activity and consequently felt very isolated, which they attributed to a lack of information about community activities available, financial limitations, or a lack of support to access these groups. Conversely, other participants reported being heavily engaged in their community, with involvement in many different groups and others with large networks of friends and family who they could engage with socially.

A1.3.1. Barriers to social activity and community engagement

One participant in his 50s who had retired several years ago due to chronic pain, felt the lack of social activity was a particularly important factor in his quality of life, and was particularly keen to find a group which would help him to interact with others.

> *I would just love a little bit more where you can source help like I was saying a little bit earlier, where you can find institutions where you can get together with people who have the same problem as you – this is how we cope, how do you cope? And put everything in the melting pot really…I would just like more to be social based with other people in a social setting where you can chat to people because I think that's half the problem just feeling so isolated. Especially not working full time and your brain's not working the pain then tends to be more in the forefront rather than towards the back of your mind. (Male, 50-65, mobility impairment)*

Another participant shared this desire for groups to provide social contact but was particularly keen to find groups aimed towards people from a black and minority ethnic background like himself:

> *I'm beginning to feel a feel little bit isolated because most of my old friends have moved away from Brighton or they have gone back, or they have finished their studies, so I have to find new friends to substitute those old friends. I'm quite eager to find active ethnic minority groups, to be an active part of the society. Rather than not active and sitting inside. (Male, 25-50, mobility impairment)*

The majority of participants who expressed feelings of isolation or a desire for more social activity tended to be unemployed and not accessing education, training or volunteering, for a variety of reasons. As such, they had fewer groups to draw on for social opportunities and friendships. For one participant, this was particularly a problem since he had only been living in Brighton for a few years and didn't have many friends in the area, having moved shortly after becoming a wheelchair user:

> *I'd like to go socialising and stuff like that. I mean the trouble is, I mean it's been going on for years now. I've lost most of my friends obviously 'cause I don't go out so my social life is pretty zero, zilch. It would just be nice to just go out occasionally. It wouldn't be regularly just sort of the odd one hit. (Male, 50-65, mobility impairment & long term health condition)*

A1.3.1.2. Lack of support to engage in community activity

For one visually impaired participant, taking part in social activities was difficult due to limited hours of support from her personal assistant. She also noted how difficult it could be to find friends who she could do these activities with, in the absence of a personal assistant.

> *That [leisure and social activities] is hard as well…I would like to be able to say, ooh, I'll get up and I'll go for a bike ride. But, hey, I need someone to do a bike ride with. Or any activity because generally people have got to be my eyes… I love swimming. I'm really, really mad on swimming…the barrier that I find is being able to see the people in the pool because I've limited vision... I have got a PA that swims with me, luckily she can keep up with me…I'd like to be able to do that more often but I can never find anyone who I can swim with. As for friends, I'm quite isolated, to be honest with you. I mean, I can make friends but... we just don't share the same interests and also a lot of people just don't want to do what I want to do…I mean, you probably know yourself being disabled, of how isolating it really is and I get frustrated when I hear about non-disabled people who go out with friends and go shopping and go for meals. (Female, 25-50, visual impairment & mental health condition)*

Even where participants had more potential opportunities for social activity nearby, if these could not be accessed then feelings of social isolation could still be evident. One participant at the University of Brighton found that the lack of personal assistant support to attend social events and interact with other students outside of academic courses meant he had been unable to build up many friendships during the two years that he had been there:

> *In terms of my university life? Well as I say I don't get out that much. A lot of students don't want to talk to me because of my disability…I've not got many friends there at all and the friends that I've got are now finished and so they won't be there next year. Obviously because I can't get out on my own I can't meet people and people aren't going to meet me. (Male, 18-25, visual impairment & mental health condition)*

For some of the participants with a learning disability, the main barrier to social interaction was having support to organise and access social opportunities. For one participant, who had a severe learning disability, there did not seem to be any barrier to social interaction as she received support from a key worker to regularly meet with friends for coffee, to see her boyfriend and even in one instance to visit New York.

However, another participant who also had a severe learning impairment and lived in a large care home, expressed a clear desire for more social contacts:

> ***What would you like to be able to do?***
> *Go out and meet people.*
> ***What kind of things would you like to do with other people?***
> *Talk to them. In the coffee shops (Male, 50-65, learning disability)*

Similarly, a female participant with a mild learning disability, while more able to travel to and participate in social activity by herself, was unaware of places or opportunities where she could make friends and did not know how to find out more information. Despite having a support worker, this support was only for one hour a week and so did not provide enough time to properly address the issue:

> *Something else I was saying to my Support Worker, my brother keeps saying you need a friend but how do you make friends? You can't just go up to someone, 'Oh, do you want to be my friend?' [Laughs] You can't do that, you know, you've got to know the person, make sure that you're getting the right person and not the wrong person,you know, you just can't trust people can you.*
> ***So what did your Support Worker say when you asked that?***
> *I don't think she really knows how to do it, to get friends. I really don't know, because it needs to be like a group thing I suppose, circle. Maybe that's what Speak Out could do, come a couple of times, and then I think after a couple of times you get to know each other don't you and things like that. (Female, 50-65, learning disability)*

A1.3.2.2. Limited choices of time or location

Some of the participants who felt socially isolated were aware of social groups available to them but felt these did not meet their needs and that alternative choices were simply unavailable. For one participant, this was due to the timings of the meeting, as fatigue prevented him from participating in afternoon and evening activities:

> *There's lots of things I'd like to do. I wanted to go Shoreham Yacht Club. They've got Sailability.. I'm desperate to go there 'cause I love the water. It's like it's been too late in the day for me. It needs to be early in the morning, high tide early in the morning but it's not. It's like later so. I've been trying to go there for the last year. I haven't made it. (Male, 50-65, mobility impairment & long term health condition)*

For another participant living in Portslade, who had a mental health condition, the lack of local groups meant that in order to attend social groups she had to travel to Brighton, which meant spending considerable time on public transport, and having to organise childcare:

> *But a hindrance I do find and what puts me off attending a lot of things is a lot of events are over in Brighton and I live in Portslade, and it generally would take me two hours at least to travel in to these events, and having two children, finding out babysitting, or after a day of being at work I just don't… and I would really like to*

> *participate in more, to encourage my social connections, but I do find a huge amount is centered in Brighton. I think there's two sides to it, I can understand why people like it locally and centrally, but for me, when I'm feeling very anxious and very nervous, the thought of getting a train or a bus all the way into town, kind of making my way to somewhere that's very busy, you know, it seems too off-putting, intimidating. (Female, mental health condition)*

Conversely, one participant with a learning disability found that the location of Speak Out in Portslade caused a similar problem for her to access it, travelling from Brighton:

> *Speak Out are really, really good. They help you, they help you. You know, it's not too much trouble to help you, they're there for you. Be nice if they're not here, it's a bit out the way, because I come right from Brighton. (Female, 50-65, learning disability)*

A common barrier to participants who were working was often the timings of group events, which excluded them from many of the groups available to disabled people. This was expressed by one participant with a mobility impairment who worked long hours as a teacher:

> *I used to love swimming and I don't swim any more. The trouble is that so many of those things are on during the day. The disabled swimming that happens locally is on during the day when I'm at work. So I can't really access that. (Female, 25-50, mobility impairment & long-term health condition)*

A1.3.2.3. Restrictive criteria of existing groups

In some cases, support groups simply excluded certain people. One participant who attempted to join a support group for people with mental health problems, in order to address her feelings of social isolation, was actually turned away from the group as she had a young baby:

> *Going to the mental health centres, I was asked to leave because I had a baby in a buggy …they have a day that's for other groups but they don't have a day for women with children for example, I mean I know there's like stigmas attached to all that but it just, to be asked to leave when you go somewhere to get help because you need that support because you're feeling a bit socially excluded and you're feeling that your health visitor doesn't understand and where do you go you know, you're left with nothing. (Female, 25-50, mental health condition)*

A1.3.2.4. Suitability/appeal of existing groups

While many obstacles to participating in social groups were practical, several participants felt that while there were certain social groups which they could attend, the groups themselves did not appeal to them. These participants were keen to engage in some kind of social activity, but with no alternative options to groups they found unappealing, preferred to put up with feelings of isolation. For these participants, simply experiencing feelings of isolation did not mean they were less selective of the activities they took part in, and retained the interests and preferences that contributed to their social identity. For example, a visually impaired woman in her 30s, felt that all that was available was a single group for other visually impaired people, which did not appeal to her. Instead, she sought more access to general groups where she could meet non-disabled people who she felt were more likely to match her interests:

> *And no matter when I speak to Social Services, it boils back down to the same thing. We can't do nothing. Or there's City Synergy. And I think, I just don't want to go to City Synergy. I want to mix with other people as well.*
> ***So you said Social Services said we can't do anything. What did you mean by that?***
> *Meaning, well, that's all we can recommend to you … it's like you're banging your head against a brick wall. I do feel that they should look into groups that are for people that are at a younger age as well, other than something like City Synergy, surely there's got to be more or even more local groups within your area. (Female, 25-50, visual impairment & mental health condition)*

Another participant expressed a similar desire to avoid condition-specific groups which she felt were unsuitable as she currently felt in good mental health. Instead, she wanted to engage in the community in a more inclusive manner by joining general community groups. In this case however, due to feelings of anxiety the participant felt unable to access general groups without basic support to make the initial visit:

> *Services for people with mental health problems …they are all well and good if you're feeling a bit alone you're not really on the planet if you know what I mean…you're not in connection with everyday life. Once you start feeling better there's no middle ground. It's either that or college or work or training or whatever but there's nothing for people who perhaps feel social isolation. I'm waiting for the Neighbourhood Care Scheme Impetus to find me a volunteer because I'd like to go join a few groups but I don't know how to go about it and my mental health team will not support me in doing that because they say I'm well enough to be able to do it myself. Well I'm not, otherwise I'd be doing it because I don't like sitting indoors every day all day twiddling my thumbs and thinking oh what could I be doing. I don't care what I do I just want to get out and meet people because I have no friends I have no family apart from my daughter and my husband. I'm really really isolated. I don't get to go out, I don't go to restaurants…pubs…cinemas…don't do any of that. I just sit indoors; I don't like watching telly I can't read very well. I used to be very literate and stuff like that but just sitting here I can feel my brain dying and I so want to be motivated and involved and do something but I just cant do it myself…I need someone to come with me because I get very frightened and panicky, anxious about new situations new people new places. (Female, 25-50, mobility impairment, long-term health condition & mental health condition)*

For some participants, existing social groups for disabled people appeared to carry a certain stigma as being old-fashioned and frequented only by older people, which they found alienating. One participant expressed a desire to avoid such groups, and instead sought something media based which could appeal to a wide spectrum of disabled people:

> *A few years back I would see people doing woodwork [at the Low Vision Clinic] and its highlighted as if it's not for me. I would like it with a different name on it – it's accessible to everybody if that doesn't sound daft. I come past and I get a view of it and I think that view is not for me whereas if it was done in a different way, maybe if it was a lot younger, middle-aged, older people like a mish mash and it had a different name then I would walk in. You know if it was something more media based like TV, video, DVD – something a bit more with-it than just a pile of videos that you can come and borrow for 10p and come and have a coffee with us – you know – something I'd like to get involved in and speak to people and bring people in myself because I am quite good at that type of thing. (Male, 50-65, mobility impairment)*

One male participant in his 30s also felt that existing groups were unappealing to him:

> *I don't belong to any other particular groups or societies, and certainly would never join a group for people with a vision impairment because they're all going to be in their 60s, 70s and 80s. (Male, 25-50, visual impairment & mental health condition)*

This was not always an undeserved stigma, as one participant, a middle-aged man in his 40s experienced:

> *I would like to join a group for blind people so I could be involved and up to date with what is happening. I want to do that. As well as improving my English. I joined a group which took place one Friday a month some were around here but the problem with that…most of the people in the group were very old…not my age group. (Male, 50-65, visual impairment)*

While these participants preferred to avoid groups they felt were unsuitable, this was not always the case. One participant, for example chose to remain part of a day centre which she felt didn't meet her needs, as she did not want the service to close. In this case, the participant clearly felt there was no choice but to stay if she wanted to remain part of a social group:

> *I use Tower House, I'm one of the few people that used to use Montague House that…one of the reasons I carry on going is so they can't close the young people's… the people under-65's, what is called the disability day centre service, it's one of the reasons why I'm still going. And it's dire, you know... Tower House is horrendous, if you're a young person, you don't need care. All the staff, there must be a team of about 12 or 15 and instead of doing 50/50 team merger, there's three staff from Montague and we're in the building that the Tower House people use, so they've kind of got in their rut. And all the leaflets and everything, it's all about pensioners and older people's services (Female, mobility impairment & long-term health condition)*

In one case, one participant chose not to take part in an available social group as he felt that his religious beliefs as a Christian were not properly accommodated in the group activity. As with the other participants, he had to choose between his own identity preferences and his feelings of social inclusion:

> *I'm a member of [a peer support group]. I haven't been there for about a year and a half. I've just…I don't know I've just...it's…it's a sort of personal belief thing cause I'm a Christian and they were bringing in all sorts of um things to do with Buddhism and I…I sat there and took it fair enough. But it just seemed to be getting more emphasis on*

> *that sort of thing and I thought it's against my… I might do some of that but I'm not…definitely not what I came for. (Male, 25-50, mental health condition*

*

For people who were more engaged in social activity, practical and attitudinal barriers to community engagement were not felt to be as significant as it was to those with fewer social contacts. While these socially integrated participants were interested in engaging in social groups, where they were unsuitable, they had stronger social networks to fall back on for alternative social opportunities.

A1.3.2. Opportunities for social activity and community engagement

Among those participants who had more limited opportunities for social activity and community participation, and consequently felt somewhat isolated, a few were able to address this to some extent with the internet. A few participants considered the Internet to be a lifeline in terms of limiting the isolation that they felt. As will be demonstrated later however, other participants were far more reticent about using the Internet. For those who were Internet users, applications like social media and online forums were identified as a source of social support.

Three participants, all with mobility impairments who found it difficult to get out and about, used the Internet to keep in touch with friends and family:

> *I've always used computers. I've used them for work and this that and the other, I can manage a spreadsheet programme, I can give you a profit and loss account, all that sort of stuff, but the actual use of the web itself, I've not been, never have. Not until recently. And the difference it's made, I think it's amazing. I think it's wonderful, actually, the web. I mean, you know, my son lives in London, and I sit here most evenings and have a game of golf with him on the X-Box with an earpiece in. I'm talking to him every day…and that sort of thing, I think that's clever. It's not a phone call, it's just, you might not even say nothing, you've just got this earpiece in your ear and you're just sat there just sort of like, yeah, it's wonderful. (Male,50-65, mobility impairment & mental health condition).*
>
> ***Do you find the internet useful if you want to contact people?***
> *Oh yeah…I think it's handy…I can keep in touch with my daughter and that as well. I'm on Facebook a lot…I've got friends on there. I've got friends all over the country that I email and that…sends me stuff…even from the states a lot of stuff comes through. Yeah I'm interested in drag racing over there and I'll get all the leaflets from the NHR…I also get newsletters from the teams and that. It's quite interesting. (Male,50-65, mobility impairment & long-term health condition).*
>
> ***Is there anything else that, you know, that you struggle to do by virtue of not being able to get out so much?***

> *I don't see people. Apart from that, it's not actually too big a problem, apart from the fact that if my mum didn't phone, and spend an hour a day playing Facebook games with me on the speaker phone, because she's mad, then I could go days and the only person I'd speak to would be the cats. I mean, it's also bad because one of my cats is deaf and so shouts back, but still, we're like an old married couple, but it's still not quite the same thing as a conversation.*
> *Sure. So does that help you, being online and Facebook and that kind of stuff?*
> *Yeah. I'm in touch with, absolutely, well, apart from two people, everyone I know is, well, everyone I want to know and be in touch with is in the same place, and the two people that aren't are the ones that can come round and drop me off a pint of milk, so that's good. (Female,25-50, mobility impairment & long-term health condition)*

Two participants with fluctuating conditions, who often found it hard to attend scheduled events also found online communities to be particularly supportive:

> *Online there's the prostate group, that's not on the Facebook, its on yahoo its over 1,000 well over 1,000 when I joined it was about 500. Though without the computer I'd think I'd go insane. The only link I have to the outside world really (Male,50-65, mobility impairment, mental health condition & long-term health condition)*
>
> *I belong to a number of kind of online community forums and things like that because, again, it's another way of…having a community or someone to talk to when, or if I'm able to, and that works better many times than actual meeting a group of people or being involved in an organised activity. (Female,25-50, mobility impairment, & long-term health condition)*

Although helpful to an extent, many participants felt that the Internet was no substitute for personal interaction. For some of the more socially isolated participants, local befriending schemes could be an invaluable service to reduce people's sense of social isolation. One participant found this support from the East Sussex Association for the Blind:

> *So the East Sussex Association for the Blind sent out a volunteer who was a student and he used to come to me on a weekly basis and it was…socially we could have a chat…go out. And I really benefitted from that, I really enjoyed it…and that's the kind of thing I'm looking for you know. Someone of my age you know or a little bit older I'm not really fussed you know…to hang out with…someone with an interest in doing it, hanging out with me. And you know, he's a really nice guy and I got on well with him. (Male, 18-25, visual impairment & mental health condition)*

Another such service was the Neighbourhood Care Scheme. In one case, as well as benefiting from visits from a volunteer of this scheme, the participant also contributed her time to the scheme by providing telephone support:

> *I do telephone support. I befriend an older lady over the phone and, um, she's a nice lady. I do that for the Neighbourhood Care Scheme… I'm also on the receiving end of a scheme member as well. Um, so I have a volunteer. And she used to come once a week, that was for an hour but she also... Now she's actually coming every two weeks*

> *and I'm waiting for someone else to come along so I can get some support on a weekly basis.*
> ***So what does that support mean for you?***
> *Well, it's... One, it's company for me and two, it gets me out or I can do certain things that I'm not able to do myself like correspondence... You know, writing. Because I just haven't got enough sight to be able to write perfectly well. Or we go out, a bit of gardening or that kind of thing. (Female, 25-50, visual impairment & mental health condition)*

It is important to note that while several participants felt socially isolated, there were also participants who were happy with the level of social activity they engaged in. What appeared to set these participants apart was the fact that they had built up networks of social contacts through their other interests. These could be networks of religion or faith, or contacts that they had built up through volunteering and employment, either previous or current. In general, those participants already involved in community or voluntary groups or other networks often had social contacts as a result of this involvement.

For three participants, involvement in the local church provided a source of social contacts and support:

> *I was told about this church that are completely inclusive of everybody but there wasn't one near me and I got told there was one starting in Brighton. That was nine years ago so been a huge part of my life since. Its good 'cause it's a really good support network I know that if ever I'm in trouble I've got people I can call to help. And they do help. (Female,25-50, mobility impairment, & long-term health condition)*
>
> *I've been a member of [a church] for about two years…we have a small group, so about ten people and sort of meet once a week and that's good. You know there are people there for you sort of thing. (Male, 25-50, mental health condition*
>
> *I'm involved with the local church. And I do the Sunday school there when I can, and again it's nice as much for the social aspect as much for the religious aspect. (Female,25-50, mobility impairment, & long-term health condition)*

Another participant found a similar kind of support through local Buddhist groups practising in the area:

> *I do try and get out and see people, because obviously you can become very isolated when you've got a disability, so I try and sort of speak to one person on the phone every day… and that doesn't always happen, but I do try. I sometimes get out to my Buddhist group, which is twice a week sometimes. We practice in our own homes and we practice sort of locally, so that's really good for me because it means I know Buddhists living very close-by, in the same neighbourhood, so in a way that's a kind of… even though I might not draw on that social support very often I know they're there so it's comforting. (Female,50-65, mobility impairment & long-term health condition)*

An older male participant maintained social contacts he had built up in previous years practising alternative medicine:

> *I've travelled this country about three times doing psychic fairs, so I've a lot of people who are still in contact with me from that time. So now and then I travel, I'll go out to Sweden now and then, I've got a friend out there and I teach the managers and managing directors of firms to stress manage and how to enjoy things (Male,50-65, mobility impairment)*

In addition to networks of religion and faith, many people had built up social networks through employment. In some cases, this was prior to participants developing their impairments, and although the nature of group activity may have changed to some degree, the networks persisted. This was the case for one participant:

> *You know like I say I used to Ski and things like that which I don't any more. So a lot of the active stuff I don't do anymore but yeah. I go down the pub, meet my friends, good social life. (Female, 25-50, mobility impairment & long-term health condition)*

For two participants, these social networks had been established while the participant was at work, and friendships had been maintained despite the participant having left employment. One such participant was in this situation:

> ***In terms of social opportunities do you feel you have enough?***
> *Yeah I think so, I've got a big network of friends from school and from my work and my MS has progressed so they're well aware of my situation so I'm comfortable with it. Most of the friends and family, they're all kind of forty odd years old with young children, we're not out to the pub three times a week, that's not, we go into people's houses and stuff like that and they're very accommodating. (Male,25-50, mobility impairment & long-term health condition)*

Another participant who had been out of work for about a decade, still had friendships which he had built up through work and travelling:

> *I'm very lucky that I have a lot of friends who come to me so I have a good social life with friends, I'm not isolated. I've got a lot of friends that I've met through travels from various different walks in life in different places and they seem to li8ke Brighton so they come and stay whenever they can (Male,50-65, mobility impairment & long-term health condition)*

Similarly, social networks had also been established by participants through involvement in voluntary work in their local community or in communities of interest:

> *I keep in touch with friends and we go out. Sometimes we have a meal, sometimes go to the theatre about once or twice a year….I've been involved in the community up in Bevendean since the age of nine when the kids in the estate helped build the vicarage, the church. I've been doing stuff on the estate ever since… I am known by a lot of people so takes me about half hour to do a ten minute walk 'cause everybody stands up talking to you. (Male,50-65, mobility impairment & long-term health condition)*

For one participant, voluntary activity was useful in addressing social isolation simply because it allowed him to meet and converse with other people, in this case the researcher conducting the interview. This suggests that voluntary activity can be important for disabled people at risk of social isolation, even where social network-building is not the specific aim. The social benefits of volunteering is a theme that will also be picked up later in the report:

> *I just keep me self going, pretty well flat out and then also meeting people again like you now, today. So you know it's a thing to come in and talk which I haven't got at home, although I do share my flat with somebody. But some days, you wake up and you'd be great and then the next day you wouldn't see him for three days, its things like this it's very difficult. He won't sit and talk very often which means I don't stop talking when I'm out and about. (Male,50-65, mobility impairment, long-term health condition & mental health condition)*

A source of social contacts for one participant, in his late 50s with a visual impairment, was through practising music. In this case, a jazz teacher had provided him with a link to a jazz workshop which provided him with social activity. This was actually one of the few cases in the research where a participant had built up a social network through practising a hobby. In most other cases, involvement in social networks came from employment, volunteering and networks of identity based on health conditions, sexuality, religion or faith.

Another source of social activity was adult and community education courses, which one female participant in her early 60s made use of in order to keep her mind active:

> *I have to do something and of course that's what's so brilliant about Brighton is that they actually provide screenwriting groups. So I've been up to, I did a course at the Friend's centre just recently. Which is the one in New England Street, which is relatively new and that is very good in terms of being accessible for someone in a chair. (Female,50-65, mobility impairment)*

In some cases, participants were able to draw on multiple sources of social contacts to prevent feelings of social isolation. One participant was part of a local Quaker network, and had also joined an informal social group set up specifically for the purpose of allowing people to make friends:

> *I belong to a sort of informal social group and I probably go out with them about once a week. Some people just set it up, there's only about twenty of us in it, but we go to a pub and try to organise outings, things like that, between ourselves…I'm also a Quaker and there's always quite a lot of Quaker activities that I go to. So generally, Sunday's quite busy and probably at least one day in the week there's another activity there. (Female,50-65, mental health condition)*

Often participants who were already involved in some kind of activity found it easier to find out about and engage in other groups and build up networks of social contacts. Those who had limited support to get out and engage in the community were often unable to "break the cycle" and make the first steps to building up a social network. As one participant in the mental health focus groups noted:

> *[Other people] don't seem to be informed and be aware of those things [social and support groups], and I think it's often through personal contacts, but I think, you know*

> *what it's like, it's a bit of a chicken and egg situation, because until you're involved in the projects you're not making those social contacts. (Male, mental health condition)*

A1.3.3. Peer support groups

A key theme to emerge from the data has been the important role that peer support groups can play in participant's lives, from acting as a source of information to providing important social and practical support. These were mentioned a number of times by participants who were generally very positive about the opportunities such groups provided. This included helping people to adapt and manage their conditions, access services such as benefits and disabled parking badges, and develop social networks of support, all of which enhanced their quality of life.

Several participants who had Multiple Sclerosis attended the MS treatment centre in Southwick. The centre provides various low-cost treatments aimed at easing the symptoms of the condition and also provided a place for people with MS to speak to others with the condition.

> *That's great, they've got an oxygen chamber in there and you can go and sit, where you put the mask on and you're breathing pure oxygen. They've got lots of treatments, shiatsus, massages, chiropodists – you know; lots of treatments there, such …. And obviously you're surrounded when you get there by other people that also have MS, so it's quite a good place to talk to people and stuff like that. (Male,25-50, mobility impairment & long-term health condition)*

In addition to the treatments available, the MS treatment centre, and indeed other peer-support groups, appeared to be most important for the opportunity they provided for people to share knowledge and information about services which people could access:

> *I actually have found I've had more help and guidance from networking there [at the MS treatment centre], just from meeting people on a social level and a couple of groups who do, getting information that way more than help, more so than sometimes through the authorities. (Female, mobility impairment & long-term health condition)*

> ***So how important has the MS Centre been for you?***
> *Yeah massively so actually and yeah really, really good. Just to meet other people and realise everyone else is going through the same stuff. It's just kind of like-minded people that are having a laugh about it. It's the one place I can go you know every Tuesday evening to just go and not care about the fact that I can't you know, doing the exercises is hilarious. None of us can bloody do them but the woman that runs it has MS you know and she's going 'Lift your legs above your head and do this and bend over and touch your toes', and none of us can do it but it does…it doesn't matter. It's lovely for that. It offers you support that you can't get anywhere else, just knowledgeable like-minded people. A lot of people go there everyday just for the company and a lot of people like me go there just 'cause it's friendly and nice and you can just be yourself and not worry about stuff and yeah it's good, it's fantastic. I think I'd feel much more isolated with my MS without that place. It makes you feel like*

> *there's support there for you. I think my family and friends can see that as well. They've never been there but they know that it matters to me a lot though. (Female, 25-50, mobility impairment & long-term health condition)*

Another participant with Multiple Sclerosis attended one of the informal social groups for people with the condition where he also gained social support:

> *Once a month I meet a small group of people that have got Multiple Sclerosis in a local cafe. That's quite nice … it's just a little group where you go and have a coffee and a chat (Male, 50-65, mobility impairment & long term health condition)*

Another peer support group which was mentioned several times in the research was the local Manic-Depressive Fellowship, or bipolar peer support group. This group actually received a small grant to run, and was hosted at the Buckingham Road mental health centre. One participant, a man in his 30s who had recently been diagnosed as bipolar, found this group to be particularly helpful in enabling him to understand his condition:

> *When you talk to people that understand because they have it – straight away, it's amazing and it doesn't cost the council anything. People want to go and help themselves and each other, they want to help others. Just by me talking to one particular woman, that first day when I went there was completely in denial, "I don't have this, why am I here? But I'm going to try this out," I spent half an hour with her there and I laughed at the number of times that she said something that I totally related to and I realised then that I had, possibly, bipolar. Now I would never have got that with a doctor, I'm a little shit sometimes, I can put up a bit of a fight, I don't want to accept that I have an illness, I'm ok, I'll get on with my life this is just a stressful time but you know what, that actually helped me to see that I need to be a bit kinder to myself, I need to recognise that maybe there is a problem, maybe I need to open my mind a little. And that's the thing, doctors and nurses can't always give that, you know? (Male,25-50, mental health condition)*

One participant who attended the MDF was very positive about the support she had received from this group in terms of social support and information.

> *The MDF, the bipolar support group... that's really good, and we're really lucky because the council give us this grant, it's a very small grant but a grant to keep us going each year, and they let us meet at Buckingham Road, so everyone's familiar with Buckingham Road because most of us go there another time, it doesn't cost the group anything, … I have friends round the country who have funding issues with their support group, which seems a bit bonkers because you only need a room and a cup of tea, I mean that's really all you need, but still if you can't, if you have to hire a room and a room costs fifty pound a month, you know…we have guidelines, it's not 'hey come to the pub', you know it's not really social at all, we have socials, but socials are separate, so we have a structure so we'll either have a guest speaker, and they're really well thought out so they're going to be someone like on nutrition or someone on maybe meditation or we had a sound therapist come once, that was really interesting... and then if we don't have that then we have a, everyone goes round and says 'how are you', 'what good thing happened to you this week', so that's really nice, and then we, at that time we say what topic we'd like to discuss and it's always the same,*

> *medication and benefits, how to deal with other people, how to get a job when you've got bipolar or disabilities, how not to lose your job (laughs)… we then have breakaway groups depending on the theme, and that's where you get so many tips, people are so helpful, they're all scribbling down, you know, I reckon that's how I've learnt about, yeah, everything. (Female,25-50, mobility impairment & mental health condition)*

Some participants accessed ME groups, whereas another participant had not received any signposting to such groups despite seeking information out. One participant engaged with the group had been diagnosed with ME over 10 years ago, and was consequently more involved and aware of groups for people with the condition:

> *I'm a member of the Kent and Sussex ME Society, and once a year they have a big conference in Brighton which I go to. And yes there are certainly some people through that...it's just nice to know there are other people out there going through the same thing and that's enough (Female,25-50, mobility impairment, & long-term health condition)*

Another participant with ME was part of a new social group that had recently been set up for people with the condition. For this participant, this group was important as it allowed him to make personal contact with people he had been in touch with over Internet-based social networks:

> *I have joined there's the new ME group and we meet once a month only about a couple of hours it's really good…*
> ***So is it at a community venue or?***
> *No it's a pub. Were all a weird lot coz everyone's allergic to everything so we all order weird stuff at the bar. But it's really good because we're on Facebook and were on the phone and we actually see each other so that's really good. (Male,50-65, mobility impairment, mental health condition & long-term health condition)*

Some peer support groups were organised around impairment groups rather than specific conditions, and while participants had more diverse needs, these groups were equally helpful in helping people to receive peer support and information. One such group was Grow, a mental health conservation project which one participant with a mental health condition attended:

> *I do attend Grow and I'm also involved with the LiVE Project. I found both very beneficial indeed, particularly again also on the sort of networking side...there's loads of information that comes through that [the facilitators] suggest may well be helpful and we're given the opportunity. I think what's nice as well is that often then, because it's put out to other people who are in the group, you often see someone there familiar, which I think always helps as well. (Male, mental health condition)*

For many participants involved with peer support groups, they often provided more support in regards to signposting than people had received from statutory services. Importantly for issues of independence, this signposting enabled participants to access services which enhanced the level of choice and control over their lives, such as financial benefits. One participant who had attended training with Guide Dogs gained more such information at this group than from his social worker, who had conducted an assessment. However, he was keen to point out that this assessment was at least a decade previously:

> *When I was first registered blind a social worker came round to see me at home, to do an assessment which I wasn't sure what it was going to be, she never explained, the sum total of her assessment was that I'd got two little sticky dots to put on the cooker so I knew where, in those days, the gas marks were, and a couple of sticky dots for the microwave, and that was the sum total of her help and I thought wow, and what was annoying is she didn't tell me then, I mean I've subsequently got a blue badge, she didn't, but I learnt more from my friends I trained with in guide dogs, 'cos I think it was them who put me onto, I actually applied and got the basic Disability Living Allowance, she didn't mention that (Male,50-65, visual impairment)*

One point which became clear in the interviews was that the provision of peer support groups was patchy, with some conditions such as Multiple Sclerosis being well accommodated while others knew of no such networks to access for their impairments or health conditions. As has been seen in relation to ME, part of this variation may well stem from participants having a lack of information, and some participants are simply unsure what exists:

> ***Do you know of any other groups for people with chronic pain conditions?***
> *No, I would love to find out if there are any organisations in Brighton now that do this where you could meet once a week or twice a week where you could talk to people who are in your position who have got a condition like you. You see lots of glossy pamphlets and leaflets but you don't know who to approach really. (Male, 50-65, mobility impairment)*

In some cases, however, participants had searched extensively and found that groups simply did not exist. In one particular case, the participant had no diagnosis at the time of interview, so had no health specific network to turn to:

> *No. It's really difficult because I don't have a diagnosis. You go to the hospital and there's, like, the Lupus Group and all these things, but the medical mystery group hasn't been founded yet. Maybe I should do that. I know someone else who's a medical mystery as well, so maybe the two of us could meet up for drinks. But, no, because there's no diagnosis there's no particular direction. (Female,25-50, mobility impairment & long-term health condition)*

A1.3.4. Access to information on community activities

An important factor regarding the barriers and opportunities that participants identified in engaging in the community was the availability of information about groups and organisations operating in the city. As mentioned in some of the interview excerpts above, lack of information could be a key barrier to community participation. Considering the scope of the research, without extensive validation activities it was impossible for the research team to be sure whether groups simply did not exist, or simply that participants lacked information about them. In many cases, participants simply did not know how to go about finding this information and had not benefited from any signposting from statutory services:

> ***So are there groups around where you live [Whitehawk] that you'd be interested in?***
> *I don't know. I don't know where to look for them and the thing is I don't like going far and I certainly wouldn't go up to Brighton on my own (Female, 25-50, mobility impairment, long-term health condition & mental health condition)*
>
> *This has always been a constant problem in Brighton and Hove, there's not enough information around. There's not even the booklets, you know, you go and ask a question, they don't know, if you go to these places like the Tourist Board. They all say "We don't know" I said "But hang on a minute, you are supposed to know" "Oh, sorry, but we don't" there's no training, there's no proper information given around at all, I think it is very bad. (Male, mobility impairment & hearing impairment)*

As lack of information could be a barrier, conversely of course, availability of information provided an opportunity for community participation. Where participants were engaged with or had found out about community activity, this could be through a range of different methods. As demonstrated previously, one important source of information has been peer support groups. In some cases, participants found out about community groups through word-of-mouth and chance meetings:

> *Very often I think about, for example, the Peer Support Service, which again has been very helpfu, to me, myself coming from elsewhere only been here for one year, it almost seems by chance that I was signposted to that service, which has been really essential for my recovery, whereas people who lived in the city all their lives or for some time, a lot of the things that I seem to be mentioning in groups people just aren't aware of, they look at me blankly because I think that they just haven't been flagged up to them, and often they are involved with mental health services in some ways. (Male, mental health condition)*

Some participants were aware of and had used community organizations as a source of information on other groups and events happening in the community[1]. One participant with a mental health condition, for example, had found the women's centre to be a helpful source of information:

> *Somewhere I went recently, actually, was the Women's Centre. And they've got loads of information there, and it's a really like safe, supportive atmosphere. It was the first time I've actually been in, but that was really nice, and they've got loads of information and leaflets so that's a good place as well. (Female, mental health condition)*

One participant had also accessed a specialised resource room which had signposted him to Mind's local involvement project, LiVE:

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[1] The role of community organisations is a recurring theme and is picked up on several other sections of this report where they have provided support related to more specific services.

> *I found that the Allen Centre, I think a lady there said they were good. [The woman] who looks after their kind of resource room, very good, I think that's where I found out about LiVE. Yeah, I think for me there's nothing I couldn't find, that's really, really well maintained. (Male, mental health condition)*

While contacts with community groups were important, even participants who had these contacts still found there were information and services they were unaware of:

> *I think there's national mental health day in October. That was from MIND I think. So I sort of have a look at their, any bulletins or whatever.*
> ***Do you feel that you have enough information and advice about support that's available for you?***
> *Oh it's quite surprising when you go…go to a place like this [Disability Advice Centre] and you see all the leaflets you think, oh I didn't know about that. So it's good just to come to these places just to sort of think ok, I'll have to have a look at that. (Male, 25-50, mental health condition*

A key point to note from participant comments is that the simple presence of community organisations is not enough to ensure information is available, but that these organisations have also had to be active in reaching out to disabled people, in order for participants to engage with them. In one case, the participant had only found out about the Fed, because of outreach activities conducted by the organisation:

> *If I hadn't have met [Fed staff member] I wouldn't have known about the federation, so it was only through him that I got to find out about it (Male, mobility impairment & long-term health condition)*

For some participants, community organisations had not always met their expectations and in some cases had not provided the support needed for them to access the service, making it harder for participants to get the information they needed:

> *If you're looking for something specific yeah, Mind works with other mental health centres and you phone them up and leave a message and they're meant to phone you back, and you don't always get phoned back… just over time it's just, these things have happened so you sort of give up using a service, even though that might just have been bad luck at the time, you don't know so it's maybe worth trying again (Female, 25-50, mental health condition)*
>
> *So I started going to the CAB [citizens advice bureau], but you can never get to the CAB and also even if they're really good I think, don't think the CAB, they're supposed to but I don't think they really think 'oh yeah this person might have anxiety because this...', the waiting room's like this big, or 'this person might have a physical disability' because you have to queue outside the door for like twenty hours (Female,25-50, mobility impairment & mental health condition)*

One significant factor when considering the issue of information provision is that between participants there were many different methods used to access information, both within and across impairment groupings. One way in which this is particularly evident was in regards to the use of the Internet for the purposes of finding information. Some participants were far more active on the Internet than others. In some cases where they were less active, participants wanted to gain skills in using the Internet whereas others found the Internet an unhelpful means of accessing information and prefered to avoid it.

One participant enjoyed using the Internet to access information, even when not seeking a specific service:

> *Just generally I, I search the internet because I love information. Anything. (Female, 25-50, visual impairment & mental health condition)*

Another participant had found out about the bipolar support group through an Internet search and felt that people with health conditions were required to do their own research in this way if they wanted information:

> ***So how did you get involved with it – how did you hear about them in the first place?***
> *I think it was a reluctant Google search, "I want to do this." Yeah, it was a Google search and straight away, type in bipolar and you come across MDF and then you find they got groups on Thursdays there and I went along. It should've been a doctor telling me that but he wasnt in Brighton so he wasn't quite so sure, so very much off my own back. That's not to say they or any other organisations aren't doing enough advertising because even just sat out there for a minute I saw so many leaflets I was like I just knew everything, so yeah it's just how it is when people fall ill, they need to do their own research to some extent, just how it is. (Male,25-50, mental health condition)*

Another participant felt quite confident in using both online resources and phone calls to the council to follow up information where necessary.

> *Most of the time I'm an online person. My partner's registered with the Carer's Centre so she gets information through them they do a newsletter that comes to her. I do look on the Council website for things and occasionally they get phone calls from me, they don't like me. That's my way of accessing things it has to be done online no-one's going to come and knock at the door (Female, 25-50, mobility impairment)*

Although confident using the Internet, one participant found that information on local community activities could often be difficult to identify:

> *I can't say there is enough information to be honest I mean there are some issues some topics, which really need more information.*
> ***Right, such as…?***
> *Social groups, social clubs. I mean you have to go to Council website for example, or you have to Google search. And its very difficult to pinpoint a particular social network. So I mean ideally it would be good, for example if they mention these societies or associations or clubs or whatever you want to call it. Under one umbrella so if I need information about for example this particular group or that particular club, I know where to find these places rather than a Google search. (Male, 25-50, mobility impairment)*

For some participants, despite having an interest in using the Internet, they felt that they lacked the skills necessary to use it effectively and were eager to access support to learn basic computer skills. Two participants, both in their 50s, expressed such an interest:

> *Things I'd like to do...like learn more about computers cause I have got a laptop and basically I'm self taught... so when I mess it up, I'd like the help to be able to try put it back together. (Male, 50-65, mobility impairment & mental health condition)*
>
> *I see these things, facebook and twitter what I should do, although I was good at keyboard stuff before I left work we had an IBM computer so when I went to Brighton and Hove Library which we have a brilliant one in Jubilee Street I said can you show me basically how to get into the 21st century and somebody sat with me for ten minutes and said You'll be ok. But what I don't understand I ought to go somewhere like the Whitehawk Inn to do a little bit more of an advancement – how to put things into practice. (Male, 50-65, mobility impairment)*

For one participant with a visual impairment, access to training with the use of assistive software such as screen readers was very limited. Despite having some basic training through his employment, he was unable to access any follow-up training in the community at an affordable rate and this inhibited his use of a computer:

> *If somebody wanted to give me a whole lot more training on my computer I'd love it, I'm not, I can't keep spending the businesses money, unless it's something justifiable, but I'm at the stage now, I've learnt to use a computer and all the training was 'well what do you want it to do, that's all we'll teach you' because that's how the software, if you like, interacted, … I don't know enough about the computer generally… I'd love to know more, and when I try to find, it's the sort of thing where if, you know, if you got to a library and there are... members of the public go to the library, there are computers there they can use, I don't know if they have to pay for them or not or whatever, and then they have training sessions for the various age groups or whatever, not for me they don't, you try and find anywhere I can get training on that sort of I'll say public basis at a modest cost, I can get one to one at a couple of hundred pounds a session, you know, half day, but I can't get it you know, twenty-five quid for a couple of hours (Male,50-65, visual impairment)*

One participant with dyslexia also found it difficult to use computers to find information about their community, and preferred to access this information through different means:

> ***Do you use the internet as a source of information?***
> *No, no. Yeah, that's right I've got a problem with dyslexia and I don't like machines you know. I'm very suspicious of…you hear stories about the internet and banking and stuff like that you know which doesn't encourage me either so no I don't use the internet. (Male, 50-65, mobility impairment & mental health condition)*

Another group of participants where some found it harder to use the Internet to find information were participants with mental health conditions. This was evident during discussions in one of the mental health focus groups run by the research team. In this case, the vast amount of information available online and the need to concentrate and focus on information of relevance created a barrier for participants, who preferred different methods of information provision:

> *I think like free magazines and things, you know, like the Seven Dials Magazine, I don't know what it's called, Seven Directory or something. You know, things that you can pick up in cafes and then take home and just flick through. I see things in there, and also Hove Library, you know, the big noticeboard, I've noticed things there. You know, especially if I'm not in a particularly good space, it needs to be things that I sort of see on my way out rather than, yeah, going to the internet, I'm just a bit bamboozled by all that. (Female, mental health condition)*
>
> *There's times when I'm able to use the internet, but there's times then that it's not a helpful medium for me because sometimes the level of concentration etc. required, and then I haven't got a computer at home so I've got to go to the library to do it, there's got to be a spare place. So it's not that… yes, it can be helpful. The Mind website as well is also a good place for information as well, but I think sometimes it can be that there are barriers, you know, again, particularly if you're not in a good place, and sometimes it's when you're not in a good place that sometimes that's when you're looking because you know that you need something a little bit new, fresh, to try to hopefully move things on for yourself. (Male, mental health condition)*
>
> *I do go on the internet quite a lot, but obviously, like everyone is saying, you have to be in a good place to do that. (Male, mental health condition)*

In summary, access to information is a critical factor in the extent to which participants are able to engage in their community. Notably, however, participants access and respond to information in very different ways, suggesting there is no single one size fits all approach to information provision.

A1.3.5. Impairment specific issues

In addition to the general issues mentioned in regards to community participation, participants in certain impairment groups also tended to experience some more specific barriers. In addition, participants from some impairment groups also identified impairment specific community organisations which they benefited from.

A1.3.5.1. Mobility impairments

For people with physical impairments the most common barriers they faced to participating in groups and organisations related to problems accessing venues used by community groups. This also created a barrier to engaging with informal social networks, where pubs, cafes and restaurants did not have access or accessible facilities such as disabled toilets.

> *I mean simple things like going to your kid's birthday parties is sometimes a problem because the venue isn't accessible or something like that. So can't sort of develop the role or identity as a parent. Another example could be that he's going to a skate boarding school now that's run by the council, because it was raining they couldn't do it at Hove lagoon so they changed it to Brighton Youth Centre, which has got a lift but it*

> *only goes up 2 floors and I think there's 5 floors or 4 floors, and the skateboarding thing was on the 4th floor so when I got there I had to sit outside while my son went upstairs with all the other parents. It left me feeling sort of discriminated against and so I'm not the same value as other parents so there's impact on your identity as well. (Male, 25-50, mobility impairment)*

Most participants with physical impairments found access to be mixed where they required level access or disabled toilets. In some cases, alternative venues (cafes, pubs, restaurants) were available for people to participate in social networks, meaning that participants took their business elsewhere where the venues were inaccessible.

> *If my partner and I are thinking about going to the pub I'll really think about how I'm feeling as to which ones we go to 'cause locally I know the ones that I can get in and out of easily. And again, it's mostly where the toilets are. Whether they're up and down stairs 'cause loads of pubs in Brighton have toilets, they're downstairs or upstairs and I'll generally avoid them 'cause after a couple of pints it's not the best idea. And again with the restaurants, they're a bit, but a lot of them are really, really good you know. Most of the time I'll find that I'll go to restaurants and places like that and they have got disabled facilities. And it's generally really, really good. I just don't go to the places that are not accessible. (Female, 25-50, mobility impairment & long-term health condition)*

A number of participants had favourite venues that they chose to frequent because they were accessible, as one participant noted:

> *There's a nice Italian place as you go into the Pavilion. They've got a nice place on the top floor level. They know me in there. I think people get to know me in places because I'm apt to go in places where you can go and spend a penny if you need (Female,50-65, mobility impairment)*

As with one participant experience with the youth centre, where specific events or groups are held in inaccessible venues, there was no alternative choice to make which meant people with physical impairments could be excluded. This was the experience of one participant who sought to access events at the Latest Music Bar and in theatres throughout the city:

> *The buildings in Brighton are lovely but not always accessible and my particular bane is Latest Music Bar which I think is big enough, they could get some sort of lift in to be honest. So a) you've got to get in and b) you've got to get downstairs. I have phoned them a couple of times and I really would, because they also, it's not just music, they also have discussions there which I would love to, and speeches, talks, so I'd love to go. Also theatres aren't so easy to get into, this is all from the point of view of my wretched chair, because many of them are upstairs in older lovely buildings but I just cannot get upstairs which is a shame (Female,50-65, mobility impairment)*

A key issue in relation to access for some of the participants was simply that many of the venues that most appealed to them were those most likely to be inaccessible. Often these were small, independent establishments, such as shops, cafes and pubs which some participants had a preference for:

> *Most of the smaller pubs aren't really accessible because they're up steps or something like that and they can't be done. Some of the newer bars on the seafront, yes, you've got no problem with them. But, they haven't got the atmosphere. I usually like pubs you know. (Male,50-65, mobility impairment, long-term health condition & mental health condition)*
>
> ***You said that there is enough that you can do in Brighton, what sort of things?***
> *For example going shopping, getting into shops, even a relatively small Tesco express and Co-op in St James's Street, I can get in the local post office, local fruit and veg, cafes aren't quite so easy, so I've had to select cafes. I have actually, I've just had a word with someone who promised to put a ramp there and hasn't and I just said to him, is it coming sometime, but I normally don't bother, but there are just a couple where I really would like to get in…. (Female,50-65, mobility impairment)*
>
> *The majority of them are good I mean…yeah you've got like British Home Stores, you've got Marks and Spencer's even though there's one lift and it's like a bit of a nightmare. All the big shops, they've all got accessible lifts. It's just the small individual ones where maybe you can't go. And you have to accept that. (Male, 50-65, mobility impairment & long term health condition)*

Some participants who had had mobility impairments for several years felt that access to venues in the community had improved significantly in recent years, as venues had been refurbished:

> ***Do you access anything like café's, restaurants, that kind of thing?***
> *I mean, I do not find any problem. I think all of them are visited. They have either ramp or disabled access. No problem you know, very, very busy. I mean if you ask me this question maybe 15 years ago I would have answered differently. But now its very good, very good. (Male, 25-50, mobility impairment)*

However, in some cases participants reported that specific venues had actually made access worse, or had not improved following recent refurbishments:

> *I was walking up George Street and they'd refurbished one of the café's and a man stopped me and he said oh madam, how would you like a coffee? And a nice menu and I looked at him and I said oh I'd like it very much thank you very much, but not in your establishment because you've just refurbished but I know you haven't got a disabled toilet on ground floor have you? Oh no, no we haven't. He said it you know as well as to say well of course not! And I thought, well he's just refurbished but….hadn't thought about it. (Female,50-65, mobility impairment)*
>
> *There's some places you'd love to get into but because of old buildings they can't be converted or anything like that . There's one that was Vavoom, just round the corner from um, Harry Ramsden a little bar there called Vavoom and it was good. I went in there once, a couple of times, and it was just a ramp straight in, lovely. And I was going past the other day and I thought, hello. The door was open. It wasn't open but the door was open. They were doing something in there and I got closer and it was a step. That hasn't been there before so I thought, excuse me! Got someone out and I said that was a ramp and he said yeah, he said we were doing some work and found it was all crumbling underneath and um, we put the step in. And I thought well, you've*

> *had to repair where it was crumbling underneath why didn't you put a ramp back? (Male,50-65, mobility impairment, long-term health condition & mental health condition)*

For two participants, the access barrier was not at venues they wanted to visit, but rather in accessing their own house. Both participants were on council housing waiting lists, but were currently housed in unsuitable properties and found it difficult or impossible to get out to access community events. One participant, a woman with a mobility impairment in her early 60s was unable to maintain her activities at church:

> *So, I don't make church on a Sunday now, you know I've got the stairs to face, do I feel well enough to go down them can I get up them again. Is there anyone at home to help me up with the handbag and the arm, no or not and all that has to be taken into account. (Female,50-65, mobility impairment & long-term health condition)*

Another participant described herself as "trapped", and "in prison", as she was waiting on the council housing list for an adapted property and was currently unable to leave her house:

> *Basically I was walking relatively well until only about 18 months ago and then one knee quite seriously deteriorated and we struggled on a bit longer. We had been on the transfer list for over a year – we were told they couldn't adapt this property any more at all so I can't put ramps in and stuff so we said ok we'll get on the list and they gave us a banding and fine. Then things started to get worse earlier this year so we wrote to them explaining this – they came back saying tough basically… they just seem to think well why should we worry you've got a house – go away. ...they can't understand that my life has come to a full stop. You have got somebody who used to be – I used to volunteer – teacher down at the Bridge – I can't do that. They've put me in prison. They have made life a lot worse and more dangerous for me and it's trying to get through to them that actually guys this is kind of important – you're strangling somebody – it's been very, very hard – incredibly hard (Female, 25-50, mobility impairment)*

In some cases, access to venues was not a question of physical features but rather a policy which made it easier for people to access. For one participant the library's policy on extended book loans made it difficult for her to access the service, as insufficient care support meant she often had to stay with family and could not travel to the library regularly:

> *I read, I go to the library, I order all the books so they're all there waiting for me…although I never go to Jubilee because they make you stand up… often you go places and there's nowhere to sit down and I get quite dizzy and stuff like that, it's just quite tiring. I also asked them if I could have the six week [return] on my books because when I had an agency the carers were real erratic, they don't always do what you want them to do, and she said I needed to be housebound before I could have that, so anyway, she refused me and I said OK, well who do I need to write to and then she gave me the complaint form, but it wasn't really a complaint, it was more 'what do I need to do to get my books on a six week loan 'cos I'm at my mum's and I don't want to get fined'. Anyway, it didn't work (Female,25-50, mobility impairment & mental health condition)*

For another participant, access to venues was actually made easier through a policy, as the concessionary schemes run by cinemas and some theatres, meant they could take a carer at a reduced cost:

> *I get about a lot and theatres no problem, absolutely fabulous the theatres here. Especially any Council run one cause you get two for the price of one there, I pay and my carer gets a free ticket (Male,50-65, mobility impairment, long-term health condition & mental health condition)*

One specific area mentioned by some participants with mobility impairments where accessible facilities were critical in enabling them to access leisure services in their community was in relation to sports and swimming. One participant, who was claiming Employment and Support Allowance and was therefore on a reduced income, found the biggest barrier to keeping fit and healthy was the lack of long-term concessions for disabled people:

> *I thought I'd look into going to the...the Council gym and things. And its so expensive, and there are no concessions, for disabled people. And I have spoken to the Councillor for this area about it and she said oh she'd look into it but go and see the doctor about it. And all they could do was that they had a three month scheme where, I confess it was cheap enough then because living off benefits you do watch every penny. So, it was fifteen pounds a month I think, and then I had... six sessions with a trainer… But now that's finished I want to sort of do things like go swimming, and use the gym, and have access to the trainer perhaps, just to ask help from. But I can't afford forty quid a month. (Male, 50-65, mobility impairment & mental health condition)*

Another participant had a more positive experience of sports facilities, and had recently discovered she was able to access swimming through the disabled swimming club at the King Alfred swimming pool, which met her needs well:

> *I have just joined the Disabled Swimming Club at the King Alfred, I don't know who told me about it, ah there was a poster in my GP surgery, and I wrote it all down and I rang them up, it's brilliant, you can go if you have no legs, you can go if you've got a walker, you can go if you can barely stand and, and they have a physio, and there's nobody else in the pool and it's brilliant, everyone's really friendly. (Female,25-50, mobility impairment & mental health condition)*

Several participants were particularly keen for support to access the beach. While some of these participants were aware of the accessible beach platform already in place to enable disabled people to get a few meters onto the beach, they expressed a strong desire to be able to get down to the water's edge:

> *It is a bit of a shame that you can't get to the waters edge. I haven't actually tried the fort that I could get onto, from behind the railway station (Female,50-65, mobility impairment)*
>
> *There must be a way and if they did. Do you know what I mean? 'Cause I'm sure there's lots of people in our position that would like to go for a swim in the sea. I used to love swimming in the sea. So, I go on the seafront there and I dream. (Male, 50-65, mobility impairment & long term health condition)*

> *But again the beach you know, is my biggest bug bear, again especially I spend that much time down the beach it's kind of really frustrating not being able to get out on the beach, down to the shoreline really, and we usually park down beside the wheelchair track thing what they've built, and it just angers us just every time I go on it, it's just like three metres nearer the shoreline it's like…no. I think Brighton & Hove should be thinking of something unique to suit our environment and getting a proper, permanent slipway down there. Not just for disabled people, I watched a couple with a speedboat dragging it and dragging it down over the pebbles getting it down. (Male, 25-50, mobility impairment)*

A1.3.5.2. Visual impairments:

As with the participants with mobility impairments, access issues could also be a barrier to community participation for participants with visual impairments. One participant experienced regular difficulty with establishments which refused access to his guide dog, in breach of the Disability Discrimination Act:

> *I'll tell you what I do like, eating out, which you can probably see, and the places where you can't go with a guide dog are, I assure you it's not racist, I can almost name the restaurants but they are usually people from an Asian background, particularly Indian or Pakistani...And it doesn't matter how much you tell them that actually it's the law… we have a shop round the corner (laughs), a little type called Mini Market, and I think they were Greeks or Turks who took it over and I went in and he said 'no, no dogs, can't you read the sign'...and I said 'well perhaps that's where the problem starts!' But of course it was one of those signs which said 'No dogs except guide dogs' so who couldn't read the sign!... I've stood my ground in quite a few other places, many in Brighton, it's got better (Male,50-65, visual impairment)*

Some services provided opportunities for people with visual impairments to participate. For two participants with visual impairments, one community service which they used was the local library, which provided audio books:

> *We've got the library, they're quite helpful there, I get audio books there if I want to or from other sources... (Male,50-65, visual impairment)*

One of the participants however felt that the level of choice of audio described books in the library was insufficient, and similarly so for films in the local cinemas which were audio described:

> *I find that a lot of the films that are audio described don't interest me at all. Not enough range at all. And I get talking books as well, there's not always enough range on them either. (Female, 25-50, visual impairment & mental health condition)*

Another issue for visually impaired participants related to the wider issue of how information on community activities was provided. As noted, participants access information in a variety of ways. For visually impaired participants, many offline, text-based forms of communication were inaccessible. One participant for example, was unable to find out about local events as these were posted as written notices in her building. Another visually impaired participant in one of the focus groups felt that more advertising of events was needed through media such as local radio:

> *My point about making communication more accessible is, I listen to Juice Radio and I know more about what's going on in town because of Juice Radio than I do because of any other reason. And so if the Council actually, you know, considered advertising their things via radio… I don't know whether they do already, that might be my fault, but that would really help. (Female, visual impairment & long-term health condition)*

A1.3.5.3. Hearing-impairments

In the focus group conducted with hearing-impaired participants, the main barrier to engaging in the community was the lack of communication support in community groups and organizations. As most of the focus group participants were sign language users, a lack of sign language interpreters meant participants were effectively excluded from community groups, organisations and events. Even where participants were able to communicate without a signer, the lack of other deaf people at events contributed to their feelings of isolation:

> *We get to the club and organisation and they all say hello to everybody as they walk in and there's a lot of them and I'm the only one that's deaf and I don't know what to say, nobody talks to me, they're all talking to themselves and I'm standing there looking like I'm out in the cold, no involvement in the groups. (Female, hearing impairment)*

At the focus group, which was held at the Sussex Deaf Association (SDA), the SDA was seen as the only organisation which provided the support they needed to engage with other people:

> *At the SDA I can get help with any problems, paperwork, I've got something to show and help me, if it wasn't here there'd be nowhere to go, there's nowhere to ask for help. No socialise... isolation, other places it's all isolation, here we can intermix and communicate with each other easily (Female, hearing impairment)*

A1.3.5.4. Mental health

For participants with a mental health condition, barriers to community participation often stemmed from a lack of support to access community groups in the first instance, which was often harder due to feelings of social anxiety or lack of motivation to participate in groups and events. One participant felt this to be a key barrier in relation to general mother and baby groups:

> *I'd say for people with mental health conditions in Brighton and Hove, and myself having a young child, there isn't resources or help for me… I found it difficult to access the groups that you go to with your baby when you first have them, but that's my social anxiety difficulties and feeling depressed (Female, 25-50, mental health condition)*

Appendix 1: Community Participation

A key point to note about community participation in relation to people with mental health conditions is the beneficial impact participants felt it could have on their mental health. One community project already mentioned in this regard was the conservation project, Grow. One participant on this project felt this had a beneficial impact on her mental health:

> *There's Grow. Which is a lovely conservation project. Well it's kind of just getting out into nature isn't it with a group of people, which is really lovely, organised through MIND. Yeah, and that's really nice, very healing and supportive and nurturing. Really, really lovely, really safe space, it's been really important, really good for me (Female, mental health condition)*

One participant with a mental health condition felt that more emotional and psychological support was needed to help people engage with a range of community activities, which could save resources in the long-run by improving people's mental health:

> *I think people with mental illnesses, it isn't their motivation to be getting online and going "Right, what's happening this weekend, I want to go do something," whereas if they can have a bit of a helping hand in that in someway…what they need sometimes is that mental stimulation in their lives to get out and do something, or at least give them to opportunity to consider doing something like that… If I can encourage rather than paying doctors loads of money, still do what you need to do, but invest a little bit of extra money into support groups, let them have more support sessions, let them arrange – I don't know, things like if the bipolar team wanted to go do something in an area together… if you got all of them together to go out for a day you'd probably lift those 10 people up more than they would've been lifted in a whole year, it would've cost practically nothing but I'd be interested to see the consequences on their medical health bills as a result of something that's just injecting a little bit of positive life into them. (Male,25-50, mental health condition)*

In relation to the issue of information provision discussed above, one specific point made by a participant with a mental health condition was the fact that information was often seen to be more valuable where it was provided from a source which had built up a relationship of trust with the individual:

> *I get most of my information from [Mind facilitator] and I trust what you give me, if that makes sense, and it makes me feel secure because I know you, I know the project, I know the ethos, I know why you'd be recommending it, so I would be more likely to go along. If I picked up a leaflet in a library or somewhere like that, which I think is a good place to have it, I think I'd be very scared, because I couldn't have a conversation with someone I knew about what it's going to be about. I know if you've recommended something I could email you, I can go 'Where is that actually?' or 'What time?'. So it would have to be some sort of… something that I trusted. (Female, mental health condition)*

Participants with a mental health condition made several mentions of the need for community events to feel like a "safe space", in order for them to feel comfortable participating. For one participant, it was important that people were welcome and included in the group even when not in particularly good mental health:

> *Just thinking about what really works for me, what's really helpful, is that even if I'm going there and even if I'm feeling in a good place at that particular week, if there's people there who are not feeing particularly good they still know that they are in a safe place, and actually it may well be something that's going to more likely improve their day, even if it's just that period of the day which is good, even if those problems are still there when they get home or what have you. To me that really affirms me, but also that I know that I don't have to be in a good place to go to that group, I can just go as I am, and that really again then takes down any potential barrier of me going there because I know that I can be there no matter how I'm feeling. (Male, mental health condition)*

A1.3.5.5. Learning Disability

As noted earlier, the wider issue of social isolation was also a potential problem for participants with a learning disability. One regular community event that was mentioned by several participants with a learning disability, in particular those participants in the focus group for young people with a learning disability, was the Blue Camel Club. All of the participants who mentioned the club were very positive about the opportunities it provided for social interaction:

> *You talked earlier about Blue Camel Club.*
> *Yeah Blue Camel Club, fancy dress party…next Monday.*
> *And do you like going to Blue Camel club?*
> *Yes I do, I see all my friends there, talking to my friends in the Blue Camel Club. [My boyfriend] is working down there next Monday night. (Female, 50-65, learning disability)*

Another group of importance to one of the participants with a learning disability was an arts-based project, which had facilitated him creating and selling artwork:

> I go to the Rockets. And we have a group and they... And they come and learn to do art. *(Male, 50-65, learning disability)*

Appendix 1: Community Participation

A2 Appendix 2: Health

A2.1. What are Health services?

This section of the report is focused on participant experiences of accessing health services in the city. In particular, the research team wanted to hear about positive and negative experiences, including any barriers participants had faced to accessing health services. The team was also interested in opportunities participants had for improving their own health outcomes.

This section includes participants' experiences about a wide range of health care services including GPs and other primary care providers, inpatients and outpatients services including hospitals, mental health facilities, respite and rehabilitation services, and community health teams.

A2.2. Approaching the Topic

Research interviews began with a general discussion about participants' lives and any barriers or problems they had faced, particularly in regards to public services. Some participants discussed health services with little prompting.

As the interview progressed, researchers asked the following more detailed questions on health services:

- How easy is it to get the health services you need?
  - What health services do you use regularly? What do you think of them?
  - Do you feel you have enough information about your impairment/disability/health condition?
  - Are you able to access all the health services you need? Is there anything else that could improve your health? "

A focus group was held for participants with a mental health condition, 45 minutes of which was devoted to health services, which generated extensive feedback on mental health service provision in the city.

A2.3. Detailed analysis

Experiences in regards to NHS health services were mixed between participants, and even despite some clearly identified problems, many were overwhelmingly positive about the importance of the NHS in managing their own health conditions.

> *I don't complain about the NHS because I think I wouldn't be here if it wasn't for the NHS. (Male,50-65, mobility impairment, long-term health condition & mental health condition)*
>
> *Since I was thirteen when this epilepsy started I couldn't grouse or moan about the NHS to be honest….. in any form because they have been good. (Female,50-65, mobility impairment)*

The structure of this chapter will begin with an examination of participants experiences in regards to specific services grouped into three main categories – GPs and primary care (dentists, opticians etc), inpatient services (including Brighton General, Princess Royal and Royal Sussex County Hospitals, rehabilitation centres e.g. Knoll House), outpatient and community services and mental health services. This will be followed by an overview of more general issues emerging for all services

The final section of the report will look at specific issues raised by participants from different "impairment groupings", e.g. specific issues raised by participants with a physical impairment, or a mental health condition.

A2.3.1. Experiences of GPs and primary care:

For many participants, overall experiences of accessing GPs had been very positive:

> *I've been with them since day one with this so I stick to them. He's really good, they all are down there. (Male,50-65, mobility impairment & long-term health condition).*
>
> *I've got a wonderful GP's practice. (Male,50-65, mobility impairment, long-term health condition & mental health condition)*
>
> *I have a good doctor, they're amazing. So I've had no real problems with them (Male,50-65, mobility impairment)*
>
> *My GP's fantastic anyway. They've spent a lot of care on me, both physically and mentally, you know, so they've kept a really good eye on me, but other than that. They've just been fantastic. (Male, mental health condition)*

The research team explored participants' experiences further by identifying positive or negative factors which people felt were important in the service provided by GPs. For participants, one of the most common issues raised was around the process most GP surgeries used for making appointments. As one participant expressed:

> *These days it's a real big deal to make a doctor's appointment because you have to phone up on the day and spend half an hour phoning and phoning and phoning while you're trying to do everything, going to the loo and have a cup of tea – it's very stressful so you feel like you've hit the jackpot if you get an appointment (Female, 25-50, mobility impairment, long-term health condition & mental health condition)*

As patients were required to phone up on the day in order to get an appointment, phone lines were busy and one participant found that physically visiting the surgery was more effective.

> *The only problem I've got with my GP is actually getting an appointment because from 8.30 in the morning you ring up and they just don't answer the phone, you know, so it's very, very difficult. Unless you get down there and wait outside the surgery about twenty-past eight in a morning, it's just virtually impossible to get an appointment. (Male, mental health condition)*

For some participants, certain impairments or health conditions affected how people slept, and more importantly how they functioned in the early morning. This was felt to make it very difficult for these participants to arrange urgent appointments either over the telephone or in person:

> *There's a slight problem with availability of appointments and the fact you have to queue at 8.15 that morning if you want to see a doctor that day. You can have the two weeks appointment system to book in advance, but if you want to see anyone that particular week you have to queue from 8.15 that particular morning, which, if I'm not having a particularly good day if I can't leave the house, if I haven't slept particularly well, if there aren't any parking spaces around at that time of the morning with the school run, it can be very, very difficult if it's urgent I see a GP then. That can have its issues. (Female,25-50, mobility impairment, & long-term health condition)*
>
> *You can phone up at eight o'clock in the morning and by quarter past eight all the appointments have gone for the day and also because I'm on sleeping tablets at night I don't normally wake up until nine o'clock in the morning. I feel they ought to have morning appointments and then a phone for afternoon appointments (Female, 25-50, mobility impairment, long-term health condition & mental health condition)*
>
> *P19 [My GP] is fine when you can finally make an appointment. It's one of those we have to phone up at eight o'clock in the morning otherwise you don't get a look in that day. And I…sleep so bad sometimes I'm not even getting to sleep until six in the morning. I'll lie there and twitch and cough and sit and feel sick and can't breathe and have to turn the fan on and get water and all that stuff and then I'm actually sleeping until midday from that six o'clock*

In the focus group with participants with physical impairments, experiences of obtaining appointments were shared. While one participant found it difficult to access a specific doctor urgently, another participant had used a more flexible system in her own surgery by asking the doctor to call her back:

> ***Respondent 1:** If you need a doctor, mine is dead easy, you've got to ring on the day and say "I want a doctor." If you want a specific doctor, that's not always so easy, they'll say "Sorry, all her bookings are gone" you've been ringing since half past eight*

> *and got through at ten to nine, you know, that's the sort of thing is the problem. But if it's urgent "I just want to see a doctor" you will get it within the hour if you need it, you know, but if want a specific… like I've got a diabetic specialist down there, and she's murder to get hold of.*
> ***Respondent 2:*** *The way round that… there's a way round that, you ask the named doctor to give you a ring back. And then they'll make their own appointments with you, but you have to know that (Male & female, mobility impairment & long-term health condition)*

One participant had used an alternative system whereby nurses acted as gatekeepers to GPs and patients were required to see a nurse for an initial assessment prior to seeing a doctor. The participant found this unhelpful as there were times when he felt he needed to see a doctor straightaway

> *In terms of doctors…I don't like going to them because the receptionist and the people in there are just so horrible, rude and unapproachable yeah I hate going in there with a passion…they have a really stupid system whereby if you've got a concern…you have to see a nurse before you see a doctor, you cant ever go and see straight to a doctor its just not possible. I think they could do with more doctors and more appointment availability….The receptionists they are just rude… they don't seem very interested in you and you know it's a doctors surgery they should seem approachable because you're going in there with difficulties. They're just…I don't like them. (Male, 18-25, visual impairment & mental health condition)*

For most participants, satisfaction with GP surgeries was often more a result of the personal relationship between doctor and patient, and in particular the general approach, bedside manner and treatment style of the GP themselves. For participants who had had negative experiences with GPs, a common issue was the level of care GPs seemed to show for their patients. In several cases, it was felt that the GP was rushed and unwilling to spend time listening to the participant. Often participants felt that doctors just wanted to prescribe something and then move onto the next patient as quickly as possible:

> *You see a doctor, you go in the door and the first thing they get out is a prescription, sometimes you don't want the prescription you know, without listening to you. (Male,25-50, mobility impairment & long-term health condition)*

One participant felt that GPs workload often meant the doctor hadn't spent any time to read up on the patient and reference their previous records, and thus didn't treat him as an individual

> *You've got ten minutes at the most, they're seeing 200 people a day or God knows what. It's another bad back to them, isn't it, that's all. They don't even know your history, they sit there and ask you questions and I'm like, "Well, have you not read the file before I walked in here then?". Simple, do you know what I mean, it's all in front of you, there's a computer there, you've got it all staring you in the face, mate, and you're asking me what pills I take? Do your job. But I don't talk to them like that, I just say yes, no, please, thank you. (Male, 50-65, mobility impairment & mental health condition)*

Another participant felt that the eagerness to prescribe medication without careful consideration meant he was so debilitated by side effects that his quality of life was impaired. For this participant, it was felt that the GP simply did not care enough for the patient's quality of life, which only improved when the patient took control of his own treatment:

> *Doctor's a waste of space, I think, to be absolutely honest…and I don't just say that about the one I've got at the moment, I say it about most of them. I have moved about a lot over the years, and even before I was ill I moved about a lot, wherever work took me. And you know, I think in my whole lifetime I've only met two that really take any interest in what's wrong with you...I mean, if it wasn't for the control that I have myself, I'd be a zombie. I mean, I had so many pills prescribed to me that I couldn't do anything. I'd get up in the morning, I couldn't find my phone, it'd be in the fridge. All that sort of nonsense, you know, and I was going mad and people were noticing it and sort of saying to me, "What are you taking?". So I had to go down the doctor and say to him, like, you know, "I've had enough of this, don't want to take this, tell me what this does, tell me what that does." So it has been rearranged, but it was only at my insistence, and even then, a very cold reception for it. Like, his immediate reaction was to prescribe more. (Male, 50-65, mobility impairment & mental health condition)*

In some cases, participants reported experiencing the opposite problem with their GPs, seemingly unwilling to prescribe medication which participants felt was necessary

> *I have moved now so I have a new GP. I think the doctor at the clinic they don't like to prescribe a lot of medication. When I was living at [my old address] I used to go into a different clinic and they [provided] extensive care there and they were you know…prescribing medication when I needed. Presently it is not the same; it's not the same level of care. (Male, 50-65, visual impairment)*

One participant who had a similar experience, put this down to financial constraints which his GP communicated to him when prescribing any medication:

> *The GP we've got now is a good GP. I actually think one of the most important things, he's understanding. Not so budget driven as some GP's have been.. So if something needs to be done he's quite happy to do it. Prior to that we had Dr [name removed]. More understanding of my condition than my partner's mental health issues. But again he was sort of like well I'll prescribe this but you know how much it costs type GP. You always felt a bit guilty about asking for things. (Male, 50-65, mobility impairment & long-term health condition)*

For some participants, negative experiences they had with their doctor were attributed not only to treatment styles but also the bedside manner and care that the GP demonstrated for their patients:

> *He's very good at filling the forms… so whilst I needed a hell of a lot of forms filled in for my insurance policy and for everything else he's brilliant, but as a people person he's not. I wasn't very well a while ago and was in hospital for six weeks and he had letters from the hospital and he never once picked up the phone to ask how you were,*

> *that kind of thing that's nice. (Male,25-50, mobility impairment & long-term health condition)*

In another case, the participant 's negative experience simply came down to the fact that she rarely saw the same doctor:

> *My surgery are all a load of locums mainly so you never see the same one (Female, 25-50, mobility impairment, long-term health condition & mental health condition)*

In contrast, participants who reported more positive experiences with their GPs were often those who had developed a good personal relationship with their doctor over time. In some cases this was made easier by small surgery sizes which meant patients see the same doctor, which one participant felt allowed his care plan to be developed and followed more consistently:

> *I am one of these people who need to have medical services and I need a good GP that I can rely on to look after me. Where I am now they are still local practices where you've got 2 or 3 GPs and people actually know you when you walk in with your repeat prescription whereas you don't have that in the bigger surgery where everybody's lobbed under one umbrella. And I find going to see her, she knows your face, she's got your medical history, she has a plan of action – you know, your diet, what medication your on, have you got any problems and she will basically help in that way. So I think from the point of view of medical services GPs I have no complaints there (Male, 50-65, mobility impairment)*

For other participants, personal relationships had also been built up in larger surgeries as well. In one case, the participant had multiple health conditions so knew most of the doctors in his surgery due to having regular appointments. For this participant, having GPs who specialised in certain areas and having access to different GPs when needed was an important factor in building up positive relationships:

> *You know, I know if I want a repeat prescription I can just ring my GP and say, 'Can I see a Doctor please?', and I go and see any of them six or seven that are down there. But I can also say, 'Can I see [name removed]?', if it's a diabetic problem, if it's something else I can see [name removed] you know and you know where you go when you go in and you know these people. You can pass them on the street and they go hey, you know! (Male,50-65, mobility impairment, long-term health condition & mental health condition)*

For another participant, having different specialists in the same surgery was beneficial for his treatment as it allowed instant second opinions to be provided:

> *What I find with my surgery is like, at the moment, I'm going through some tests for something they expect I've got and because my particular doctor wasn't 100% sure, she buzzed through to another doctor and then, for a second, he hadn't got a patient, so he come in. And so you're getting a second opinion there and then, on the spot, no messing. In the old days, I mean you'd have to make another appointment a week later to see somebody else, but not now. (Male, mobility impairment & long-term health condition)*

Often participants who had positive relationships with their doctors experienced long waiting times at their appointments. However, they were happy to wait as they believed that the GP spent as much time as needed to provide their patients with an appropriate standard of care. This also indicates how positive relationships can influence patient's experiences, which might otherwise have reported waiting times in a more negative light:

> *I'm really, really lucky, my surgery is brilliant. It's a very small client base, all the reception staff know me, I fall asleep in the waiting room sometimes waiting for my doctor because she takes so long, she takes so long because when you get there she doesn't chuck you out, so she's, she does find things out for me… (Female,25-50, mobility impairment & mental health condition)*

> *I've got the same Doctor as me flat mate, the same practice anyway and he said they were good and it's proved true. I mean they are actually so proactive down there. I go to see Dr [name removed] and you know you've always got to wait. If it's a five o'clock appointment in the afternoon it's gotta be quarter to six, you know. You know that and you're ready for it because when you go and see her it's not a seven to ten minute turn around. You can be in there forty minutes talking and when you've got something to say and ask they'll be there listening and doing. So, I'd rather have the wait and not be rushed out with a quick prescription. (Male,50-65, mobility impairment, long-term health condition & mental health condition)*

In one case, the participant's positive experience of her GP simply came down to how understanding she felt the surgery had been during her period of illness:

> *My GP's absolutely amazing. I mean I, I registered at [name] and I'm still there because they're so good. It's a bit of a mission to get out there but it's worth it I think. They're very, very helpful. They'll do anything for you. Yeah, they're very understanding. I mean my GP's just retired and I've got a new GP but she's just as nice as the old one so that's alright. And the nurses are all very good. I had quite a lot of mental health problems a few years ago. I'm sort of better now but I had some big issues while I was at Uni and they were so perfect with them. I had a bit of a red flag next to my name for a while but yeah they're very understanding and helpful. (Female,25-50, mobility impairment, & long-term health condition)*

One factor which influenced how participants perceived their GP was the extent to which they proactively treated health conditions and one-off problems. For one participant this was felt to be inadequate, causing further problems and meaning she needed to access additional services:

> *Dr [name removed] is a lovely woman, but she tends to say when I go there, "Oh dear, what a shame," and no further action. Like, I've been going back time and time again about my knee, just told to take pain killers and rest it until um, I just ruptured the ligaments. (Female,50-65, mental health condition)*

Conversely, another participant felt that his GP had been proactive by recommending that he received a regular flu vaccination, which helped to avoid a crisis situation where he needed to access services urgently:

> *When you have got a disability another thing can happen - things like getting a bad dose of flu or a cold – I have a flu injection once a year with all my other problems I have to have a flu jab in October because even just having a mild dose of flu or a mild cold will basically amplify it into really bad flu conditions and again living by myself you don't want anything that is going to start making you feel unwell so you're laid up in bed. Then you would need services to call on then but I would not know who to call to do things – you would have to rely on neighbours or friends. (Male, 50-65, mobility impairment)*

Many of the participants we spoke to in our research had long-term conditions which were often rare, and thus less commonly encountered by GPs. Often participants in this group had less positive experiences of their GPs as they felt they did not understand their conditions and lacked the expertise to treat them effectively:

> *Well, there have been times when I have gone to the GP because I have been having an MS attack they are generally really clueless and what help can they do anyway – what do I expect? (Female, 25-50, mobility impairment, long-term health condition & mental health condition)*
>
> *I think I mean they're a brilliant team but they need to find out about the condition that I've got and also to find out about with my syndrome there's so many different medical things that are an important factor. (Male, 50-65, learning disability)*

Participants with rare conditions often felt they had to research their own conditions to improve their understanding and treatment outcomes, due to the lack of knowledge of their GP:

> *I had to find out things me self you know the Doctors, well I have found quite a few of the Doctor's are pretty useless and didn't know about CFS and that's always been the thing. The thing is there's no diagnosis for it and there's no cure for it, Chronic Fatigue Syndrome. (Male, 25-50, mobility impairment, long-term health condition & mental health condition)*

Where participants have been living with conditions for some time, they had often gained considerable expertise, not only into how their symptoms presented and interacted with other factors, but also regarding ongoing developments in research and treatment for the condition. This knowledge came from a range of sources including other specialists and Internet sources such as online forums and condition-specific websites:

> *It's funny actually MS because I've seen god knows how many GPs I've had and I know, it's probably like yourself, I know a darn sight more about MS than my GP will ever know so I can take whatever I know. Whenever I go it's them reading the book when I say something and I know that you self-medicate yourself to a degree. I just need a doctor to tell me how much I can take of this, once he tells me I make it round with the drugs myself.*
> ***So where do you get your information from?***
> *It's from life, it's just from what's happened, the neurologist, consultant, GP, reading books, reading the internet and you're stuck with it, you're interested and everything aren't you? You get the journals, the magazines and everything else relating to things*

> *so it's quite full on reading. GPs to be fair to them, they know a little bit about a lot, they don't focus on MS forever, like the neurologist at the moment, he's a neurologist but doesn't focus on MS. (Male,25-50, mobility impairment & long-term health condition)*

> *At this stage, I've been discharged from all the clinics; it's only my GP I can refer to for guidance. And he takes guidance from me because he knows I'm on the internet and belong to IBS groups, ME groups, Prostatitis groups. All three groups are all saying the same, singing from the same hymn sheet which is nothing works. So he relies on me, in fact I don't really see him these days it's usually by telephone if I've got an issue because he knows for me to go to the surgery is such a palaver. (Male,50-65, mobility impairment, mental health condition & long-term health condition)*

For participants with extensive knowledge and expertise of their own conditions an important factor in how they rated their GP was the extent to which their GP involved them in treatment decisions. In some cases, the imbalance of knowledge between patient and GP was such that participants simply wanted a GP who would prescribe treatment or equipment which the participant had already decided on, "to do what they were asked":

> *My doctor's fabulous, very good GPs very good – I've come up against some now and again I would like to slosh and they just look at you and make up their own mind about whatever they want to and you try changing their mind…I have a bit of a thing about doctors. No these two are absolutely brilliant I think they have done everything we've asked them to recently. It was my doctor who recommended me the wheelchair when I asked him. And he said Yep no problem – he actually sent me these forms to fill in and then when he got another set of forms he phoned me up – so yes absolutely fabulous both of them have been so amazing (Female, 25-50, mobility impairment)*

> *I was with a GP in [name]. And it was very, very good, very efficient. I moved to a new GP now in [name], you know. They are very good, very helpful …I mean you ask for it, you get it. (Male, 25-50, mobility impairment)*

One participant who had had ME reported a more negative experience with a GP who wanted to take her off medication she had been using for many years without consulting with her:

> *My GP wanted to take me off medication I'd been on for, been about thirteen years at that stage. The medication was working very, very well for me, it wasn't even a discussion about how would I feel about being taken off the medication it was a case of pretty much in the first meeting that I'd seen him, looking through the notes and wanting to take me off that medication. One of the medications I was on was an antidepressant, which I was on not because it was an antidepressant, but because it's a very good painkiller. But he saw the medication, automatically assumed it was an antidepressant and made a note in my medical records ... about my appearance and that I didn't appear suicidal... he just hadn't bothered to read anything about my medical history or ask me about how I was doing on the tablets or anything, he'd made assumptions and hadn't talked to me about it. (Female,25-50, mobility impairment, & long-term health condition)*

Another participant with a mental health condition reported a similar experience when using a new GP, in this case a temporary locum:

> *My regular doctor that I see is very nice, well I've had two but one of them left and I was given another one, but I had to go and see a locum one time and I'd discussed with my doctor how we were going to deal with my problems and he tried to change everything and it was just a one-off appointment with a locum. I felt quite bullied by him really. But my normal, the regular ones have been fine. (Female, mental health condition)*

In some cases, participants felt they had to be quite insistent in order to access the treatment or referrals they wanted. One participant found the GP tended to comply when her mother accompanied her to appointments and helped advocate for the treatment the participant wanted:

> *My GP is good. He really is. Unfortunately, he is incredibly frustrated and feels very guilty. He said that he, him and the NHS have failed me, and I agree, and I know that he feels guilty, but that's not my problem. And he really needs to keep pushing, because I'm not prepared to just go, oh, well, never mind, and then it's just a case of just going and poking him and getting the next thing on, and I had to ask for an appointment at the pain clinic, and he should have done that two years ago, and he's been very reticent about me getting a neurology appointment. So that did take a visit from mother. Every now and again, my mum comes down, and comes with me to the doctor and he tends to comply at that point. But he has been very good. He is a good man. He's just stumped, because I'm stumped. (Female,25-50, mobility impairment & long-term health condition)*

For some participants who felt less able to challenge treatment decisions, this lack of involvement alienated the participant from using the GP surgery. For one participant with a mental health condition, the perceived lack of involvement in treatment decisions was not just disempowering, but also a source of considerable stress and anxiety as she felt at risk of having her child taken into care, and consequently changed surgery:

> *I haven't yet got a good relationship with my new GP, I moved to Hove and so when I joined a surgery that was more about me seeing a midwife as I went through the pregnancy, then after that I went to see the doctor and I would say maybe she was an old fashioned doctor and I left that surgery because I didn't want to go back there because she said to me that she wanted to put me on Lithium and that's a huge decision to go on Lithium, and I really don't want to do that, and then she said the phrase, "well, you wouldn't want your child to be taken off you if anything happened", yeah, and I thought, "God, do people really think that about mental illnesses these days?" …so that was a bit upsetting, but I phoned the surgery manager and said that I thought that was really inappropriate, really upsetting and I moved surgeries... because that woman saying that and it really you know, put the fear of God in to me that she could have that power, that if I didn't take this medication (Female, 25-50, mental health condition)*

For another participant, who had a mild learning disability, involvement was more about providing access to treatment when she felt it was necessary. The lack of clear explanation for how the participant could access an appointment actually resulted in her using accident and emergency services:

> *When I was at my old doctors they used to refuse, because I'd only go to my doctors if I'm feeling that bad, you know, I wouldn't go down there if I had a cold because that's stupid. There was loads and loads of times that she turned me away. I used to say 'Alright', and I used to go up the hospital, just go up there, I thought I'm not going to be turned away. Then I decided to move my doctors, I'm at [name]. They're brilliant. You know, nothing's too much, you phone up, you say 'Can I see a doctor?' and they'll tell you over the phone if they're booked or they've got vacancies, which is good. (Female, 50-65, learning disability)*

A final issue raised in regards to treatment styles and attitudes regards the level of disability awareness shown by GPs. For one participant, this was felt to be lacking although overall he was happy with his GP:

> *My GP's really good. She's excellent. She's excellent, but also funny in that....um, I was asking for something. Oh, it was something like getting a blue badge. And she said, "but you don't drive anymore!". I said, but no you can put it in the car. Know what I mean? You know, she's really good at things and then she's not. (Male, 50-65, mobility impairment & mental health condition)*

As can be seen from the participant's accounts above, experiences of GPs have been extremely mixed. Where they have been negative, some participants have sought to change GPs, which for some participants raised a further issue regarding how easily participants were able to choose which practice they used. One participant felt that the GP surgery created unnecessary barriers to changing GPs:

> *I had an absolutely excellent GP who then left the surgery, and all her patients were then transferred onto another GP. I saw him a couple of times and it was very clear that he didn't understand ME he didn't understand, kind of the link-in conditions that go with it, whether it was the joint pains or the possibility of fibromyalgia or, kind of any of those bits that went with it...I remember at the time thinking that this was not the GP for me, but it was the most convenient GPs practice and I wanted to swap to a different GP but within the same practice, and was told that, 'that simply wasn't possible' and that he was just as qualified as any other GP there. And it took, perhaps two to three months or so to try and swap to another GP within the surgery, who was very, very good and who did a kind of complete review of me, saw that I hadn't had blood tests in a while, organised that, went through all my medications, did a kind of a top to bottom health check and review, which I probably should have been having more regularly, but that was very, very good. (Female,25-50, mobility impairment, & long-term health condition)*

The issue of a lack of choice over the GP surgery which was used was also raised by participants who wanted to keep their existing GP when they moved elsewhere in the city. This was often because participants perceived the quality of GPs to be highly variable. As one participant expressed:

> *The only thing that does puzzle me with these GP's is I wish they'd hurry up and bring out this thing where you can have a GP in any local area, rather than have it specifically for the one that covers your small vicinity. Cause it's a pain. You can get one good doctor and then you move and then you've gotta try another one and hope you get a good one, which quite frequently you end up getting a [censored] one. (Male, 25-50, mobility impairment, long-term health condition & mental health condition)*

For one participant, he felt that regular changes of GP when he moved through various locations in Brighton had a negative effect on the care he received as he did not stay with one GP long enough to get specialist referrals. This was finally resolved when he was able to keep his GP despite moving:

> *My GP is [name]. There is a local GP here. They do have a surgery nearer, but I've moved around a lot over the past few years, and I'm trying so hard to get appointments at the hospital and this, that and the other, to get this sorted, and to do that you have to get on with the doctor first, so I decided to stay with that doctor and not move, because, and that's worked, I mean, I've got an appointment at the pain management clinic, so it is coming along. To see some neurologist and some consultant surgeon, and hopefully they might be able to do something. That's taken three years. I get to know one GP and then I move, and then I get to know another and I move, and up until now, I've been in private rented accommodation. I got offered this flat by the council last year, so I'm not going anywhere now. This'll do me. (Male, 50-65, mobility impairment & mental health condition)*

One participant had made a specific effort to keep his GP when he moved, which was complicated by later decisions to change the surgery catchment area. While the participant had nevertheless been able to keep his GP, he reported that the community district nurse team had put pressure on him to change GP or else lose his regular visits from a district nurse:

> *I'm having to battle to keep him [my GP] when I was moving. Before I moved I said to Dr. [name removed], can you tell me where I can move to and still keep with you and he said well where are you interested in, well I said well my partner wants to be in such and such and he said no that's definitely alright we'll certainly keep you on the books. And then of course when they started to change attitudes, not them but the primary care trust changing their attitudes they started to insist that I was not within their…in their catchment. And this is one of the reasons why I'm having problems with the district nurses because they say they are having to go out of area and that I could actually change to another district nurse team which I said I was prepared to do, I said provided they can guarantee that that district nurse team still sent all my notes to my GP. And they said they couldn't do that, that if I had a different district nurse team then I'd have to have a different GP and so that's been my battle to keep them. (Male,50-65, mobility impairment & long-term health condition)*

A2.3.2. Other primary care issues

One participant had had negative experiences with the emergency GP callout service. As with some participants' experiences with GPs, the participant felt the team did not involve him in their treatment decision, resulting in an unnecessary visit to accident and emergency:

> *I've had to report them every time I've called them up. I've had to report them for what I would call gross misconduct. Last time I had to call one up I didn't need to go to hospital it was only a bit of pain down the side here but that was coz where I cough I ripped the lining of my stomach and that you know between the rib and the lung gets inflamed. I told them that and they didn't want to know because it was raining she sent an ambulance round…I got rushed to the hospital needlessly and I had to make my own way home. You know, no money…how do you do it? There was no need for it. It was only because she couldn't be bothered to come out. (Male,50-65, mobility impairment & long-term health condition).*

Another participant expressed positive feedback regarding how he accessed his regular medication without needing to visit his GP surgery:

> *I don't have to go and see my GP for pills. I don't like going to the doctors, I only have to go now every six months or something like that. Because I pick up my pills somewhere else it just seems easier, you know. You don't have to wait in that environment where everyone's, you know, what's up with him, what's up with her, you know, it's somewhere you just pop in, it takes me 10 minutes, and it's much better. I must admit it probably clogs up the doctor's surgery, people going there just for repeat prescriptions. (Male, mental health condition)*

A2.3.3. Experiences of Inpatient services

The majority of participants' experiences of hospital services related to Royal Sussex County Hospital, or in a few cases the Princess Royal Hospital in Hayward's Heath. Most experiences were quite negative. In a few cases, this related to perceived poor standards of care which were felt to have put the participant or their relatives at risk. For one participant, the care his mother received was of great concern:

> *Most of my experiences [with the Royal Sussex] has been nursing my mother [in 2006]. Which has been just horrendous, wouldn't want anybody to go through what we went through. It's just unspeakably awful. She developed a chest infection and she went into an awful ward, like a holding bay to die…and she was on this ward which was almost, wasn't a proper ward it was a corridor to a ward, where she was sort of ignored and ignored until the lung infection became serious and she was on the point of dying. Then they moved her to a proper ward off that and nobody was taking holistic care of how she was, I had to go in and do everything. I had to wash her. I had to go in and make sure I was there when any specialist came because nobody was keeping…they couldn't even write the notes up and on one occasion I was there and I said I'm very worried my mother's been on nil by mouth but you're not giving her any fluids and they said oh yes that's fluid and I said no that's not. They said its fluids, I said that is an anti-biotic drip which was switched off three days ago and she's had the line in and nobody's touched her since then. It turned out that the nurses hadn't understood the instructions, they hadn't actually written down that she was meant to be on intravenous fluids, the woman after three days was dehydrated and with sats of eighty three or something and was virtually on deaths door. This went on and on for*

> *seven weeks and it just became one nightmare after another (Male,50-65, mobility impairment & long-term health condition)*

For another participant with a long-term health condition, her personal experience was that she was left waiting eight hours for urgent treatment in accident and emergency. In this case, the patient was able to achieve a positive outcome from her negative experience by pursuing the issue with the patient advice and liaison service PALS:

> *I've had a bad experience with an A&E department last year [2010], where I was poorly sick and they didn't treat me quick enough, in fact they left me in a little room without fluids despite the fact that I was losing all, everything I needed to maintain and there is obviously a risk element that the more you lose the more likely you'll have a cardiac arrest, and they put me in a room with no one, I fell asleep because it was early hours of the morning and I woke up to find a nurse kind of shouting at the actual doctors because they had left me for eight hours and not dealt with me, which I had to deal with. I went to PALS and I told them, I said that this isn't good enough, every time I come in I wait six hours before I see someone overall, until I see a renal consultant, that's before I've had any treatment and it just makes the situation worse so I need something to help that.*
>
> ***And what kind of response did you get from PALS?***
>
> *I got them to speak with my consultant who, together, they decided it would be best if I had a letter that I could bring in on reception to present to the receptionist saying that I needed immediate treatment within thirty minutes of admitting myself, which I've tried and tested and it has worked. So the outcome is positive, I'm now being treated better than I had before, which is good. (Female, 18-25, mobility impairment & long-term health condition)*

For some participants, negative experiences were attributed to the lack of continuity of care that they received from nurses. These participants felt that the presence of many different nurses working short-term shifts meant that nurses did not know their patients and often made errors when administering treatment:

> *[in 2010] I mean most of the nurses were great but there weren't that many nurses, there were a lot of, I want to call them Bank, where they get them agency staff, which wasn't good at all because they'd get agency staff that were in for a day, didn't know you, didn't know what your condition was, didn't know your name or anything so they'd come in, earn their cash then go on to another job. There weren't any day to day nurses that got to know you, there were one or two of them which was great, but there were a lot of strangers coming and going. (Male,25-50, mobility impairment & long-term health condition)*

For one participant who stayed in the Royal Sussex hospital in 2010, this problem was compounded by a lack of communication between nurse and doctor which resulted in conflicting decisions regarding his discharge from the hospital:

> *When you're in a big hospital and you got so many change over's and so many bank nursing staff you don't know who's what, and they don't know about you. I was asked when I was in there if I would do a urine test you know for the diabetes and they gave me a set amount of water to drink in a certain period of time and the doctor came in and said oh you're discharged. And they said, no he isn't. I'm discharging him and they said no he's not he's already going through bloody tests and he's on one now and the*

> *right hand don't know what the left hand's doing. (Male,50-65, mobility impairment & long-term health condition)*

In addition to poor continuity of care, participants also reported problems where they or other patients required personal care from nurses while in the hospital. One participant with MS required assistance with toileting, and experienced long delays due to the lack of nurses to help. This resulted in missed physiotherapy appointments and thus affected the participant's treatment:

> ***How was your experience of being in hospital recently [in 2010]?***
> *It was crap. Haywards Heath Princess Royal rehab and I was in there for six weeks, it was crap, absolute crap. I'll give an example, I missed all three physio appointments with the doctors because I was sitting in the toilet waiting for the nurse to come and give me a hand to help get out of the room – I did the, you know, you do the buzzer and you could be waiting, probably twenty five minutes for someone to come and help you get into your chair so you can get to the physio.. If you wanted to go to the loo - have a wee - you'd have to wait twenty five minutes for a nurse to come help you, not so much the nurses fault, there weren't any nurses; they were just, numbers were so low so it wasn't good at all. But when you think you're there for rehab and to miss your valuable physio sessions because when you're waiting for someone to come and help you off the toilet into a chair for twenty five. It got so bad that when I used to go to the loo I would always take either a newspaper or a book because I knew I'd be waiting, waiting that long and you'd read two chapters while you're waiting for someone to come help you, you know. (Male,25-50, mobility impairment & long-term health condition)*

One participant witnessed similar problems for other patients in accessing assistance with toileting, during her recent stay after she broke her elbow:

> *Even things like most of the women on the ward were elderly and had new hips, hip repair, and they were very slow at the bed panning. I mean I couldn't understand why they didn't just leave a clean bed pan by the side of the bed really. I mean I know you're supposed to help them on it, but the time they took to come, you know the old dears….because it meant they created more work because often the old ladies just ended weeing the bed and then they got to strip the bed anyway. But, no, I thought they were very uncaring. (Female,50-65, mental health condition)*

One participant, who had a background herself as a nurse, was relatively pleased with her own surgical treatment but was shocked by the poor hygiene standards in the hospital and the lack of support from nurses for patients personal care needs:

> *The surgeons seem good. I mean it was a terrible break to my elbow it was completely shattered. But you know, I think considering the mess I made of it he did a good job. I think the nurses are rubbish. I mean speaking as someone who was a staff nurse, I think patient care is bad.*
> ***Anything in particular?***
> *Hygiene. Basic hygiene, there was an old lady on the same ward as me who was completely blind and they didn't even bother to feed her. They just stuck the food in front of her and gave her a spoon and left her. Because she was old and she was constipated she picked at her bottom, and she was blind too and I thought the staff were very rude and said oh look this dirty old woman's been picking, and they didn't*

> *clean her nails properly. I in fact told one of her visitors, that she'd got all poo down her nails and they went and reported it to the staff nurse, and they said it's not our remit to clean nails. So, this man did it for her. (Female,50-65, mental health condition)*

Another participant echoed the lack of support available to fellow patients for basic care such as toileting which he saw during his stay in 2011:

> *I was admitted for a day about four weeks ago and I try to avoid the place, they're horrible. Especially with, with asthma, like I say you're in with old people anyway and it's, it's just a horrible experience really. I mean most of the staff are okay, but sometimes they seem inundated and they can't spare the time to really talk to you and that you know. And I just feel sorry for the really old people that are up there and need a bedpan or something and can't get out of bed. It must be so awful for them, so undignified. (Male,50-65, long-term health condition)*

A third participant, coincidentally also with a background in nursing, was very critical of the approach taken to feeding patients which she witnessed during her current volunteering work as a listener on hospital wards:

> ***How was your experience of the Sussex Hospital?***
> *Enlightening with the new nursing the way its done. And yes it's quite an eye opener yes. I'm very critical of how the men and the women come round with the drinks trolley and food and stuff and just leave it laying around especially if somebody's there that needs feeding…when we were nursing, you used to just have somebody obviously do the food, and then you used to give it out and then you used to know your patients that couldn't or wouldn't really be interested in food so you used to sort of egg them on and try to get the food down them. And then you could see this food now being sort of just left on the corner unless of course the relative then comes in. (Female,50-65, mobility impairment)*

In one case, a participant felt that attitudes of the nursing staff were to blame for the negative experience they had had in the hospital. This participant had extensive knowledge regarding rules and regulations in hospitals due to his previous work, challenged his nurse during his stay and described extremely hostile treatment he received in response:

> *Brighton Sussex University's Health Trust. Yeah the County. When I was rushed in there in February 2010 after a fall I was taken on to the ward at six in the morning and the nurse in charge says get this man a catheter and I said you what? And she said I don't have any man on this ward unless they've got a catheter. I said you, you do not mean that do you? And she said yes. Well I said under the Coldicott Guardianship of the NHS you cannot do something against my will unless I am sectioned or I am unconscious and I'm saying you're not fitting me with a catheter. She said oh, we'll soon sort that out and put me on a drip! And she said that'll make you go and we'll see when you start begging me to fit you with a catheter. And I didn't need it you know*
> ***So sounds like not a great experience.***
> *It wasn't and when I came out I picked up an infection on my back from inside there and I had boils all down my back. I had four of them and had to have district nurses come in and dress them everyday. (Male,50-65, mobility impairment & long-term health condition)*

This same participant was also critical of the staff providing food for conversing in front of patients in a foreign language during his hospital stay:

> *Most of the people who were doing the food I don't know what language they were speaking but they wasn't speaking English. And they would talk between themselves in the foreign language which was very disconcerting to people and especially elderly cause they had no idea what was being said. Whether they were talking about them or not. And you know if you're working in an English hospital you should be speaking English while you're in staff. You can do it in the corridors if you're talking to each other or in the kitchen while you're heating up the food but you don't talk it in front of patients 'cause it's very disempowering. (Male,50-65, mobility impairment & long-term health condition)*

Other problems participants experienced during hospital stays have included difficulty relating to bed availability. One participant was put onto an overflow ward during his stay and found it very busy and disruptive:

> *I was in for a day about four weeks ago, but the last time before that I was in for about two or three nights. I was, I almost got my clothes and walked out in the middle of the night it was so awful. It was just so, the nurses, well it was they were really busy so we were put into like an overflow ward and there was all these people screaming and shouting and that. And then I, I couldn't sleep so I wanted to read and the nurse told me I couldn't put my light on and things like that. (Male,50-65, long-term health condition)*

For another participant who had a rare condition which meant she often needed to access specialist wards, she found this was often impossible:

> *I suppose it's the good old fashioned [comment] in terms of NHS services, especially the A&E, there's never any beds. I can never get onto renal wards, I'm often plonked in god knows where which is, I think I know that my condition is manageable in any ward, I think it is still nice to know that if someone could have that sort of area that you can go to through people who are knowledged in the renal department for me is much more comforting than being in sort of an Alzheimer's ward or something. (Female, 18-25, mobility impairment & long-term health condition)*

Feedback around waiting times was not all negative. One participant found waiting times in accident and emergency to have improved due to the use of a triage system. However, he still felt A&E waiting rooms to be quite unsafe and wanted to see greater security:

> *The last few times I've been up there I've found that the A&E side of things has improved a little bit.*
> ***Oh okay, in what way?***
> *When you go up if you've booked up in advance and a doctor has said you're coming up then you virtually go straight into the waiting area and see a doctor, like a triage type area and they decide where you're going next, so that bit's improved. If you have to sit in that, those areas for any length of time you've got all the, all the druggies and the alkies and that and you, you are quite vulnerable. And you know I felt better once*

> *there was, there was a copper up there looking after some, some ill girl or something there and I thought well, 'cos I can't, when I'm really bad I can't do anything to protect myself you know. They could just walk up and take my money and go away. (Male,50-65, long-term health condition)*

One of the participants with a rare condition found that as in GP surgeries she also encountered ignorance in relation to her condition from A&E doctors. In these cases, she found she needed to be the expert in her own health and had to instruct A&E staff in how to treat her. She found the response to this could be mixed and doctors did not always take her seriously as an expert patient:

> *I think constant challenges are when I sort of go in sick, because you always meet new A&E staff, so again have nothing to know about your condition and they can either think you're being funny or making it up or lying because you know far too much. I've often had to be quite strong and persistent that I have a renal consultant that they can speak to, this is what happens and they do deal with me but I've had my fair share of them looking up on Google and suddenly understanding what it's all about, through Wikipedia. (Female, 18-25, mobility impairment & long-term health condition)*

Many of the participants who had experience with services in Royal Sussex County Hospital as an inpatient were quite negative about any stays in hospital. However, participants who had been treated on the Digestive Diseases ward were more positive about their experience. For one patient, the support and information provided at the department by Crohn's and Colitis UK helped him to cope with his diagnosis:

> *When I was initially diagnosed they're quite on the ball, they give you a pack and basically it's got all the information about support groups you can join and all the benefits, what you're entitled to, basically about what you can eat, what you can't eat just, just an array of information … the Disability Discrimination Act and stuff like that 'cause I was a bit worried about taking time off and how it was going to affect my job and stuff like that. But no it was very beneficial (Male, 25-50, long-term health condition)*

Another participant, who had had the negative experience with his mother in 2006, had a far more positive experience at the Digestive Diseases ward with his aunt in 2009. For this patient, the main difference in experience came down to greater continuity of care and organisation among the specialist nurses working on the digestive diseases ward:

> *I had an aunt who we nursed up on the Regency digestive ward which was '09 I think and it was run by an old fashioned manager matron and it's absolutely fantastic. It was wonderful, and the way they took her through to death and gracefully and elegantly and on her terms, you know. The whole family and her were treated impeccably and that's been my only good experience of the place. So I've said to doctors and things that if I did have to go somewhere I wouldn't go unless I had to go onto the Regency ward for Digestive Diseases. I think from my experience of it, the permanent nurses and the surgical nurses that are on surgical wards and they are very specialist and very disciplined and in surgical wards work well. When you get onto medical wards it's mostly agency staff so there's no particular care or consideration from one shift to the next. There isn't time for handover because it's so chaotic. They are not interested in*

> *handing over properly; I mean that was my big problem that I could see the handover just wasn't being done. And so there's no kind of continuity to the care. (Male,50-65, mobility impairment & long-term health condition)*

This issue of participants building up a rapport with permanent staff who consequently provide a better quality of care was a recurring theme in some of the interviews. It seems to be a key factor in how some participants characterise their experiences as inpatients. One patient felt similarly about the Hurstwood Park Neurosciences Centre located at Hayward Heath Princess Royal Hospital where he stayed following a stroke. For this patient, continuity of care was also greater because it was a small ward with permanent staff:

> *Hurstwood Park well if it hadn't have been for that place I wouldn't have been here, I wouldn't be sitting here today, I wouldn't have been alive...But the nursing care out there is brilliant. I think the County Hospital is just too big really because no-one actually gets to know anyone in there. Whereas Hurstwood Park it's actually a designated ward and there's only about twenty patients there at any one time. That's the difference, you know all the staff by names, all the cleaners and…...it's actually one-to-one care. (Male, 25-50, mobility impairment & long-term health condition)*

Another participant had a similar experience at the rehabilitation facility at Knoll House, in Hove. The participant here found staff to be friendly and was very positive about his experience:

> *Because from the left hip I kind of, it was mostly the same staff this time as when I had my right, left hip done so they kind of "oh no, not you again [name], get out (laughter), bye". No, they all kind of, they had to have a joke...They are good out there, the staff out there are amazing....it was nice because yeah, you have your own room and I had a nice walk-in shower, that was cool, in my room. (Male, 25-50, mobility impairment & long-term health condition)*

A2.3.4. Experiences of Outpatients & Community Services

Participants also accessed a range of services from outpatient clinics and community visiting teams. Some participants' negative experiences of outpatients services at Royal Sussex County Hospital focused on the length of time they had to wait to see a consultant when they attended appointments:

> *Royal Sussex…it's been very good apart from the waiting times sometimes. Six hours late. Yeah we had to wait six hours. Yeah, but then again if you book with popular consultants sometimes it just gets like that.*
> ***Right, yeah. And which services do you access?***
> *Neurology, Rheumatology and the Lawson Unit. (Male, 50-65, mobility impairment & long-term health condition)*

A participant with moderate learning disabilities also experienced a long wait, and in one case his case notes were lost:

> *I think I've had problems up the Royal Sussex where you have a time allocated to see someone and you have so many people turning up at…for the same time appointment and sometimes you're…you're waiting longer....And also I've known for my case notes to be missing. (Male, 50-65, learning disability)*

One specialist set of services which several participants have used have been the various pain management clinics in the city. One participant had a positive experience of this service as they offered a wide range of treatments for him to try:

> *When they sent me to the pain clinic, to try and control the pain of the prostate, they diagnosed me as having ME. When I was at the pain clinic, I have tried various treatments there and they were good they tried Western acupuncture, electro-stim machines, different drugs, oh, a version of the CBT which raised my eyebrows because people with ME are just sick to death of hearing CBT is the cure, it certainly isn't. (Male,50-65, mobility impairment, mental health condition & long-term health condition)*

Another participant had been referred from his pain clinic on to a pain management programme at Brighton General Hospital which he found was useful as it took a practical approach to helping him live with his pain levels and also allowed him to benefit from the experiences of other patients:

> *They have a Pain Clinic [at Sussex County] which my doctor referred me to … basically they try to tell you what is causing the pain and how to take steps in doing things which alleviate the pain to some extent hand in glove with the medication you're taking. And from there they referred me to [Brighton General] hospital which has a Pain Clinic where you have other people who have got different types of pain. So there was about 8 of us in this group…which I found interesting because you could put your voice forward to the physiotherapist who was giving the actual lecture, and he then talked about what causes this pain and everybody participated and he then went on to say how you can try and stop the pain or try and ease the pain by doing certain tasks throughout your daily life. I found that really interesting. It was helpful to get the input from other people because …everybody is inputting different things and telling you their experiences and how they can stop pain or finally alleviate the pain. (Male, 50-65, mobility impairment)*

Although this more psychological approach to pain management was of benefit to this particular participant, another felt that they were less appropriate for her. In this case the participant was referred back to the service as her first visit had been unsuccessful in finding a treatment for her. While a treatment was eventually agreed, the participant found staff to be less than helpful on her second visit:

> *Pain management at the polyclinic, they're not so nice, they're mixed... I haven't had great experiences at pain management. I saw a clinical psychologist that deals with pain… I was there for like an hour and a half, I was exhausted, it was when I was more sick, she told me to read a book… then my lovely GP just re-referred me, she just re-refers me and she just puts me back in the system, I love her, and then some other guy was really rude and really horrible to me, and he said 'I don't know why we're bothering with you, obviously nothing works for you' and he was just really, really out of order. However he recommended the injections, and failed to write to my GP and*

> *tell her what they were, so between us and the internet we worked it out, and fortunately she's brilliant, and then I went for the day case and it wasn't him it was his deputy that did the injections and he was all really kind and the nurses were really kind... (Female,25-50, mobility impairment & mental health condition)*

One service which was rated well by two of the participants with MS was the neurophysio clinic. Participants found that this clinic was useful as it provided ongoing practical support for living with the condition, and in particular was able to be flexible around the participants needs, whether through practical sessions outdoors or home visits:

> *The neurophysio's have been completely brilliant, absolutely amazing. I sometimes go and see them every couple of weeks. Sometimes you know they'll cut it back to sort of every six months and let me just get on with stuff but they're brilliant at trying out new walking aids with me and just having a good look at what's going on and sorting out my posture and how I walk and everything…The last time I was there I said to her look you give me all this stuff to do in here and I do it all with you and then the minute I step outside the hospital I feel like I've gone back into all my bad habits. So they were like right we're going to go and do a whole session outside. So they just took me outside the hospital and walked me around up and down slopes and up and down the curbs and all the things that I find difficult and did the whole session outside. So yeah, they're completely brilliant. They'll listen to what you're saying. (Female, 25-50, mobility impairment & long-term health condition)*
>
> *I go once a week to neurophysio at the Brighton General. That's quite good…I don't do much that's limiting but it's good to go there. Keep things moving.*
> ***So how often is that? How long have you been doing that?***
> *Once a week. For I would say probably six, seven months I suppose. Yeah, on and off. I have a break now and again… But the plan was I was going to carry on until my bathroom's been done and they're going to arrange a second visit to come home to see how I manage and stuff like that. That's the plan. I don't think it's gonna be like never ending. It's going to come to a stop at some point. (Male, 50-65, mobility impairment & long term health condition)*

These experiences contrasted with one participants more negative experience with the deep vein thrombosis team, who were unable to tailor their treatment to the participant as a wheelchair user:

> *The NHS are fantastic if you are ill and are going to get better. But they don't seem to grasp you're disabled – they don't seem to get it. An example was because I became very, very inactive at the beginning of last year which was when one of my knees went and I just sort of sat there terrified to move because of the pain I was in - I got DVT deep vein thrombosis. But they had these fantastic DVT nurses and I went in in my wheelchair and she told me exactly what to do like injections and all the rest of it and then they said well now what you have got to do is walk half a mile a day. And I sort of looked at her and I almost went – wheels – wheels – and I sort of looked at her and I said I can't actually walk. No you've got to walk - I can't actually walk. And we had this conversation which went round and round for ten minutes. And she said no, no, no you've got to do this. I've got arthritis I really cannot walk that far and she said well can't you walk on the pavement outside your house? And I looked at her as if to say*

> *am I being stupid here or are you? She couldn't grasp the fact I had DVT and I was disabled. (Female, 25-50, mobility impairment)*

Several participants had accessed a specialist nurse service for a long-term condition, and reported contrasting experiences. One participant simply hadn't been able to access a specialist nurse as they were on long-term sick leave:

> *The only problem I have is the specialist nurse. I still haven't met the nurse yet. Even though the consultant referred me and he's referred me again and I've had a letter and I've phoned her. But apparently she's been on sick leave for quite a long time. Long term sickness so probably that's the reason….I was quite surprised there's nobody standing in for her. So basically you don't get any. (Male, 50-65, mobility impairment & long term health condition)*

In contrast, another participant had been able to access a specialist nurse and found it to be a valuable source of support and information. Her only criticism was the way in which the nurse made her own assumptions as to what information to provide:

> *The nurse again was good …I remember the first time I went in there I just burst into tears and said I've just needed somebody to know that somebody was there to just talk to about anything. And she was really good she met my boyfriend as well 'cause we were thinking about having children and whether or not to have kids and she was fantastic with all of that. So yeah that was great… I asked her whether there was any sort of support groups and stuff and it still bugs me today that she didn't tell me about the support group…. it was the physio that told me about the group. So I then got in touch with them, went down there. It was the most amazing place. Went back to the nurse and said look I've found out about the group. I've been down there and it's brilliant and she was like I don't like to tell people about it because there's people down there in wheelchairs and I feel like people don't want to see other people with the condition in wheelchairs. And I was like, oh my god! Absolutely horrified and I said you know that's completely wrong. (Female, 25-50, mobility impairment & long-term health condition)*

Another participant who used a specialist nurse for support with his condition, although positive about the service, was critical of the high rate of turnover of specialist nurses with little explanation:

> *The nurse is ok but they keep switching nurses on me and when you're long term, you get used to somebody and you know you haven't got to keep going back over everything again. And then its ok when somebody's you know, I'm moving on or I'm, I'm pregnant or whatever you know, what I consider a good reason. I'm moving on because I've got a better job offer. But when your nurse says well this is the last time you're going to see me and I say well why's that then? Well, my contract's finished. And I said, well have you got anywhere to go? No. And I thought well there's me without my friendly specialist nurse and then a few months later I get a note from somebody I've never heard of saying come see her. (Male,50-65, mobility impairment, long-term health condition & mental health condition)*

Specialist teams such as nurses and neurophysio's in some cases appeared to play a key role in helping participants to adapt to their condition and learn how to get around and carry out daily tasks with minimal support. Another service which provided this kind of support was the Low Vision Clinic, which helped one participant to stay in work. One point to note from this participant however was that the referral appeared to be the result of a chance meeting rather than established process:

> *About two years ago when I lost that bit of sight, I was actually in the hospital. I went up to the County here because they thought I might have had a brain tumour, and while I was waiting to get the results I bumped into the Eye Clinic Liaison Officer, the ECLO in Brighton, and I ended up getting a referral from her when I lost that bit of sight as well. And it was through there that I was offered some counselling, and as far as I was aware at that time she just got me in before the budget was cut, and that just played such a crucial part in me getting my head around what happened. So if it wasn't for her and that service I think it would have been a lot more difficult. I didn't have to have any time off work, and despite this big… it was hard and I was very upset, that service helped me to carry on doing what I was doing. So I kind of wanted to say how useful that service was that she provided. (Male, 25-50, visual impairment & mental health condition)*

Some participants also made use of community visiting teams to help them manage their health conditions more effectively. One participant found the community respiratory nurses to be particularly useful in providing advice and information over the phone.

> *The respiratory nurses who now deal with us in the community are brilliant, they are absolutely brilliant.*
> ***And how often do you get to see them?***
> *Depends when I need it. It depends on my health I can always ring up and ask for advice and they'll advise over the phone. If I need a visit they'll talk to us and ask if I need a visit and then they'll come out and see us. They are stationed up at Brighton General. They are nice people up there, nice girls. (Male,50-65, mobility impairment & long-term health condition).*

Another participant had access to a similar service from the AsthmaTeam, who were able to make emergency home visits, which meant the participant was able to avoid calling out an ambulance:

> *I've also got the Asthma Team, so they recommended that I go through pulmonary rehabilitation. They're a national team and they can come out and they say call them if I'm really breathless and I might call an ambulance, call them first maybe. If I can't decide what to do and they come out on weekends and things. And in early evenings. So it's better to call them, although they're only nurses but they are dedicated to the asthma side of things so they know as much as a GP on asthma. And some of them can even prescribe. So it was a good service, I didn't know it was there til three to six months ago. (Male,50-65, long-term health condition)*

One service which a participant found particularly valuable was a community matron, which allowed her to better coordinate multiple health appointments and blood tests. This gave the participant more choice and control as she was enabled to receive blood tests in her own home:

> *The community matrons, all this disconnectedness and non-communication and everything that goes on, it's their job to actually sort it out, so if we're told to have a blood test at nine in the morning and see somebody else at three in the afternoon, they could often sort that out, you know and all this sort of rubbish. I mean they arranged for me to get all my blood tests and everything done at home instead of having to pound down to the doctor's surgery a mile away at nine in the morning (Female, mobility impairment & long-term health condition)*

Most of the services mentioned by participants were part of NHS clinics. In one case, however the participant also benefited from a respite service run by a community organization. This was particularly important to the participant as the opportunity to sit out in fresh air improved her symptoms and overall quality of life:

> *I go to the Martletts once a week, they come and get me coz its not just cancer they look after its COPD as well coz were degenerative life threatening as well, you know, so I go there once a week. I've just started that a fortnight ago.*
> ***OK, what do you do there?***
> *Well, not a lot actually. I do some craftwork or art if I want to, and actually I make a beeline for the garden and bless them they let me sit out there practically all day unless there's something else going on I want to be doing coz I love sitting out in the air. That's when I feel better. (Female,50-65, mobility impairment & long-term health condition)*

A2.3.5. Experiences of Mental health Services

In addition to several interviews with participants with mental health impairments, one of the focus groups carried out by the research team was specifically focused on health services for participants with a mental health condition. These interviews and focus groups yielded considerable data on participants' experiences of mental health services, including inpatient services, mental health teams and counselling services.

A2.3.5.1. Counselling services

Several participants had accessed counseling services which helped them work through episodes of depression:

> *Any counselling I've had through work or through my GP practice has always been a useful tool for me to work my way through whatever it is that needs doing. So that was a good experience, … I had a relationship with someone who would focus any kind of negative, like any argument or row, around the fact that I wasn't coping with my sight loss. I was able to fend that off externally, internally though it kind of got internalised, so I then went and got some counselling support because I started to feel that I wasn't coping with what was happening in my life, and combined that with some antidepressants. Yeah, ongoing project, but worked through a lot of it. (Male, 25-50, visual impairment & mental health condition)*

For one participant, this support was provided over the phone which suited her well:

> *A couple of years ago, I got very depressed and my doctor got me on some support and this woman phoned me every couple of weeks or so and when I first spoke to her she said, okay, do you want to give me a bit of background, and I told her what had happened to me in the last three years. And at the end of it, she went, yeah, I can see why you're depressed, and talking to her did help, because I think the problem was that I knew something was wrong, but I didn't realise it was depression, and now that I know that it is, it's much easier to deal with. So that was good. She was great, and she was kind of, I'd go through all these conversations and stuff with her, and then about three hours later, I'd go, wait a minute, because she'd just sort of set my mind running, and so she was really good. (Female,25-50, mobility impairment & long-term health condition)*

Another participant who had a social anxiety condition found the counselling support invaluable in helping her to access education. In this case, the participant was enabled to benefit from this service by a flexible approach to appointments which accounted for her "avoidance issues" which stemmed from her mental health condition

> *Well at the time because I was also doing my Masters the therapist decided to sort of tailor it to the social anxiety side of my problems in order to keep me in to university, so when the tutors, even though they were asked not to do things and it might have happened and I might have got distressed, once a week I would have my therapy and we would talk about that and I'd be able to sort of challenge my fears.. you're offered so many sessions and I received a little bit more because she realised that I was, I had what they call avoidance issues, so when something's difficult you tend to avoid it quite clearly, so she sort of gave me a chance to not turn up a couple of times sort of thing until we got in to it and had our sort of trust developed or whatever. (Female, 25-50, mental health condition)*

While experiences of counselling were generally positive, there was considerable variation in how easy participants found it to access such talking therapies. For one participant, an assessment at Millview Psychiatric Hospital signposted him towards counselling from a community organisation which he found effective:

> *Well because of the problems I've been having recently, with neighbours I've been very depressed for more or less the last six months. Bad things happened with the neighbours. I've gone to the doctor and told her about my depression and stuff…They sent me to Millview Psychiatric Unit there for an assessment and he told me about a counselling service rather than having to go on to anti-depressants, which sounded a lot better to me. And they've helped me quite a bit, especially with the advocacy, advocating for me with my problems getting somewhere else to live. (Male, 50-65, mobility impairment & mental health condition)*

In contrast, other participants found it considerably more difficult to access counselling and felt GPs and psychiatrists relied too much on medication such as antidepressants as opposed to talking therapies:

> *There's a general take drugs and get on with it attitude and you need to push for the counselling, you need to push to say that you want to be on that list and that's what you want, you want the talking therapies and you don't want to be medicated because once you're given the medication there's other sort of side effects and then you're dealing with them and you're sluggish and you're not actually living a life anyway*

> *because you don't sort of come round till the afternoon, so yeah, it's a bit of a push for, to say what you need and to have that happen. (Female, 25-50, mental health condition)*

One participant who had experience both as a mental health service user and an advocate for others, felt that in some cases medication was simply inappropriate and could cause additional problems:

> *I always find, I've found that psychiatrists are too quick to prescribe as well. I mean, I almost sometimes wonder whether they've got shares in the pharmaceutical companies because I mean, literally, you know, they want to throw drugs at a problem, you know, or medication at a problem and it's not always the issue, you know. I'd much rather see a psychologist before a psychiatrist. Like someone might actually be in grief and grief is a real feeling, you know, it's not something that necessarily drugs are the answer …it just gives you another problem doesn't it. (Female, mental health condition)*

One participant perceived that the tendency towards medication rather than talking therapies stemmed from pressure on GPs to defer referrals to overstretched mental health teams:

> *My friend has just gone to his GP for mental health assistance, and this process started about three months ago, and the first step is the GP gives you medication, antidepressants, which haven't worked and haven't had an effect, and he's gone back and said, "No really, it's not working, I would like to talk to somebody." And instead of actually doing the referral, she's just increased the antidepressants and said, "Let's give it another couple of weeks." It seems to be better for the practice and I think this may be because of the pressure on the mental health teams to defer referrals, to keep dosing up until "Okay, this person is now really, really badly in crisis, I'll have to refer them." (Female, mobility impairment & mental health condition)*

In one case, problems accessing counselling services stemmed not from treatment decisions but physical access barriers. One participant who had a visual impairment, had an initially positive experience of counselling. However, he later experienced problems due to a lack of personal assistant support to help him travel independently, which led to the service being withdrawn:

> *The counselling services understandably there is waiting times for them you know but they've been good when I get there…I then got referred to the local service and basically they negotiated with my university to get some more counselling for me which was good but they basically said that because of my disability and my inability to get out that they personally wouldn't be able to send anyone to me from their team and I one day got a letter from them saying that I'd been discharged but I hadn't discharged from them and they couldn't help me…they hadn't even consulted with me about it I just got a letter saying I'd been discharged. (Male, 18-25, visual impairment & mental health condition)*

A2.3.5.2. Crisis support

For some participants, one aspect of mental health services which they felt could be improved was the support available to people in periods of crisis. One participant felt that a 24 hour phone service which linked to other sources of support was needed, as an alternative to hospitalisation:

> ***What type of support would you think would be most useful in a crisis?***
> *Rather than actually just telling you to go to hospital there should be somebody on the end of the phone 24 hours a day, you know, because if you're in crisis you're going to need help straight away, so yeah. You need somebody to speak to and if they feel on the other end of the phone that you need more, then you should be able to get it. (Male, mental health condition)*

Another participant who identified as bipolar felt that improved access to psychiatrists would help him to manage during periods of crisis:

> *What you find if you're ill right, Monday I'm ill and then my wife will phone up Monday afternoon and they say…we'll make you an appointment with Dr [name removed]. Alright, thanks. When is it? Oh about three weeks time. And she's saying he could be better then! You know, so we want to deal with it now, in effect there's no help…no one to help me deal… you might just need someone to say oh what's happening? You still taking your medication, you're doing this, oh that's sounds ok, yeah don't worry about it, come and see me in three weeks time…but what we get is oh well - we'll make you an appointment. Oh, well can we talk to Dr [name removed]? Oh he doesn't talk to people on the phone. And I said to him why don't you talk to people on the phone? He said well I can't advise you to change your medication and all that unless I see you. I said …I hate to mention it here, but when I was at my previous practice I used to phone up and say, I'm feeling a bit hyper. And he'd say oh just decrease your anti depressant by 75 and just come back to me if there's any problems. I thought what's wrong with that. He said well that's how I am. (Male, 50-65, mental health condition)*

For one participant, all that was considered necessary to help her deal with crisis was having somebody she could talk to face-to-face, which she had been able to do at the local mental health centre:

> *They have been very helpful and there's a nice lady there that I've spoken to but when I go there I always feel as if sometimes I just need someone to talk to and I try and say to them, "I just need someone to talk to," but they feel like they need to sort of suggest practical things and sometimes you don't need that (Female, mental health condition)*

For several participants, periods of treatment were often followed by periods of receiving no support which left them ill-prepared for future crises:

> *I was actually discharged from hospital last year, all they gave me, my CPA wasn't done properly and all they said, "Well, you've got contact numbers for the Samaritans, you've got your mental health line," and basically that was it (Female, mental health condition)*

> *Once you access help through the hospitals you're, I was on the waiting list for cognitive behavioural therapy, and once you receive that you've had your help and that's it sort of thing, you're just, you're referred back to the hospital services and then just told to maybe get further counselling or things like that. (Female, 25-50, mental health condition)*
>
> *Finally, I got someone from the transition team and, you know, it was only like a short-term thing, so I'm seeing her for four weeks and I'm fine at the moment, and I know I'm going to be signed off next week, and she hasn't come this week either, she didn't call when she said she'd call. I mean it's fine because I'm in a good space but, you know, when the next crisis hits what happens again? (Female, mental health condition)*

Another participant found that even when support was requested, this could not be effectively accessed until the participant hit crisis point:

> *There's always like promises of things happening, of offers of help and then like they need to sort of wait until like they see you like desperate or crying or something, or get to the point where then they make the decision from the evidence that they see because you look particularly tired or distressed, then they'll go, "okay, we'll act on it", rather than it being preventative you know, putting the respite in place in order for that not to happen, for you not to get to the point (Female, 25-50, mental health condition)*

For some participants, it was felt that periods of crisis could instead be avoided by the provision of regular, one-to-one support for participants with ongoing mental health conditions:

> *In my personal opinion I think by assigning you one worker who talks to you and keeps in contact with you you're less likely to get into a point of crisis because they're going to pick up the signs, and it's going to be less strain on the NHS and system because you're not forced into this point of complete desperation with no support, you know. It's just, I think it would save them money personally and, you know…when I'm with my mental health it's just like having, you just want someone to talk to (Female, mental health condition)*

In contrast, another participant who had accessed a community psychiatric nurse who could provide this kind of one-to-one support found that it was not helpful to him. In this case, he instead found support from a mental health day centre:

> *I didn't find CPNs particularly useful, to be honest, they didn't really help me very much, they just seemed to want to come round, smoke my cigarettes, drink my coffee (Laughter). But I'm really happier seeing less, you know, so I think it shows that things are progressing for me, but I do go to day centre so there is a contact there if I need it, you know, so it's good to have that support as well. (Male, mental health condition)*

A2.3.5.3. Inpatient services

In several cases, participants had at some point reached periods of mental crisis and had been admitted to Millview Psychiatric Hospital. These experiences were generally reported as negative, with one participant feeling there was a lack of effective treatment:

> *I did have a spell in Millview and that was a waste of time. Is all I can say. Apart from that it was nice you got your meals cooked.. Um, nothing really planned and nothing really structured. I was there for two weeks and it's cause I'd attempted suicide basically, six or seven times. (Male, 50-65, mobility impairment & mental health condition)*

A couple of participants reported problems accessing medication during their stay at Millview. For one participant, this was seemingly due to administrative error by the pharmacist:

> *The only problem I did have was in Millview, which was last year, where medication wasn't available for me. I mean on the ward itself I had to wait a day for medication because the pharmacist hadn't delivered, you know, and I needed it. I mean, to actually give me medication they had to use somebody else's, which is, it's against the law anyway, they're not supposed to do that. (Female, mental health condition)*

In another case the participant reported being unable to access her diabetic medication and consequently discharged herself from the hospital:

> *In the hospital in Millview I was in a few years ago and my sugar levels were really high and they wouldn't give me the diabetic medication I needed because I was out of time it had gone twelve o'clock or something and they couldn't give it. So I asked them to phone up the on call doctor so they phoned up the on call psychiatrist who said they weren't allowed to give me the drugs I need. So I had to discharge myself from the hospital to walk from Mill View in Hove all the way to Essex Street in Kemptown to get my diabetic medication. So that was a nightmare and also I find they don't look after…there's no on call GP in mental health hospitals and the staff are not medically trained.. and I've also had a lot of trouble with like when I've needed help in hospitals medically and they wont get [a doctor] for you because they say the psychiatrist can diagnose it. (Female, 25-50, mobility impairment, long-term health condition & mental health condition)*

A2.3.5.4. Benefits of alternative therapy

Some participants reported receiving considerable benefit from alternative therapies and courses aimed at improving mental health. Several members of the mental health focus group mentioned one particular project run by Mind:

> *There's Grow. Which is a lovely conservation project. Well it's kind of just getting out into nature isn't it with a group of people, which is really lovely, organised through MIND. Yeah, and that's really nice, very healing and supportive and nurturing. Really, really lovely, really safe space, it's been really important, really good for me (Female, mental health condition)*

One participant in the interviews also mentioned the importance of courses of alternative therapy in helping her to address her mental health problems:

> *I have done like courses of meditation outside of the NHS. I did one called Living Well with Pain and Illness, it was really good, it was all about accepting and breathing into pain and coping. I've also done the MBCT course, which is Mindfulness-based Cognitive Therapy, and that's about dealing with depression and anxiety through the same methods, through mindfulness, so that's a really good tool, they do do it on the NHS, so I do that another week. (Female,25-50, mobility impairment & mental health condition)*

A2.3.5.5. General mental health service issues

In some cases, participant experiences of mental health services cut across multiple services and offered insight into service provision more generally.

Coordination between services

Several participants with ongoing mental health conditions felt that different mental health services and teams often lacked coordination. In the focus group discussions, several participants suggested that the current split of mental health services between crisis, transition and recovery was unhelpful as communication could break down:

> *I'm really not sure how helpful this just passing between teams is, in fact I, it seems to be causing a lot more problems than it appears to solve. I mean, it seems to be a good idea to specialise in particular areas so that you've got people particularly trained for recovery, transitions and crises, but there's so many problems involved in changing between teams that it creates problems and you could end up going into the recovery team and by the time you get seen by the recovery team you need a crisis team. It's just preposterous. (Male, mental health condition)*
>
> *A team should be looked at differently, it should, like a football team, you don't have two goalkeepers and two fullbacks do you, you have one of each position sort of thing, you know, so rather than all the transition people being together they, on a team there should be one person from transition, one from recovery, one from psychology or whatever (Male, mental health condition)*

One participant specifically felt there was no coordinated work between his transition team and other services to prevent him going into crisis:

> *I found with the transition team, because I had them before, I've had them twice, one was when I actually transferred from Mill View, and I was going into crisis and they couldn't do anything, not a thing, they couldn't even refer me to my CPN. All they could do was pass the information on (Female, mental health condition)*

For another participant, the need for communication between GP, psychiatrist and community psychiatric nurse caused delays in changing his treatment:

> *I've been talking to my GP and she's agreed to actually take me off one of my antidepressants, but she contacted my CPN and I've been waiting now for nearly three and a half months to come off one antidepressant. She's agreed, he's just wrote a little note and put it on the psychiatrist's desk, and I haven't heard. (Male, mental health condition)*

Returning to the discussion of the need for one-to-one support, one member of the mental health focus groups felt that a single allocated worker could potentially improve the level of coordination of teams, or at least reassure the participant and keep them informed:

> *But I don't ever fully understand, when you get referred into a system why you're not just given one worker who you check in with, which is your kind of port of call, so whatever you're experiencing, for whatever you may need that's the person you contact that say, you know, "Okay, we're going through the process of referring you to crisis, we're referring you to this." I know that's what a supposedly CPN is meant to do but there's so many different departments now, there's in-crisis, there's transition, there's recovery, there's so many and each one has their own referral process and no-one's holding it all together barring yourself, and you're not very well… I just don't know why you're not given one worker that you can ring up, even if they're kind of honest because you respect the honesty of them saying, "Okay, we understand and this is what we're doing, but there is honestly going to be a wait." Just that conversation, that reassurance. (Male, mental health condition)*

Waiting times

For some participants, problems they experienced with mental health therapy simply came down to long waiting times to access treatment such as cognitive behavioural therapy:

> *When I went to see my doctor he referred me to hospital to see a psychiatric nurse and I went there and they said that they'd give me some sessions of therapy but it was over a year before I actually got them, so after the first initial appointment when I was assessed it was over a year, and a couple of times I phoned them up and sort of chased it up to see what was happening because I felt like they'd forgotten me, you know. They did literally take over a year.*
> ***And when you did get the support after a year, was it good quality?***
> *It was good, yeah, what I had was good. It was just I had to wait so long to see someone. (Female, mental health condition)*

One participant felt that these long waiting times could be used as an opportunity to pursue alternative therapies which prepare people for counselling, to ensure they could get the maximum benefit out of therapy once it started:

> *When you realise that maybe talking to somebody and having the counselling is going to be better for you long-term than just taking this medication, you're then put on a waiting list [for CBT], and I was on that waiting list for two years before I got the cognitive behavioural therapy at the hospital, and that's a long time... I thought if there*

> *was something in place for them two years while you're on the waiting list where you begin to look at your own issues or you begin to have some sort of other counselling, which, I mean counselling's not always, yeah, if people were prepared and had already, could highlight some of the issues that they had to look at before they got to therapy, that might be of help...so if there was something in place for that rather than people just be given medication, that there was a place for them to, in their own time you know, some sort of, I don't know, thing, class, group, I mean they could just start to become aware so that when they got to therapy it was more successful . (Female, 25-50, mental health condition)*

Attitudes/treatment styles of mental health professionals

One point raised by participants was the need for mental health service providers to take an understanding and caring approach to the treatment, in order to ensure treatment was taken up by patients. For these participants, where they had negative experiences with the attitudes of mental health professionals, they chose to withdraw from treatment rather than seek to resolve the issue:

> *Depression is a real pain and....I did go to see a psychiatrist here in Brighton. ....I saw three different ones. The first two well to me were excellent as in they listened and they tried to help. The third one, when I first met him, and I just told him sort of basically how I was feeling that day, he basically just said to me, "what do you expect me to do about it?". Immediately a wall went up and I just went through motions of the session, made an appointment to come back and then a couple of weeks later cancelled it. Never bothered. (Male, 50-65, mobility impairment & mental health condition)*
>
> ***If you felt you weren't getting on with someone and wanted to change, can you do that?***
> *I mean you're so grateful to be receiving help that you'd find that difficult, and if you're already you know, feeling a bit low, when people are feeling low they don't feel confident enough to challenge these things… if somebody was to give you a follow up call to say so how did that meeting go, and to sort of monitor how things are…then somebody would know if it wasn't working for you and that's why you don't want to go to your appointment, and that maybe if you had somebody else then they could help you further. But you're just sort of left with a, "oh, I don't like him he doesn't like me, I don't want to go", you know, so you don't get the help. (Female, 25-50, mental health condition)*

For participants in the mental health focus group, an important issue regarding attitudes of mental health professionals was the extent to which they involved patients in their own treatment:

> *The thing about health I think though, particularly with psychiatrists but also GPs is that they should treat the patient with more respect, as regards just generally but also with particular regard to the knowledge of their own experience and their own insight into their own condition. Because, you know, obviously you're going to know yourself better than someone who's meeting you only, even three times a week or whatever. That's just kind of obvious, unless it's because your condition is so severe that you have no*

> *insight into what's going on, then you are going to have more insight into it, into your own condition, than anyone else. (Male, mental health condition)*

Two of the focus group participants identified experiences where they felt they had not been effectively involved or listened to regarding their treatment preferences. As a result, one participant ended up trying new medication obtained from overseas without medical supervision:

> *I mean this has took me years to get on the type of medication that I wanted to be on. I've only been on it two months but the way that I got it is ordering it off the Internet through a pharmacist, a reputable pharmacist, and then taking it for a month and then convincing my psychiatrist to prescribe it for me. That's how it happened. It's not because I convinced the psychiatrist to prescribe it. I think, quite frankly I think it's probably the hippocratic oath, which is essentially doing no harm but they don't seem to realise that doing nothing can be as harmful as doing something which may have risks attached to it. I think that risk was like a calculated risk which is worth taking rather than being in the vegetative state that I was in previously. I think they did listen to me, they just weren't prepared to take the risk of me becoming manic even though I thought it was something you could monitor and take more stabilisers or stop taking the medication if necessary. (Male, mental health condition)*

One participant recounted a lengthy battle with mental health professionals to access trauma therapy which she felt was necessary

> *I had various kind of, yeah, very bad experiences with psychiatrists kind of like bandying around different labels, do you want this one, do you want that one, this one involves this medication, this one involves that medication and, you know, yeah, and him refusing that I actually had post-traumatic stress because I didn't tick all the boxes that he knew in sort of five minutes. Then kind of, "Well if you're not going to take the medication I don't know what you're doing here," you know, help yourself type thing. Yeah, so it's been, you know, might as well just bang my head against a brick wall a lot of the time, and being told that, by the doctor that I had no insight into my condition and all this kind of stuff (Female, mental health condition)*

This participant was eventually able to access treatment, with the help of an advocate from Mind, and is now benefiting from the treatment:

> *I've been seeing a trauma therapist that took me so long to get, I mean it got ridiculous. I was, I had an advocate from Mind, thank God, because the ridiculousness that I went through. I'd get home and I'd contacted lots of people and the best one was this phone call, this message that I had from the NHS, they said, "From the NHS." No voice, no name, no whereabouts in the NHS, but this is the NHS, it's like this is God, you know, and we deal, we're trialling access trauma therapy, well all the books are shut and there's no point in applying for another six months. No contact number at all, 1471, nothing. Eventually, I kept persisting and I saw a trauma specialist and it was basically just to tell me, just to kind of placate me and say that there wasn't anything and she'd written the letter saying that everything was closed and I told her my story and then she just turned round and said, "Well, I think you've gone through enough, I'm going to take you on, like in a couple of weeks." (Female, mental health condition)*

Provision of information

As with participants using general health services, there was a feeling among participants in the mental health focus group that information from health professionals on mental health services was often lacking. One participant felt this to be a particular problem for people with mental health conditions as they were often less likely to be able to access this information without support:

> *When I first went to see my doctor he didn't really tell me what was available. Then my therapist told me about Buckingham Road, but the thing is that I'd spent a whole year without any real support and there was something just round the corner from me that I could have gone to and I didn't know about it because my doctor referred me but I wasn't told about anything else. The thing is if you're not very well it's quite difficult to sort of be able to get together to do that kind of thing yourself, isn't it? You need somebody to help you really, don't you? (Female, mental health condition)*

One participant felt that information provision should be included with an individual's care plan to ensure the information is available in one place:

> *I think all the information you should get, it should be put in your care folder, you know, so you've actually got the information there with telephone number and everything, rather than just leave you hanging. If that's not done then you're just going to lose everything. (Male, mental health condition)*

A2.3.6. General issues regarding health services

In addition to issues relating to specific service areas such as mental health services, a number of cross-cutting issues were identified by participants in relation to the provision of health services more generally.

A2.3.6.1. Waiting times

A common factor in how participants rated their experiences with health services was the length of time they had to wait to be referred into new services. Experiences often varied depending on either the urgency of the problem or the availability of the service in question. One participant was seen very quickly when first diagnosed with Multiple Sclerosis:

> *The GP I saw for the first time ever when I went with what I thought was a skiing injury, he was amazing, really, really good. Gave me an emergency referral, an emergency neurology referral and I was seen within a couple of weeks I think. (Female, 25-50, mobility impairment & long-term health condition)*

In comparison, several participants commented on long waiting times for comparatively non-urgent outpatients appointments to come through. This was also a problem where participants had to reschedule appointments, necessitating a further wait:

> *Waiting times is always like long waiting times*
> ***Really? Waiting for….?***
> *Well appointments to come through. You're constantly having to chase things up and stuff like that. But that's part and parcel with the NHS. (Male, 25-50, long-term health condition)*
>
> *We have hospital appointments that get cancelled or, you know, you can't make one appointment then you've got to wait another four or five months for another one or something like that, and you get lost within the thing. (Male,50-65, mobility impairment)*

Not all differences in experience regarding waiting times were based on factors which participants could understand (e.g. urgency), and left participants feeling confused as to why they had to wait. One participant experienced this:

> *And then they referred me to Physiotherapy Department. There is a long queue. I received a letter well, maybe two weeks ago and confirmed, just acknowledging the referral, you know, made by my GP. But still they ask me to wait you know, another, god knows! And funny enough when you go to the appointment you will see nobody there. I mean it can't be ten cancellations in one day, you know. I mean very often I go there I see like five, six nurses around and just two patients. And I don't understand. I don't know how it works. (Male, 25-50, mobility impairment)*

In comparison, another participant with the same health condition experienced only a two week wait to get referred to physiotherapy at the Royal Sussex County Hospital.

One participant felt the reason he had to wait so long for an appointment was because of his age. This demonstrates how a lack of proper explanation for appointment delays can cause participants to make their own assumptions which often affect how they later characterise their experiences of services:

> *It's [referral to digestive diseases unit] supposed to be done in a few weeks but my doctor did actually ring me because she had not heard from the specialist at the hospital*
> ***So your GP or?***
> *Yep, was concerned it was taking a long time. I think, are they not, operating age preference I think they've started, some of these specialists, doctors. Works against you if you're old. (Male, 50-65, mobility impairment & mental health condition)*

A2.3.6.2. Provision of information

As seen in mental health services, in relation to other services an issue which was mentioned by several participants was the provision of information from service providers regarding their own health condition or health services from which they may benefit. Information provision was felt to be extremely patchy at times. For one participant it was only during crisis when she could find out about services available:

> *The lack of information from the NHS is appalling, I've been struggling for over two years because I'm constantly drawing a blank. In July, I got seriously ill and suddenly I'm overwhelmed with domiciliary service providers, you know, I've got a community matron and a community respiratory nurse and you name it, I've got it. But I've repeatedly asked for help and just drawn a blank before that. (Female, mobility impairment & long-term health condition)*

For one participant, it was felt that while information had been given, it was important that this was provided in a more permanent fashion, as often remembering what had been said in appointments could be difficult:

> *I think important things, I do remember I had, what was it, this must have been setting up a prescription, and I think it was my fault and not paying attention properly, but I didn't appreciate whether the first prescription had already been done or was going to be done if I filled in this form, the receptionist didn't know, the chemist didn't know, I sort of yes, whereas I think, you know, if I'd just had that written down... (Female,50-65, mobility impairment)*

A2.3.6.3. Administration: records and appointment scheduling

Another issue relating to health service provision was the way in which records were maintained. Two participants reported experiencing problems where their medical records had been lost. For another participant, when accessing her medical records she felt that important events and treatments were actually missing from her records, causing her problems when trying to obtain evidence that could be used to support her with a benefits assessment:

> *I've been in a bit of tussle over my medical records, because I'm so worried about this DLA business, and I wanted to see my medical records so I paid ten pounds to see my medical records and the receptionist made an appointment for me to go in, but it was a little bit like, oh well what do you want to look at? And she sort of looked at them and picked our certain things. But there was things missing and inaccuracies, and I wasn't very happy, and I sort of that complained to a locum I saw. I've had a letter back saying "Oh, well if you want to see them, you'll have to come in yourself and go through them yourself." Well I don't feel very confident about doing that on my own…I mean I did get certain things photocopied. But it's so important because they want to know things like on the DLA form, do you wander? Are you safe at night? Things like that. Now, unless you can prove it, you're not going to get it. Now I've been to…I know I've been to casualty a lot of times and I've not felt safe at night. There's no record. I went to [place name] and tried to kill myself. There's no record. (Female,50-65, mental health condition)*

As seen in the discussion of community services, one participant found the community matron useful to help keep multiple appointments organized. For another participant, however, the coordination between different health services seemed to be lacking, resulting in the participant making seemingly unnecessary journeys:

> *But you've mentioned the Polyclinic and it's really, really bad organisation. Now, if my doctor says "You've got to have blood tests" I have to go to the Polyclinic, ……if my diabetic specialist team say I need a blood test, I can go straight through into the outpatients and have it done. But to go all over to the Polyclinic from here is a long journey on the 5B whatever it is that goes there, you know, to start with, and it takes up a whole morning to go out there and back again...And a similar thing, I've just been in to have some minor surgery at Haywards Heath and after having the pre-operative assessment, it was longer than 12 weeks before I went in, so they said you've got to have your MRSA swabs again and I said "Fine, can I have them done in Brighton?" "No, they don't do them."So an hour on a bus out to Haywards Heath, to the Princess Royal, for them to do (makes strange noises) and I went home again, but I couldn't go straight home because the bus is only once an hour. Now, surely, two swabs can be done somewhere in Brighton (Male, mobility impairment & long-term health condition)*

A2.3.6.4. Accessing specialist treatments

Several participants used specialist treatments and medications to treat their own conditions. For one participant, this was a one-off piece of equipment which he felt had helped him to keep out of hospital, which he had been able to purchase himself:

> *I have a nebuliser at home as well. . It's like the inhalers people use, it's fitted to the electrical supply so I can use that.*
> ***Yeah. So who provided the one you've got at home?***
> *I did, I bought it. Well just about a hundred quid on the Internet. It's good, it's kept me out of hospital loads of times.* **.** *(Male,50-65, long-term health condition)*

Another participant with MS used an electrical stimulation unit which enabled him to maintain his walking ability. In this case, while the participant was willing to pay for the equipment, lack of information on how to obtain it meant that he was required to go through a lengthy process for the Primary Care Trust (PCT) to fund it:

> *I use ATS on my leg which is the electrical stimulation so I use that, if I didn't have that I'd be in a wheelchair permanently but I use that as well… PCT can be very slow. My ATS unit, although it's only, I think the cost I found out was only 250 quid for the unit, took maybe six months to get, I got to the stage where I was just begging someone to tell me where it is and I'll go buy it myself (Male,25-50, mobility impairment & long-term health condition)*

In contrast, a participant with a long-term health condition found the PCT unwilling to fund any treatments for her condition and struggled to pay for the treatments herself. In this case, the participant had shown significant improvement in her symptoms which she attributed to the private treatments and which she felt had enabled her to avoid the need for statutory care services:

> *I wasn't diagnosed for 10 months and the NHS don't treat it, so it's been a very, very sort of difficult five and a half years because I've not been able to get any treatment on the NHS… at the moment I have private treatment, which has included antibiotics and neuromodulating therapies, and immunomodulating therapies and detoxification*

> *regimes. So there are therapies that kind of reduce my symptoms or sort of keep them under control, but it's all private treatment…the sort of problems of not being treated on the NHS and trying to sort of fund my own treatment, that is my biggest obstacle (Female,50-65, mobility impairment & long-term health condition)*

For two participants, it was felt that decisions on treatment made by the PCT in response to funding pressures had negatively affected the standard of care they had received. One of the participants who had been accessing specialist treatment at the National ME Centre for over a decade, suddenly found herself required to visit a team which lacked the expertise she had previously received:

> *I had a very, very good specialist at the National ME Centre, and it was him that suggested, kind of how to manage the ME and carry on doing school and kind of building up. And that carried on until...the PCT stopped funding specialists outside the area, so after seeing him for sort of fifteen odd years I was seen by the local ME specialist team only to find out actually they weren't ME specialists they were GPs or surgeons with an interest in ME... and it certainly felt like, at times, I knew more about my condition and what I should be doing than they did. And their waiting lists were huge; it was I think two years or so before I got seen by them…(Female,25-50, mobility impairment, & long-term health condition)*

For another participant, the PCT attempted to change their medication which had disastrous consequences and resulted in seemingly avoidable hospital admissions:

> *Some of the medication I'm on is very expensive for them to just keep offering it on the NHS. When the new government came into force the Primary Care Trust obviously had to look at cost cutting and one of the things they did with the local GP was look at every patient who had long-term prescriptions and what they could reoffer in terms of "better but for less cost" was their slogan about it. So they came up with this drug on the market…my doctor and my consultant at Brighton agreed that they would give it a try and my consultant made the dose and said to take I think it was six four times a day, which I did for two months and I started to feel very poorly, I had pains in my chest and couldn't explain why, it was just gradually getting worse. I was sick and ended up in A&E on a heart monitor and they said in the hospital that the tablets I'd been taking were not sufficient for the condition and if anything it was a risk to my health, so that wasn't very good…My GP was more furious because she took the Primary Care Trust's word on this new drug being effective and it wasn't, so we were back to square one. (Female, 18-25, mobility impairment & long-term health condition)*

A2.3.7. Impairment specific issues

A2.3.7.1. Physical impairments

The most common barrier faced by people with physical impairments when using health services was limited access to buildings, particularly due to the lack of parking. This was particularly a problem at the Royal Sussex County Hospital where participants found they could rarely park near the hospital. One participant overcame this by parking on double yellow lines but this caused problems with other traffic:

> *The hospital…I have a problem with parking but because I've got blue badge I park on double yellow lines outside the hospital, on the main road. I mean I get some honking, causing passersby to say something but you know, what can I do? (Male, 25-50, mobility impairment)*

Another participant used the bus or lifts from friends and family, but in some cases her limited mobility required her to use a taxi which quickly became too expensive:

> *The fact there is no parking [at Royal Sussex], or parking is very, very hit and miss. It's either getting a bus, which sometimes that's fine, getting a lift if there's someone available to give me one, or getting a taxi. But if I have to go every week and it's £30 round trip for a taxi, every week, plus they're suggesting that I go swimming…another couple of times a week on top of that, which again there's no real access to the Princess Regent, I think it is, in Brighton. It's a money issue and it all starts mounting up and while DLA helps…there's only so far it goes. (Female,25-50, mobility impairment, & long-term health condition)*

One participant found it so stressful to access the County Hospital that he chose to travel to Worthing & Southlands hospital where this was an option:

> *[My diagnosis] was [at] Worthing Southlands hospital, which I don't know how I ended up there, I think it was more because of parking. It's simple to get over there, that's why I stayed there even though that's West Sussex because you could park near the door and it's flat. Sussex County was an absolute nightmare, absolute nightmare. You were stressed before you even leave the house to go to the hospital, there's never any parking, all the hills are like this, you've got a 10 o'clock appointment you know you're not going to get seen until 11 o'clock and it's just kind of the whole thing's just stressful. A few times I just went private because I just couldn't put up with the stress. (Male,25-50, mobility impairment & long-term health condition)*

Another participant also sought to avoid problems accessing Royal Sussex County Hospital by choosing to access her physiotherapy treatment elsewhere. However in this case she was told that no alternative was available*:*

> *I'm having physiotherapy, which I've been waiting a while for, I'd specifically said that I really wanted the Hove Polyclinic because there was parking and it was far easier to get to actually than the centre of Brighton, for the hospital up there. But I wasn't given a choice I was told I either had to go to central one or there was no physiotherapy available for me. Whereas, yeah I was under the impression that I could choose between the Polyclinic or the main hospital and the Polyclinic would have been much, much easier. (Female,25-50, mobility impairment, & long-term health condition)*

Access was also an important factor in how participants characterised their experiences of their GP surgeries. In some cases, participants GP surgeries met their access needs and were rated well:

> ***In terms of like getting to either the Doctor's surgery or the hospital, how easy is that?***
> *Oh, it's very easy. They have lift as well. Oh, yeah easy. There are one, two, four [parking] places I think for disabled, yeah… (Male, 25-50, mobility impairment)*
>
> *The surgery as a whole is brilliant. It really is. It's great. It's on a couple of floors but they've got good access with, with proper powered doors and a lift and stuff. So any mobility level can access it which I think is good. (Male, 50-65, mobility impairment & long-term health condition)*

For participants in the physical impairment focus group access within some of their surgeries was limited due to difficult doors or disabled toilets which were too small:

> *I have an issue because I can't open the door, we're waiting to get moved and it could be another two or three years yet, to a new building, so no, I have a problem with the door.*
> *You're not in [surgery name], are you? They've got double doors but one is always bolted, so I have to ring the bell and wait for someone to come and unbolt the other door, then I can access it. (Male, mobility impairment & hearing impairment)*
>
> *I can't get into the disabled lavvy at my doctor's surgery and it's a mile away from home and I'm almost always kept waiting for an hour and the nearest lavatory I can use is in Churchill Square.*
> ***Right, is that because it's not big enough or…***
> *It's not big enough, I can't shut the door behind me and it's the same up at the hospital, half the disabled toilets, lavatories, up there, are too small for me to physically shut the door on. (Female, mobility impairment & long-term health condition)*

Even where GP surgeries were accessible inside, problems with accessing the venue, whether due to limited parking or poor access routes for public transport made them problematic for participants:

> *The surgery is very accessible to get into but there's nowhere to park so I can't get close enough to it …it's on a busy road. Occasionally you can get one in the side streets but then it's the distance between the two to get there – I used to be able to hobble across the road but now I would just fall flat on my face (Female, 25-50, mobility impairment)*
>
> *They moved the surgery as well to different places – it's slightly less accessible than it was which is like irritating but whatever… It used to be right by the bus stop but now it's further down the hill so you now have to go up the hill and down the hill. I mean they have made kind of a walkway so it's more accessible for the bus stop but it's still more difficult anyway (Female, 25-50, mobility impairment, long-term health condition & mental health condition)*

Another participant using the same surgery expressed her frustration that access was such a problem, and felt that consultation with disabled people when the building was being planned could have helped to avoid problems and prevent the need for costly alterations in the future:

> *When they designed this brand new building they should have asked people what they thought of it. As to where it was going because it's such a long way to walk from a disabled parking bay into the reception desk and then our doctor is the furthest one right down the end. And they've got a thing that says no electronic buggies past this point so you can't bring your electronic buggy in there. I don't know what you'd have to do, you'd have to have a friend with a wheelchair with you to put you in that and push you down, or a zimmer frame with a seat or something. Because it's such a long way I have to have a friend with me, no doubt I can't do that.*
> ***And have you raised these concerns with the surgery at all?***
> *Yes and obviously other people have. They are going to move disabled parking but I don't know where they are going to move them now but it might mean excavating all the flower beds they've put in. Why they don't ask peoples opinions on the plan. Because I would have said, well make an entrance round there for the disabled parking where there's a door where the doctor is. Easy. (Female,50-65, mobility impairment & long-term health condition)*

For one participant, this type of consultation in regards to building design was evident through his involvement with the 3Ts project to design the new building development at the Royal Sussex County Hospital, a process he rated well:

> *I feel that 3Ts it is actually a really positive experience. You know, almost 10 years before that hospital's going to be fully up and running they're actually consulting people about that. My experience through work often is that consultation is a lip service, but it feels like the panel is already having impact on what's going on, and I think because there's already time and effort being invested in way finding and how arts can be used as a way of making an environment accessible, it feels at this stage like it's a positive experience. (Male, 25-50, visual impairment & mental health condition)*

While most access barriers related to how participants could access a GP surgery itself, for one participant it was more due to issues with public transport. This participant felt a more flexible approach to appointments was necessary which took account of these problems:

> *If I've got an appointment at ten twenty and I'm a few minutes late they say oh you can't come in…they wont see you. The bus I need to get from here to my GP surgery comes every twenty minutes and the ramps don't normally work or the drivers don't know how to use the ramps, so therefore I have to wait another twenty minutes for the next bus to come, and I can't get that through to the GP surgery. Sometimes I phone up for a taxi and they say no wheelchair accessible taxis available. I think it would be a good idea if they could have disabled people or people who are unable to walk a distance who rely on buses to have variable appointments if it's possible. You know or short term cancellations if they can. (Female, 25-50, mobility impairment, long-term health condition & mental health condition)*

In several cases, participants had been completely unable to access their surgeries for various reasons, but had received home visits from doctors which had seemed to work well:

> *I have a group, a GP practice, not that close, I picked it out, and I've already had a couple of home visits when my back was particularly bad I just couldn't get out of bed and I just couldn't get into the wheelchair, and I thought that was fine (Female,50-65, mobility impairment)*
>
> *I can't get out to medical help, my doctors have to come out to here or dealing with phones or letters. Luckily I have got a fantastic doctor. (Female, 25-50, mobility impairment)*
>
> *Dr [name] is pretty good. He says "if, don't bother coming down to see us", he just told me to ring up and "if you're in so much trouble we come out to you". (Male, 25-50, mobility impairment & long-term health condition)*

Some participants had used hospital transport in order to overcome problems accessing certain health clinics and recounted positive experiences with this service. In one case, an individual assessment was required for a participant with a specialised wheelchair which appeared to work well:

> *I use transport to hospital where necessary, now I would take, I can go on the bus, I would go a certain distance but I had to have a scan in Hove, and I took the ambulance for that and they were very good about it because it's all a bit one-offish, a bit unusual and they came and assessed me and brought the ambulance round with the ramp and individual service, I thought it was fantastic…Booking the ambulance was also good and that can be an enormous problem in other parts of the country, believe me. (Female,50-65, mobility impairment)*

For another participant, the use of hospital transport was actually beneficial in improving treatment outcomes by eliminating the stress he experienced getting to the hospital:

> *They arranged for hospital transport to go up to physio [at Brighton General]. The thing was I was going to physio and because of the stress of getting the bus I was exhausted. By the time I get to physio I couldn't do anything. But now, I've got the transport and I'm…she says she's noticed it straight away how much more relaxed I was. And I could do a bit more. (Male, 50-65, mobility impairment & long-term health condition)*

A2.3.7.2. Mental Health

In regards to general health services, some participants with mental health conditions experienced specific issues relating to how well services met their individual needs.

One participant with a mental health condition which affected his memory had a positive experience with his GP surgery, which provided him with regular reminders of appointments:

> *Where I go now for my blood tests and pick up my pills, if I'm not there by sort of 11.30 they actually phone me up, which is really good, so they're sort of proactive, which is really good. Even my GP surgery now as well, and my dentist, they phone me up the day before to say, "Remember it's, you've got an appointment tomorrow," which, I know it costs them a phone call but I mean the amount of time it must save them, you know, wasted time…(Male, mental health condition)*

For another participant, who also had problems with memory and organization, he found his surgery to be less understanding which caused a problem when he needed urgent access to medication:

> *There seems to be a major problem with urgent access to medication. Often I've lost medication or lost a prescription or for some reason I haven't got it, or I've run out before, and I've forgotten to order it and it's quite common because I have memory problems because of my mental health problems, and the receptionist, until I explained that I had mental health problems that made my memory poor and this in turn caused me to be disorganised, they were quite rude quite frankly. Also, I went in a couple of weeks ago, three weeks ago, and and I explained this was quite an urgent situation, and could I get a prescription urgently, and they said no, the clinic was totally booked up, and I was like, "Well, that's not very useful for me," and I'd already been to the pharmacy and asked them if they could give me one tablet just to, as an emergency access and it was a blank no. The whole situation seems set out to cover their own form-filling rather than provide medication which, you know, for someone with mental health problems it can be quite important. (Male, mental health condition)*

Lack of understanding on behalf of GP surgeries was also a problem for one participant, who felt she was given no privacy when discussing her prescriptions:

> *I've receptionists in front of everybody kind of claiming that I've already had my prescription, kind of making me feel as if I'm trying to get drugs, as if I've got a drug problem, in front of everybody, no privacy whatsoever, and then it was found out that they had made a mistake and sent it to my home address. There was no apology. (Female, mental health condition)*

A2.3.7.3. Hearing impairments

For participants who were deaf or hearing impaired, the biggest barrier to accessing health services relates to the support provided to communicate with service providers. This appears to be a problem across health services. In most cases, the participants involved in the research relied on sign language interpretation to communicate.

For regular appointments participants typically booked sign language interpreters. One participant had experienced problems due to the interpreter not turning up, which required an appointment to be rescheduled:

> *Waiting for the interpreter to come, they never turned up at the Dentist and then had to make another appointment for another date and it was really annoying and it's twice*

> *that's happened to them where the interpreter hasn't arrived (Male, hearing impairment)*

For another participant, despite booking a sign interpreter for an initial hospital appointment, when the appointment was rearranged this was subsequently forgotten:

> *Awaiting hospital appointments and we ask for an interpreter and they say they've got it and the date's fine and the time comes nearer, gets nearer to the time of the appointment and one week to go and they cancel it and move it and there's no interpreter booked when it does eventually happen. So the first one they remember to book the interpreter, but when they change the appointments there's no interpreter. (Male, hearing impairment)*

One participant found that on visiting the hospital, despite the hospital having staff who knew sign language, skill levels were too low to provide adequate communication support:

> *Sometimes the Hospital will say they have a signer but they're only level one basic sign, it's not enough for medical jargon and detailed information to give us that information, I don't know anything and they've forgotten how to spell, if they're spelling things, it's not good enough, really need to know word for word what the doctor is saying, there's not enough in level one sign language certificate (Female, hearing impairment)*

A recent development in how participants could communicate in some health services is the use of the computerised Sign Translate system. One participant expressed problems with the system due to a lack confidence using computers.

> *The doctor tried to use the computer sign translate but she prefers to have the actual interpreter, she couldn't use it, she didn't like the computer. You don't have your own computer or nothing, no? So she's never used a computer herself to experience using one now is difficult for her to accept (Female, hearing impairment)*

For some other participants, this system was useful, but it was found that despite having a system, doctors often did not automatically offer this service to participants, who were unaware that it existed:

> *Some doctors surgeries have sign translators and the doctor can phone and the person who's deaf is beside them and they can sign to the computer and the computer can sign back, and then they can voice back to the doctor through the telephone, some doctors have that but they didn't tell us they had it and we're in there waiting and they're waiting for us, "Please have you got sign translate please?" and they have got it but they don't... the doctor doesn't let everyone know, the doctor just sits there and doesn't ask anything or doesn't offer it to the deaf person even though they've got it set up. (Male, hearing impairment)*

For the majority of hearing impaired participants, despite the use of equipment such as sign-translate, they still faced a barrier in communicating with their GP surgery remotely. This required them to visit the surgery to book appointments which could be difficult when unwell:

> ***What about when you want to make appointments with doctors, easy for appointments?***
> *They both physically go to make an appointment, if I'm collapsed and I can't and I need an appointment for the doctor - he's saying you can't, he's saying he'd have to crawl his way there and get to make an appointment, he's got no other way of contacting them, no other way, nothing.*
> ***Yeah, so always you'd go face-to-face and book appointments?***
> *No, they're all saying face-to-face appointments, they've got no other way of booking an appointment, which is difficult if you're very ill (Male and female, hearing impairment)*

For one of the interview participants, he used mini-com equipment to communicate over the telephone. However, he experienced difficulty with an appointment booking service which ignored the doctor's instructions for how to communicate with him:

> *I tell you, my biggest problem is, the doctor writes off to this centre who are supposed to ring you and ask you which hospital you would like to go to and in my case, they never bothered to read the doctor's letter to say at the top 'please dial 18002 before all the rest of the number' and it seems to be a very big problem and I did bring this up with my doctor. And I said to him "Well, look, they're not phoning me" he said "Well, we'll make sure, we'll put it quite large for them to see" and they're still doing it, they're still ignoring it. So it's alright offering you a choice of hospitals, but hang on a minute, how about them thinking about us and taking a bit of care, just looking at the doctor's letter and saying "Look, oh, this person uses a minicom" and it's one of the biggest problems I have. (Male, mobility impairment & hearing impairment)*

As noted previously in the report, many participants found it difficult to book urgent appointments with a specific GP. For one deaf participant, this issue was more significant as it made communication more difficult:

> *The only problem you ask for a doctor the same day the doctor's out so that means a locum comes in and it's really difficult with a new person, prefer my own doctor who's regular, the locum it's really difficult to explain and communicate with, yeah (Male, hearing impairment)*

Several participants also expressed frustration with automated displays at GP surgeries which were used to call patients into their appointment:

> *Before I went to the doctor and they had the display up there and went to the room six, you could read it and had to keep reading. And moved to the new doctors and there's no information there, when the doctor needs me he comes in and opens the door and sees me and tells me to come in so that's better but before reading that information all the time it made you go blind, reading that repetitively 'cause you're worried about missing something (Female, hearing impairment)*

Appendix 2: Health

A3 Appendix 3: Social Care

A3.1. What are social care services?

This section of the report is focused on participants' experiences of accessing social care services in the city. For the purposes of this report, the research team wanted to hear from people regarding sources of support with aspects of daily living, such as personal care, shopping and cleaning. The research team was interested not only in formal services such as direct payments and home care services, but also sources of informal support such as friends, family and neighbours. The research team was also interested in equipment and adaptations which people accessed, as the availability of these often played an important part in the support that people needed in their day-to-day lives.

In particular, the research team wanted to hear about positive and negative experiences, including any barriers participants had faced to accessing services and how services, informal support and equipment and adaptations affected the levels of choice and control that people have over their lives.

A3.2. Approaching the Topic

Research interviews began with a general discussion about participants' lives and any barriers or problems they had faced, particularly in regards to public services. Some participants discussed social care services and informal sources of support.

As the interview progressed, researchers asked the following more detailed questions on social care services:

- Please tell us a little about any support you receive with your everyday life
    - we want to know about people who help you with personal care
    - we want to know about people who help you with domestic duties (cooking, cleaning, shopping, childcare, etc.)
    - we want to know about people who help you to access your community (leisure, etc)
    - we want to know about equipment and adaptations you use

  How well is this support working for you? Is there anything that you would like to change about the support you receive?
  How important is it to you? Do you want it to continue?

The only participants we spoke to who were in some form of residential care were 3 participants with a learning disability. None of the participants with mental health conditions or physical impairments were in residential or nursing care. Several participants were users of direct payments and others users of formal care services such as home help or care agencies. Many participants spoke about help they received from family, friends and neighbours.

A3.3. Detailed analysis

A3.3.1. Direct Payments Scheme

Several participants in the research accessed support with day-to-day living through the Direct Payments scheme. These varied from long-term users who accessed 24-hour support from personal assistants, to participants who had just started the scheme, and those who used low levels of support (e.g. four hours a week).

All of the Direct Payments users we spoke to were positive about the opportunities that using Direct Payments provided them. For one participant, it was empowering as it allowed her to get out and about and participate in society:

> *I've got a really good care package. It's essential. It's really, really important. If I didn't have the care package that I've got now I wouldn't be able to do half of what I do even sort of getting out and about and... It's, it's really important because I would just be even more dependent on the services that I'm already dependent on otherwise. (Female,25-50, mobility impairment, visual impairment and long-term health condition)*

Another participant echoed this view and felt that full-time Direct Payments allowed him to exercise choice and control over his life and participate equally in society. For this participant it also alleviated the burden on his partner and made him more positive about life in general:

> *It's only the last two years probably where I've getting adequate direct payments and I can organise me package which way I want and, you know, and I can get things done and actualise me potential really... it's eradicated the dependency upon me wife most of all, so it makes me feel better about meself I'm not feeling a burden all the time.. Just generally I can do what I want, you know, what I want to do when I want to do it like every other human being to a certain extent. And I'm a lot more optimistic about the future and…just generally it's just a life-enhancing thing you know (Male, 25-50, mobility impairment)*

Another participant with a mobility impairment had anxiety issues getting out and about, but was able to do this with the support of a personal assistant employed through Direct Payments:

> *I'm mostly house bound these days. I have someone come in and help me with stuff but I don't get out very easily.*

> ***This person that supports you in the home are they there for just sort of house hold tasks or how do they help?***
> *Yeah for sort of personal care when I need it and household tasks and things as well. Just to do the bits I can't do…I don't tend to go [to town] on my own. I always go with my carer who helps 'cause I have some anxiety issues. That plus the mobility issues I could end up in all sorts of trouble so I tend to only go with the help. (Female,25-50, mobility impairment, & long-term health condition)*

One participant, who had a condition which meant she could not talk, conveyed her feelings in a text-based interview. As a former resident of nursing and residential homes she found Direct Payments gave her more control and improved her mental health:

> *I run my own care package myself via Direct Payments and this amount of control is okay for me. I have experienced life in various institutions - hospitals, nursing homes, residential homes, where I have had very little control and it was not good. I was often bored and depressed. I now advertise, interview, recruit and pay my own carer. This takes up quite a bit of time and means that I don't just have to accept carers agencies send. My family don't seem to understand this- they will when they get old. (Female,25-50, mobility impairment and cognitive impairment)*

For Direct Payments users such as the participant above, Direct Payments were important as they gave the participants a greater degree of choice and control over who provided personal care. This was also the case for another participant who was able to choose personal assistants with specific skills she needed:

> *I have carers provided to me through the council, through Social Services…I have PAs with me twenty-four hours a day. I employ them myself through Direct Payments. It works really well. So I've been doing it for a long time... It works well in terms of the fact that I'm employing people myself so I find the right people. I find the right people with the specific skills that I need. (Female,25-50, mobility impairment, visual impairment and long-term health condition)*

In some cases, care assistants provided by an agency (as opposed to personal assistants recruited directly) simply couldn't meet the needs of Direct Payments users adequately. One participant with a mental health condition needed regular support from somebody she could trust in order to prevent her becoming overwhelmed. For this participant, this support was best provided by someone she chose:

> *I had an agency for a year and a half and it's quite problematic, it's OK but you don't have the same person, you can't be flexible, I was always cancelling 'cos I had to go to the doctor's, or because I was sick, get that, so I had to cancel because I was sick because I had to go to the hospital or something and I wouldn't be back in time, or when I came back I'm far too tired to deal with a new person… what you're saying is you can do most things but you can't do them all on your own and you can't do them if you're overwhelmed and you just need someone to help you, it seems quite simple but agency just cannot give that whatsoever, there's no delivery of that unless you're really, really lucky, but virtually none. It's like, you know, your washing up's done, have you got a meal, and that's it, and it kind of just didn't meet my needs in any way, (Female,25-50, mobility impairment & mental health condition)*

As noted in the section of this report on community participation services, one participant on Direct Payments spoke very positively about using a personal assistant. Her only negative feedback was that the support was insufficient to enable her to access leisure opportunities as often as she wanted:

> *With my PA, as I say, we go swimming, everything like when I go into hospital or hospital appointments, or there's anywhere I need to go in general, whether I need to perhaps take out the mother-in-law or... then they'll help me... That's every week, five hours a week. .. It really does boost my confidence, knowing that I can do a couple of the things that I want to do. I'd like [the hours] to be more actually. But, obviously I understand finances.*
> ***What would more support mean for you?***
> *Great. You know, I'd be able to do a little bit more, you know, I would like to swim at least twice to three times a week like I used to. (Female, 25-50, visual impairment & mental health condition)*

Participants' experiences of accessing the Direct Payments scheme in the first place were in some cases quite negative, and instructive regarding the barriers that people can face to using the scheme. For one participant, on contacting social services she was not signposted to the support that she was looking for. This participant was eventually able to access support, but only after her sister contacted social services on her behalf:

> *Things came to a head last year and I just wasn't coping. I wasn't leaving the house. I wasn't talking to anyone and my sister phoned social services on my behalf to see if there was any help available and a lovely woman came round and sorted everything out for me. Cause I didn't really know that there was anything available so, she asked the questions that I wasn't quite up to asking… I tried to phone social services first and I got sent to about six different people and no one knew what to do so I gave up on that and handed it over. 'cause I think sometimes when you need that help you're not always able to get it for yourself. (Female,25-50, mobility impairment, & long-term health condition)*

Once this participant had been able to access an assessment, however, her experience was more positive as she was signposted to the Direct Payments scheme:

> *I knew that I just wasn't coping you know some days I couldn't get dressed and I certainly couldn't get myself out of bed and stuff so I started paying my friends out of my own money just to help me and then when I spoke to social services she said you know we can work something out and now I pay half the money and they pay half the money to allow me to have four hours care a week…which makes the world of difference. I was kind of paying for an hour a week and …if someone came Tuesday and got me up and out of bed …I was still in bed you know on Wednesday going I don't know what to do! Now I tend to have help about four days a week, but with flexibility so if I was fine on Wednesday then Thursday she would come in and help me if I was struggling the next day. (Female,25-50, mobility impairment, & long-term health condition)*

For other participants, lack of signposting to the Direct Payments service simply resulted in them not being assessed for any support. One participant was forced to temporarily move to live with family outside of Brighton and Hove, which prevented her going into crisis.

> *When I first got ill I tried to contact Adult Social Care because I was really very ill, and got absolutely nowhere. I phoned them twice, I phoned them when I first got really, really ill, nothing happened, they never got back to me. They said they'd put me on the waiting list for assessment but nothing happened. I then phoned them about six months later, again, and again the same thing happened… my sister really was the one that rescued me. I mean, had it not been for her it would have been… I just don't know what would have happened, because I went and stayed with her for three months when I was really, really ill (Female,50-65, mobility impairment & long-term health condition)*

For another participant, social services signposted her to children's services when she was looking for additional support with day-to-day living, which caused considerable stress and anxiety as she felt her parenting ability was being questioned:

> *One time, it wasn't so long ago, I had a very bad MS attack – really struggling to do anything – walk or anything I thought oh, well I'll try to get a PA or whatever to help with my daughter to walk her to school. That was really difficult when she was still at nursery actually. I phoned loads of people up – I said I want the Access Team for Adults because the issue was my disability as a disabled parent I need some help. And they kept saying Oh no, you need the Children's Families Team and they kept saying What's the name of your daughter – we'll refer her and I was like No, you don't and all this stuff and she kept phoning up and got absolutely nowhere with that it was so stressful I wish I'd never started. Luckily there's a friend who lives quite near who is able to help me out and I paid her and that all worked out fine but if they hadn't been there it would have been really difficult – it was very, very stressful and I didn't need that when I was struggling so much at the time (Female, 25-50, mobility impairment, long-term health condition & mental health condition)*

One participant who was able to access a social worker assessment for additional help was assessed not to be eligible for support. This participant felt the assessment did not adequately consider her physical and mental health and meant she continued to struggle with aspects of daily living:

> *Because I don't look obviously physically disabled and I know mental health, that's not obvious to people, you know, I'm perceived by the services as very able-bodied, you know, also because I work, which also as I said when my partner left to get some sort of support because obviously trying to run a home, have two children and do physical things that, with one hand is exhausting and tiring and painful. I tried, I was given a Social Worker, and she briefly spoke about direct payments that people had said that you could use, but apparently I didn't warrant it because I was independent enough. But I'm being forced to be independent enough, you know, I'm in pain because I'm forcing myself to do, because there is no-one else to do it. I've been given a mental health champion because of kind of returning back to work and taking on the extra burden and all the rest of it, which is lovely but it's a lot of just paperwork. It's okay,*

> *what are your stresses, let's write them down, how do we feel… I mean, I could write my stresses down and my problems till the cows come home but there's still no practical solution, you know. With the best will in the world, she's lovely, she's going to tell me, "Well, if you write a list each day and do a little bit each day," that's still not going to help me tonight when I've still got to go home, feed two children, do a, do this, do that with, when I'm tired and ill and my mental health and on medication and dozy (Female, mobility impairment & mental health condition)*

One participant, who spoke positively about the current level of support he was receiving, recounted his negative experience when first going onto the direct payments scheme. Despite being assessed as needing 24-hour care and put onto the Direct Payment scheme, this participant was given no choice but to breach minimum wage legislation in order to employ carers:

> *I mean I've had some terrible experiences with social workers. For example just when I was living in Brighton & Hove the last, say thirteen years …when I first got direct payments they were expecting me to pay £30 for a eight hour shift. And it was kind of like when I says, 'but that works out, that's below the minimum wage.' And the social worker lied over and over again and says, 'no that's what direct payments is about.' And I was saying, 'no, as far as I'm concerned direct payments is about allowing disabled people to attain independent living and all this' and she was like, 'no, no' and she was saying, 'there's a ceiling, you've reached the ceiling and there's a maximum' and I was reading the guidelines from the director of social care and he was saying, 'there's not a ceiling' and I was saying, 'you know read your guidelines.' And she was saying, 'no, no' and she was going back to her manager and she, at the end she was like kind of saying, 'my manager's tearing her hair out and I'm going to get me hands slapped when I go back if I say that', and I was like, 'aye right.' It was just like gatekeeping the resources, and that went on and on for…oh for probably ten years I would imagine. I was trying to get by on inadequate direct payments and so was still dependent on my partner, I was still feeling a burden you know, and it wasn't anything like independent living. (Male, 25-50, mobility impairment)*

For this participant, inadequate funds for 24-hour care caused him considerable difficulty in recruiting employees. Ultimately, he was only able to secure funds to pay above the minimum wage following a complaint to social services:

> *It was down on the care plan 24/7 but when you looked at all the figures it was like, kind of like it's impossible to get... she kept saying, had this term, 'it's down on the care plan so you've got to manage' and I was like, 'what does that mean?' She was like, 'well it's down on the care plan what you need and that's the money, so you've got to manage with that' you know, and I was like to her like, 'but I cannot manage, people ask and the first thing they say is 'how much is it an hour?' and when I say 'oh no it's I'm on direct payments it doesn't work by the hour it's £30 for eight hours' and they're like, I mean they're were working it out and like 'it's about £4 an hour something like that' and like going, 'alright thanks bye*
>
> ***So, what do you think, what do you think is the reason why you managed to get more support in the end?***
>
> *Because I knew it was my entitlement as a disabled person, as a human being, to have the funding for direct payments. I made a complaint and said I was going to go to the media, I think that's what it was. ... But it would be better if the system was just a straightforward system for us and……we didn't have to go through that because I*

> *mean it's such a stressful thing anyway, at the end of the day we've always got that threat of kind of like if it all breaks down I could go into a home you know. (Male, 25-50, mobility impairment)*

Some of the participants in the research had been assessed by social services and offered Direct Payments, but chose instead to have care provided by other formal sources such as home help or care agencies. One participant felt that using Direct Payments would reduce the hours of care he received as he would be required to put some of his funds towards administration of the scheme:

> *I said I don't want to be involved working out National Health Stamp (sic) income tax and I said I'll go to the Federation of Disabled People. They will take some of the money off to actually pay for it so that means I would have less time now if I did that than what I'm getting now. I said and I don't like people sitting in an office and pushing everybody outside work so they can still sit in the office and do less and less work. So I said I want them to work hard. So I keep them going. You know and they don't realise 'cause they said you get the same amount of money. I said yes you would get the same amount of money but if you're having the top slice taken off for the administration of it you're going to lose that money. You're not going to get the same service. (Male,50-65, mobility impairment & long-term health condition)*

For another participant, she was initially deterred by her perception of the work involved in setting up the scheme:

> *Well the first social worker that came to me said I should have Direct Payments and that was like three years ago and she started saying 'you know, you could go out with this person and stuff' and I'm looking at her and I'm, I weigh about five stone and I've really been quite sick, 'cos I was so poorly and yeah, and I'm like 'I don't think so', and I thought 'I don't know what you're talking about', and actually in retrospect she was really nice but I was scared, I didn't have the confidence and I rang her up and I said 'I can't possibly do this, recruit somebody, I can't do this, I'll have agency'.... (Female,25-50, mobility impairment & mental health condition)*

This participant was eventually persuaded to adopt Direct Payments following problems using agency carers and reassurances from her social worker that support was available to use the scheme. This resulted in her accessing support from the Fed's Direct Payments advice service which helped her to set up a care package which met her needs:

> *The second social worker came and she... I have to say social services have been, have always been really nice to me, the encounters that I've had... the second social worker said 'you really should do Direct Payments' she said 'if you don't you'll probably lose it 'cos you're not really using it in the right way', so she promised me that the Fed would help me and that's how it works. I was still quite scared, I still put it off for three months and I stayed at my mum's. But then I decided to initiate the process and I was allocated a person to help me, and [he was] absolutely brilliant, reassured me, came to my home and listened to all I said, listened to me cry, sort of said 'yeah, I can write a personal description, I know what you want' and didn't, just like the social workers actually, didn't belittle me for actually really needing what agencies can't provide you with, which is support… so he helped me massively, he did all the interview process and they helped me when I rang and asked about the PA board 'cos I wasn't getting*

> *any applicants, and I approached a couple and in the end this one girl came forward, and I've only had it for one week so I can't say any more than that 'cos it's took that long to put into place, but she's just brilliant, she exceeded my expectation from when I met her, and I said to [my DP adviser] after the interview, I said 'so how long do we have to wait before we offer her the job, like one minute!' (laughs), he went 'yes', so yeah, she's just great, she's really supportive, she really gets it, she's really non-judgmental, she puts all my medicine in pots, she cooked my dinner, she picked up my contact lenses and yeah, I'm happy, I'm really happy (Female,25-50, mobility impairment & mental health condition)*

This participant felt that greater encouragement and reassurance was needed to help people like her benefit from the scheme:

> *If I'd have known that the Fed was going to be this supportive then I'd have done it years ago, and the only criticism I had, I said you need to help people understand that this is possible and that you will get help, and that, even though you do employ someone, you know, it's not that scary, the Fed has already sorted out an insurance policy, you know it's like it's not that bad, 'cos it's way better (Female,25-50, mobility impairment & mental health condition)*

A final barrier identified by participants in the research to accessing Direct Payments was the charge care users had to pay. Although a concern to other participants, in one case the charges directly prevented the participant from accessing social care:

> ***Do you know on Direct Payments schemes whether you could get someone through that?***
> *I do but I have to pay the first eighty one pounds which I can't afford. (Female, 25-50, mobility impairment, long-term health condition & mental health condition)*

A3.3.1.1. Day-to-day management of Direct Payments

For participants using the Direct Payments scheme, an important issue was how well the process of recruiting, training and managing personal assistants worked. One long-term user of the scheme felt that support for this was improving but that more could still be done:

> *I think the system is improving and I think there could be more provision for people, for both the users and for carers employed through Direct Payments. (Female,25-50, mobility impairment, visual impairment and long-term health condition)*

One participant who had recently joined the scheme spoke positively about the support she had received from her direct payments adviser on the recruitment process:

> *[My DP adviser] took what I wanted and turned that [into a job description], and then he had these amazing questions to ask in the interview which were just, I just wouldn't even have thought of because you know I haven't been in work for a few years (Female,25-50, mobility impairment & mental health condition)*

This participant felt positive about the support provided by the DP adviser and felt it was a good point of contact should any problems arise managing the scheme:

> *I know that I can ask [the Federation DP adviser] for any help that I need but yeah…I know that I can ask him or [my social worker] if I…even if they couldn't help me I know that they would direct me to the people that could. So…it's quite nice because I felt quite on my own with a lot of it over the years so its quite nice to k now I've got a point of contact if I do struggle. (Female,25-50, mobility impairment & mental health condition)*

Another participant was less positive about support available in the event of any problems:

> *What I find is that Social Services know what they have to do and once they finish doing that might take two or three months maximum, they forget about you. And you won't see them until one year has passed to check that everything you need one year ago is still the same. And they don't take a personal interest in you. And if they can help you nine to five, lovely. If you have a problem in the evening, you are on your own basically. (Male,50-65, mobility impairment, visual impairment and long-term health condition)*

For two participants, a key issue in day-to-day management of Direct Payments had been finding employees who could drive. Although one participant found this had improved, the other participant chose to give up her adapted vehicle due to the problems she had encountered:

> *I've got me own adapted vehicle that me partner or personal assistant drives. That's dependent on the personal assistant driving. Lately I've been quite lucky but in the past finding PAs who can drive has been an absolute nightmare. Especially getting assistants from agencies where they've ticked the box on the application form saying they can drive and then they get in and suddenly confess they've never drove in the UK before. (Male, 25-50, mobility impairment)*

> *I used to have a wheelchair accessible vehicle and PA that drove for me but I found the difficulties with finding and employing PAs that drove and then the logistics around organising my rota with the PAs that drove on days when I had activities that I needed a driver for just became so complicated that the disadvantages outweighed the benefits. So I don't do that anymore. (Female,25-50, mobility impairment, visual impairment and long-term health condition)*

For another participant, the main problem employing personal assistants was finding individuals willing to be self-employed so that the participant did not have to manage the payroll administration:

> *Finding a carer that is willing to be self-employed is incredibly difficult*
> ***And why do they need to be self-employed?***
> *Because they manage their own taxes, their own time, little bit of everything, I don't need to bother with their situation, they just come to work and that so. If they are sick they need to take good care of themselves because if they don't come to work they don't get paid. (Male,50-65, mobility impairment, visual impairment and long-term health condition)*

A3.3.1.2. Concerns about the future

Two participants received support from both social services and the Independent Living Fund. For one participant, the uncertain future of the Independent Living Fund caused him great concern about his care funding in the future, particularly given his previous difficulties accessing Direct Payments support:

> *It's a constant fight for adequate payments to attain independent living you know? To live, to live like everyone else you know, have the same choices and control as everyone else. That's a formidable barrier that I've faced…for all me life really, but especially the last thirteen years, and I'm really concerned about what the future holds in regards the independent living fund especially, because I'm going to lose, most of my budget comes from that. Especially when the local authority are supposed to be going to make up that balance and their budgets are already going to be slashed. That's a really big concern of mine at the moment. (Male, 25-50, mobility impairment)*

A3.3.2. Other formal care services and general feedback

One participant who had been assessed as ineligible for Direct Payments had instead been directed towards rehabilitation support from care assistants over a six-week period. However, as a participant with a long-term disability this support was unsuitable as it focused on teaching adaptation strategies rather than providing practical support:

> *When my carer left, I was referred into community services, what they do you only get a certain period but they come and help you learn to adapt to life now being less abled, but I've been born this way so I was kind of like, you can't really teach me how to live because I already know how to do it. They were quite good and kind of put some adaptions into the property that I had to pay some towards and kind of promise that I'd give back if I ever go or do anything. I think it's a six-weeks period you're allowed and how they explained it to me is if someone had gone into hospital or had a stroke or something like that they would obviously be learning how to adapt then less abled. These carers come in and teach you how you can cook or open a jar or wash and dress then being less abled, whereas I was kind of, "Well, I've already learned adaption techniques for how to do this," so there wasn't a lot for them to do. (Female, mobility impairment & mental health condition)*

Two participants in the research used home help schemes funded by the council for support with aspects of day-to-day living. One participant received assistance every 10 days with laundry and cleaning, and was happy with the support she received:

> *I have a home help, yes, and manage with that…they come about every ten days just to do my laundry and clean the house really, which I can't do.*
> ***Would you like more support and that from her or is that...***

> *No, no, I quite like this independence. I think... because I, you can sort of pick your own times then, if you feel like doing something or not. (Female,50-65, mobility impairment)*

For another participant, the home help was beneficial but the time restrictions of the scheme prevented him from accessing more support which he felt he needed:

> *I have a home help first thing in the morning to help me get out of bed. And so they have to come and they get me out of bed and give me a shower and help me dress. And then they do the housework on a Tuesday and my washing and that, on Thursday's they do shopping for me and on Friday's they do the ironing from the washing… I'm finding it harder in the evenings to get undressed. I have help to get me dressed but I have been having problems getting undressed. It may take me quarter of an hour to get me shirt off because I just can't move the shoulder's to…to do it. But then again who wants to go to bed at six o'clock at night? I'm a carer to a couple of people and you know they have the home help sent at six o'clock, seven o'clock at night to put 'em to bed. If you're ninety odd, yeah ok if you want to go to bed, go to bed! But I'm still young and still active (Male,50-65, mobility impairment & long-term health condition)*

This participant was generally positive about the service provided but also found that home help assistance occasionally caused difficulties for him to participate in volunteering work which involved regular meetings:

> *They're very good. Timing isn't always easy. Yeah and you may find your home helps not turned up and so you phone through and then you find that they have to faff about trying to get somebody else. Well, I've got a meeting at ten o'clock, I need to get out of bed so they have to take it. Well, they say we've got to take somebody off somebody else. I said yeah. You have a contract, do it! It's not my fault. You have a contract to bide by. We'd normally negotiate because sometimes I get very short notice of meetings to go to. Maybe 48 hours or I've even had 12 hours notice and I've had to phone up when the meetings not done when it's s'posed to be done and you have to meet the next day I have to arrange the home help to do like Tuesday or Thursday and Friday do the other bits besides getting me up. So I do get what I need but it's not always at the time that we both really need to (Male,50-65, mobility impairment & long-term health condition)*

As with Direct Payments, care charges for other formal sources of care were also a problem for one participant:

> *I've got to pay for a carer...but at one time, you could get free care, but now, hang on a minute, if you have 'x' number of hours, you've got to pay for…and I couldn't afford it like that, it's about £45 a week for each week, well you can imagine that, you know, by the time you've worked everything out, that's the worst problem (Male, mobility impairment & hearing impairment)*

A3.3.3. Informal sources of support

Several participants received support with aspects of day-to-day living from sources other than statutory services. In several cases, these could be through commercial services such as online grocery shopping. In other cases community schemes were used. One participant, for example, used a home help scheme run by Age UK:

> *I pay for home help from Age UK. It's [name removed] she comes once a week to clean… and she'll also, I'll also phone her up first see if I need any shopping, she'll call into the supermarket on the way down. So she's here for two hours. (Male,50-65, mobility impairment, mental health condition & long-term health condition)*

For another participant, occasional practical help from a subsidised handyman service was important to enable her to manage at home:

> *Occasionally I have to get people in to sort of do things in the house, you know, like unblock the drain or whatever. I make good use of the Handyman Service that I heard about through the Federation. It's a charity, it's a charitable service, it's based in a Housing Association I think, can't remember which one now, but they employ two handymen, and if you're disabled or on Incapacity Benefit they work for a subsidised amount. So they can do minor repairs to your house for up to two hours, that take up to two hours of time, as long as it's not like building work… so I make good use of them, because its £10 an hour I think if you're on benefits. (Female,50-65, mobility impairment & long-term health condition)*

In other cases, participants made use of money from their Disability Living Allowance to pay for occasional help around the home, such as cleaners or in one case a personal assistant:

> *I'm able to get help that I need, I have someone to help me in the house, because I've got arthritis in my hands. So yeah, I can use my Disability Living Allowance… I have a cleaner, but I also have a student who comes in and she's fantastic because she does almost everything, because she's brilliant with computers, she'll help me, she'll teach me how to use the computer, she'll carry and move things around the house, she'll phone, you know, if I'm really struggling with sorting out a kind of problem with a bill or something like that, because sometimes you just sort of get to a point where you think 'I can't sort of cope with this', whatever it is. It might be some stupid company that wants to overcharge you for something, she'll sort all those. She's like a PA really in a way, but she comes in anywhere between one and three hours a week and she'll do whatever needs doing. (Female,50-65, mobility impairment & long-term health condition)*
>
> *I don't use any other care thing other than if I do get somebody to come in and give me a hand to do something I just pay them, but nothing organised.*
> ***So where do you get someone from if you…?***
> *Well sort of friend, or something like that. I've got some stuff that needs moving at home cause I've got to sort out my room, um, could he come and give us a hand? Yes, well here's a tenner. Thank you very much you know…'get yourself a couple of pints'. That's all really. My flat mate does do the laundry cause we've got a launderette downstairs. (Male,50-65, mobility impairment, long-term health condition & mental health condition)*

For one participant, however, increased costs due to housing benefit changes made privately sourced help for cleaning too costly:

> *With the reduced help on my rent and my travel to work now is £200 a month, that's my disability allowance gone. I mean if you pay a cleaner to come in they're £10 an hour at least and they have to have two hours or four hours, that's your allowance gone. Although I'm very, very grateful, the disability allowance does make a difference to my life, it nowhere would cover generally paying outside sources to come in and assist with what I would need around the house (Female, mobility impairment & mental health condition)*

The majority of participants needing some form of support with aspects of day-to-day living tended to rely on support from family, friends and neighbours, which reduced the need for other services:

> *My next door neighbour who lives near me, if I need anything I just knock on her door but I try not to bother her. Unless I really have to. (Female, 25-50, visual impairment & mental health condition)*
>
> *I'm lucky that I've also got my family who, you know, try and help me if I'm really stuck with something. (Female,50-65, mental health condition)*
>
> *Coping with all these steps and that it's a nightmare. On a bad day I can't even go out. In the winter we're iced in here. You can't even get out here because the council never come out round here. So I'm stuck…I can't walk up the shop or anything. If it weren't for neighbours I wouldn't be able to survive…literally. (Male,50-65, mobility impairment & long-term health condition).*
>
> *I do lots of staying with my mum, you know, 'cos then I don't need a carer do I and then I don't need anything, I don't have to go shopping, I don't have to do cooking, and you know, my brother comes and visits me (Female,25-50, mobility impairment & mental health condition)*

One participant noted that he often didn't think about the extent of support he received:

> *Like my father, he's in his mid-70s, he drives me around everywhere, and my mother and my sister sometimes as well, and my partner I have now does come shopping with me, you know, and I can manage certain things. You don't think about the things that actually have an impact because it's part of your life. (Male, 25-50, visual impairment & mental health condition)*

Another participant, who had concerns about falling at night, benefited from having a lodger, who provided reassurance rather than any form of physical assistance:

> *I do actually have a lodger who lives with me, which means that I'm not totally alone physically in the house, which is nice. You know, I sometimes get quite frightened because at night when I'm really bad, my pain levels are really bad, and I sometimes have to get up and take medicine, or sometimes, like in the heat, I have to throw myself into a cold bath, and I sometimes get a bit scared because I know that I could easily fall downstairs … I have nearly fallen downstairs a few times, so I'm glad I've got someone in the house, because if something went wrong there'd be someone there. (Female,50-65, mobility impairment & long-term health condition)*

There were also some examples of participants who had mutually supportive relationships with family. In one case, the participant lived with her daughter and provided support with her mental health condition while the daughter assisted with day-to-day activities:

> *My typical week consists of perhaps twice going out, one with a friend or my daughter in the car so they can nip in and out of the shops for things I want to get, saves me doing it…I live with my daughter… she's sort of looking after me and I'm sort of looking after her, helping her mental state, helping keep calm and balanced. And she has to keep helping me, well, cook for me and read for me and fetch that for me please and unplug this and that. All the usual things you'd find so easy when you're, you know, physically fit and things you find you can't do if you get dizzy every time you do them or you can't do that because you can't breathe and then you've got to spend all those minutes recovering. (Female,50-65, mobility impairment & long-term health condition)*

Another participant lived with her daughter and husband who both had physical impairments and supported each other. However, in this case the participant was concerned with these arrangements as often they were not well enough to cook for themselves. This participant also expressed that she had problems with budgeting and did not access care support due to the care charges which she felt she could not afford:

> *My daughter is my carer, she's on carers allowance but she's also very ill… My husband has a trapped nerve in his back and problems with his legs so…he's also got a stomach ulcer so he's not well either. The three of us look after each other but quite often we'll go two or three days without having a meal because nobody is well enough to cook …My daughter does what she can, my husband does my personal care, he does the bathing, the washing, the hair washing you know that sort of stuff and my daughter will get me dressed and get me lunch sometimes when she's up to it and has a sweep round.. If none of us are well enough to go and get milk we have to give our neighbour money to go and get milk and you know here's a fiver go and buy yourself some fags for going you know, stuff like that so it goes really quickly..I did have a cleaner employed I gave her forty pounds a week and she did five hours but because my daughters left full time education and is getting carers allowance my moneys dropped by one hundred pounds a week I can't now afford to employ her. (Female, 25-50, mobility impairment, long-term health condition & mental health condition)*

In some cases, participants supplemented support from friends or family with other schemes and private arrangements:

> *There are people I can phone up and say oh I've run out of bread, I do that now again but I try and I get Sainsbury's and home help (Male,50-65, mobility impairment, mental health condition & long-term health condition)*
>
> *I've just, well I've just left my cleaning lady to finish off actually and she comes once a fortnight but that's all the help I have. I've got two sons… and I can call on them any time and they come. My older one...he's coming and doing something in the flat for me. He's a more DIY man rather than my other son.*
> ***And is that enough support?***
> *Yes 'cause I have as I say I've got friends that take me out (Female,50-65, mobility impairment)*

One participant benefited from support from an individual in his community who provided informal support for many different people in the area

> *I'm not well enough to go up the shops I'll ring [name] and ask him if he can and if he can he'll get stuff down to us. He's a godsend…he's a really good bloke. He runs the chemist and everything and actually I just sent a repeat this morning to him and he'll take it down to the doctors, he'll pick it up. He helps a lot of people out here coz of what we've got wrong you know. (Male,50-65, mobility impairment & long-term health condition).*

Not all participants were simply receivers of informal sources of support. One participant in his early 60s, for example, provided support to other residents for his council estate as part of an informal group of disabled people:

> *Most of us are disabled on the estate, yeah, but we still help one another although we're disabled ourselves. We found that it's easier to do that, helping one another, than asking for it because we know that we don't get it, or if we do get it we've got to wait longer to get it and then when you do get things done the attitude is, "Oh well, you're only a disabled person, what the hell" you know, and you don't get a good job.*
> ***What kind of help do you provide each other?***
> *Anything really….if they're ill we can help them through their illness. Sometimes it comes to death through cancer or something but we still do things for them, you know, so that they can do it. Although they have carers, I feel that most of the people don't like the carers because they're, it's not personal, they like somebody who they know rather than somebody who just comes in, does a couple or a half-hour work and then buggers off…There's no real one-to-one, we tend to fill that gap in, so we know what they're on and sometimes they don't like saying to the people, "Well, this is what's wrong," so we have a chat to the carers and say, you know, "They're worried about this and that and the other because they don't want to talk to you about it."*
> ***So I mean you say we, do you meet as a group, like tenants?***
> *Yeah, there's about three or four of us on the estate, and there's all different things wrong with us…it's a lot of things that we do for others, you know, rather than ourselves. It's the only way because I think quite honestly in politicians' eyes disabled people are forgotten and being old-aged and disabled you're definitely forgotten. (Male,50-65, mobility impairment)*

When the research team probed on how participants felt about their support arrangements, several participants relying on support from friends, family or neighbours were content with this arrangement, preferring not to rely on state support. Some participants felt this made them more independent, but characterised independence as self-reliance, in contrast to the definition used throughout this report:

> *If I need like changing light bulb, curtain, I call my friend to help me, I don't use those kind of things [direct payments], those are my problem, I don't, or if I want to lift big stuff, like changing beds or, I call my friends, but the rest I don't need someone to come to help, I just like to be independent, I always have done, I don't rely on people to help me (Female, 18-25, mobility impairment)*

> *I haven't got a carer. I'm totally independent. You know, so I just get on with life as best I can and pretty well, with a little bit of help, but I haven't got any official carers…*

there are people worse than me, a lot worse than me. Let them have the carers and things, till maybe, one day, hopefully not, but I will need them. Then I will apply, but until then, what I can manage I will. (Male,50-65, mobility impairment, long-term health condition & mental health condition)

And have you ever been assessed for Direct Payments or anything like that? Is that something you'd like to?
In the future, maybe, when I need to. I mean I know I can cope. With a bit of help I can cope. (Male, 50-65, mobility impairment & long term health condition)

For several participants, assistance was provided by their partner and they preferred not to access any external sources of support:

Do you get any kind of care support like direct payments or anything like that?
No, my wife is my carer, she's my official carer.
And have you ever been offered anything like that or ever been interested in anything like that?
I haven't, not that I haven't been interested in it but at the minute things are going ok, you know my wife is my carer, I'm doing as much as I can independently at home, you don't want to give in, you want to do as much as you can for as long as you can. Unfortunately my wife is doing more and more for me, more for me now. If I'm having a really bad time then she'll do a lot for me, if I'm ok then I can just about get through. (Male,25-50, mobility impairment & long-term health condition)

My boyfriend's brilliant and he does a lot. We've kind of got quite a small flat. It doesn't need too much stuff doing to it. So I can cook and he'll carry things around the flat for me if need be. So no I don't really struggle too much with that now. I can't do cleaning and I can't carry stuff around the flat. But I'm lucky that I can use the DLA money to pay a cleaner and my boyfriend. If I was on my own I would have to access a lot more stuff I think. (Female, 25-50, mobility impairment & long-term health condition)

What kind of support do you receive from your partner?
Day to day care, helping to clear up the mess I normally get in to in the mornings, help with the bathing, cooking, driving, shopping, everything. Picking me up when I fall over. It's all very much physical care and at the same time in the past I've been my partner's carer in terms of mental health issues. So we've been mutually supporting each other.
And how well is this kind of working out for you at the moment?
For me it's fine. I think my partner is finding it stressful at times. (Male, 50-65, mobility impairment & long-term health condition)

It's just the two of us and we want to keep it that way, we really want to keep it that way for as long as possible. She was diagnosed with a lower back problem last year, she has been told not to put too much stress on it – kind of difficult when she's doing everything and at some point she may have to have an operation and the problem that's facing us is that they may not let her come home if we're still here and then our two lives are buggered. She's it, she never used to be – I used to get around and do things but can't now. We cope – we want to keep coping. We don't want to have to turn around to the Council and say "can you do a care package", don't want to do it, don't want any other people involved…but she's also backup care for her own parents as well –she's got that responsibility as well (Female, 25-50, mobility impairment)

In some cases, it was unclear whether participants were content with their current arrangements or simply lacked any alternative options. One participant, for example, in her late 20s was living with her parents and didn't feel there was any other option:

> *Currently I'm living with my parents…I think that's probably the only thing I could do at the moment. But I need to have someone there for cooking and for helping me do, kind of, day to day activities. If I wanted to move out I'm…I don't know, I wouldn't know how to at this stage, being on Incapacity Benefit… Again, no one's ever said, 'this is what we could offer, or we could help you do this, or have you looked at doing that?' (Female,25-50, mobility impairment, & long-term health condition)*

In other cases, the dependence on family, friends and neighbours for social care support had a negative impact on participants. Sometimes participants felt as if they were a burden on their family and had to be grateful for whatever support they could get, even where it wasn't quite enough. These participants wished they had other means to support themselves:

> *I'm very lucky I've got all three of my children living in Brighton but they are working, they are busy they've got lives. I've never been one to go ohhhh you've got to come round every night and urggghhh. I would prefer my younger one to go and, if she finds a place she can afford, go and live somewhere else. Not because I don't love her, because I don't want her to feel she's got to stay behind and say no no no to everything just because I'm not well. I said to her if you're not here I'll probably move into somewhere like a sheltered housing where I know I'll get some meals and people coming to check on me and all that stuff, then you won't have to bother. And of course she's still like no no I want to do this. Well, I want you to have a life like the other two have had, because they are older and I don't want her to be stuck with me. I'd like to have things in place from the government and the council so I know how I could do that and still have some kind of help and support when shes not necessarily doing it all the time. That's not fair. (Female,50-65, mobility impairment & long-term health condition)*
>
> *You don't want to ask your children to do things, you don't, you have to be very humble and appreciative for what you are given and you don't want to be in the position, you want to be independent (Female, mobility impairment & mental health condition)*
>
> *It's that thing of being incredibly grateful all the time for the help that you get, even if it's not quite the help that you need as well, it's being in that really sort of vulnerable position, which is part of my thing anyway, feeling really vulnerable. (Female, mental health condition)*
>
> *I do have people I can text and say, could you come by with a pint of milk, but there are only so many times you want to say that to someone. (Female,25-50, mobility impairment & long-term health condition)*

In several cases, the dependence on unpaid carers created tension and conflict between the participant and their carer, particularly where the carer felt forced into the position, with a negative impact on the participant's lives:

> *My husband helps occasionally with personal care, although in private he will make remarks which suggests he resents helping (Female,25-50, mobility impairment and cognitive impairment)*

> *My mental health deteriorated drastically and my ex-partner was put in the position of carer. He didn't want to be but he had no choice. He, they offered support, did a care plan three times, lost it three times, never got any support, he was just forced into the role which then he's obviously very angry and negative against me, which is understandable. (Female, mobility impairment & mental health condition)*

> *I used to get support from my next door neighbour...Then one day, she just sent me this text about how sitting around and doing hobbies all day wasn't real life, and I should get someone to fix my illness so I could get back to work. It's, like, where did that come from, because we were very good friends, and she knew all the things that were going on with me, and she could see the amount of bloody medication I take and it's, like, yeah, I just do this for a laugh, so that was quite hurtful. (Female,25-50, mobility impairment & long-term health condition)*

Some participants simply felt their needs were not being adequately met by their current reliance on unpaid carers for support. As noted in the chapter on community participation, some participants felt unable to participate equally in the community due to the lack of support. In other cases participants struggled with day-to-day activities:

> *I can't do a lot anymore and I'm really getting resentful of having to do things like housework when I'm not really well enough to enjoy myself…That I find very difficult and it actually makes me cry, by the time I've washed up a few cups I want to sit down and my arms are just like that, you know that one, when you just want to go ahhhh. Because there's not the strength in my limbs, I can't scrub floors like I used to and ovens like I used to. (Female,50-65, mobility impairment & long-term health condition)*

Another participant felt that support from friends was simply too inconsistent and unreliable to be relied upon:

> *There's nothing guaranteed, there's nothing consistent, I don't know if anyone's going to help me and eventually people normally do but, yeah, it's kind of I don't know when that help's going to come, which is really difficult (Female, mental health condition)*

One final point raised by a participant regarding support from unpaid carers was the importance of respite for the carers themselves. In addition to requiring support himself, this participant had at one time been a carer for his mother several years previously and reflected on a particularly difficult time:

> *Carers need to have respite care. It is essential. If it wasn't for Crossroads, I would be in prison because I tried to kill me mother twice in one night by putting a pillow over her. And counted to ten both times and every time I lifted it she came up laughing. And I said she ain't going to go tonight then I went in the sitting room and sobbed me heart out that I'd even thought that. But I hadn't slept for three months cause she slept during the day and was awake all night. And she came into my bedroom and hit me so hard she knocked two fillings out cause she didn't know who I was. She had Alzheimer's and she thought I was just a man so she hit me…so I went to the social*

> *services and said I tried to kill me mum last night twice and they said well you go home and we'll come up. And then they were sitting outside my flat waiting for me to get home and they gave me emergency respite cause they said we can see you're just cracking. And they had reports from the home help how bad she was. (Male,50-65, mobility impairment & long-term health condition)*

A3.3.4. Equipment & Adaptations

A3.3.4.1. Significance of equipment and adaptations

The participants in the research had accessed or were waiting to access a variety of equipment and adaptations to help with aspects of daily living. In most cases these made a significant difference to participants' lives. For one participant, for example, the council-funded conversion of his bathroom was vital to minimise risk he faced when bathing:

> *They fitted me a brand new kitchen so that I didn't have to reach. And they gave me a walk in wet bathroom cause I used to black out in the bath and the home helps would have to get me, get in, get me out and make sure I didn't drown. (Male,50-65, mobility impairment & long-term health condition)*

Another participant, who had been unable to access support with the adaptation process and was looking to privately fund a wet room conversion, also felt this was important to help minimise his risk of falling when using the bath:

> *At the moment we've got a bath with a shower over it. It's a pretty rickety thing. We're not even allowed to drill in to put proper stabilising bars up. We've got to use these self adhesive ones that fall off at three in the morning and stuff. I need my partner to hold me up and help me shower. But I'm always wary the bar is going to fall off the wall again. (Male, 50-65, mobility impairment & long-term health condition)*

A third participant, who had privately funded a bathroom conversion, noted that the adaptation had given him more freedom and was an important factor in his decision to stay in his current home:

> *We built another bedroom in the house on the ground floor with an ensuite bathroom toilet which is a lifesaver because upstairs it was very difficult going from bedroom to bathroom in the morning, in the middle of the night for a wee, that was all stressful and tiring and everything else and it was always every night I'd wake my wife up, you know, tossing about two or three times a night, spasms or whatever so we built another … to give me freedom… we were quite close a few years ago in considering moving to a bungalow, but then we kind of said but hang on, if we do this, if we do that it'll buy us another how many years, the stair lift getting up and down the stairs, brilliant, the room downstairs – the bedroom with the wet room, that's fantastic you know. So the garden, the garden's flat, we've done some extension work downstairs and it's all; you can go from the kitchen to the extension, the front and back room, bedroom, it's all in one and it's flat floorboards so you can get round easily, that's not a problem. (Male,25-50, mobility impairment & long-term health condition)*

For one participant, who was seeking to get electronic assistance fitted to the communal door to his council flat, the issue was less about risk but instead about his ability to get out and about:

> *Be great then I can start taking my dog out again which would be great cause I could then control him and get the door, and you know, as I say I miss taking him out. I really do (Male,50-65, mobility impairment, long-term health condition & mental health condition)*

In some cases, equipment was equally important as major adaptations in giving participants independence and improving quality of life. For one participant who found it difficult to get out of bed for long periods, an array of small pieces of equipment allowed her to carry out day-to-day activities. This equipment was sourced privately rather than through social services:

> *My needs are quite individual really, and I have a friend who worked on these, and actually built my bed, and it's brilliant, and it becomes a sort of day recliner, and really just at the touch of a button I can make it into a bed. So that's one part, and I'm really set up with my little mini oven next to me, because I literally can't get up and go into the kitchen and cook, I've even got an induction hob, that's my latest, so I fry next to the bed. [laughs]. It works, it is fine. I'm obviously not doing anything that spits everywhere. It's very convenient. I've also worked out an amazing way of washing my hair in bed which I can now do myself... using a little paddling pool which you can buy for hair washing and the water runs out into a bucket under this specially made bed. (Female,50-65, mobility impairment)*

Other participants had accessed equipment from social services which enabled them to carry out day-to-day activities by themselves:

> *It makes such a difference, I mean I can…its things like they gave me this sticky bit of plastic and so on the rare occasions I am able to cook I can put my chopping board on there and then it doesn't move around and small things but they make a real difference 'cause I'm a bit…I lack co-ordination so every time I try and chop a vegetable I end up chopping my finger or burning myself on the oven so things that you know help because my hands don't always do what my brains telling them to do unfortunately. (Female,25-50, mobility impairment, & long-term health condition)*
>
> *The adult social care is brilliant. I've got equipment that I've been given over the years has been fabulous and made such…simply a step to get into bed. Simple as that and then something big like the shower, that was amazing. Changed my life. It took two years to get it but…three weeks before my civil partnership I was so pleased. So they do everything from the little to the big…that's fantastic. (Female, 25-50, mobility impairment)*

For one participant, a key piece of equipment was a telecare alarm which had provided vital support when he needed it:

> *It was when I lost me balance I was trying to catch my mother when she fell down the stairs and she broke her hip and I broke me neck. So we were both lying there. Thank God we had the life line buzzer.*

> ***So how do you find the care link service? Does that work quite well?***
> *Yeah, it's done it's job you know when I've not been well. Pressed the button and they got somebody there. Ambulances they'll normally be about ten minutes. (Male,50-65, mobility impairment & long-term health condition)*

A3.3.4.2. Assessment process

Participants' experiences of accessing equipment and adaptations were mixed, with some having been signposted toward the appropriate services and being provided with extensive support, while others had been simply unable to access support they needed.

Participants had been directed toward occupational therapy assessments through a variety of means. One participant had been signposted towards access point by a council housing officer who had inspected the property

> *The only problem I have really is getting in and out of the bath and stuff like that on occasions. There is a group called Access Point, I think, that someone's given me the number of, which I will ring soon.*
> ***Who signposted you to the Access point?***
> *The lady from the council when she came round to visit me, two or three times they've been round this year to inspect the place (Male, 50-65, mobility impairment & mental health condition)*

Another participant had recently accessed the occupational therapy service through self referral, which he found more useful than through the GP:

> ***So how easy was it to get an appointment with the OT?***
> *I went through adult social care since I was diagnosed so that's very easy because you can self-refer yourself now through to an OT because before when I first got involved with them you had to be referred by your GP to them and then the OT would assess you (Male,25-50, mobility impairment & long-term health condition)*

One participant had been provided with equipment through an NHS occupational therapist following a stay in hospital after a fall:

> *I had a walk in shower unit and the NHS people put one of these things that are there for you when you're sitting on the toilet. You can push yourself up….That was because I had such a bad fall. And they kept me in for a week and then it came on from there. So then they looked round the flat to see if there was anything that needed doing and that's what came out of it. (Female,50-65, mobility impairment)*

For one participant, he was required to go through an occupational therapy assessment to make his own adaptation as he lived in a shared ownership flat. In this case, the participant had considerable difficulties accessing the service:

> *It took us three years to get a shared ownership flat. Building's got two halves. Council tenants and shared ownership. All the disabled facilities, totally including*

> *disabled car parking spaces, disabled adapted flats, disabled lifts, doors all in the Council side. Shared ownership side, nothing. We've been battling with them for a year for permission to put in a level access shower. And we've still got to go through the procedures as if we were Council. So we have to apply for an Occupational Therapy assessment. And the woman comes round trying to put bath boards in. And then we've got to wait for them to do this financial assessment before they'll turn round and tell us they're not going to give us any help before we can actually start the work…I had to contact social services and again it was, do we really have to do this? You're not in our priority bunch. So it seems very much we're not the priority. They're too busy. I know they're stretched so no body's really that interested. (Male, 50-65, mobility impairment & long-term health condition)*

Once participants had reached occupational therapy teams, one factor which affected their experiences was the amount of information and advice they received in regards to equipment and adaptations which they could benefit from. One participant, who had used the occupational therapy service when planning renovations to his bathroom, found the advice he received from the occupational therapist to be invaluable in helping him to ensure the adaptation suited his needs:

> *The occupational therapist is great because she advises me on what I need, like when we were having the bathroom and toilet fitted downstairs; when they first started doing it was going to be far too small, we didn't realise it should be big enough for a chair to go in there and for the chair to turn around in the bathroom otherwise you're going to be stuck with nowhere to move and she said you know, it needs to be that much bigger and we thought "Oh God, what?" And then now we think thank god she did come round and advise us as we went along while the builders were still there so we got her in just at the right time, to hold our hands and guide us through the process. And there're certain funds and grants that are available that I wasn't aware of and she made me aware and sort of holding my hand through the process. (Male,25-50, mobility impairment & long-term health condition)*

One participant with extensive support needs felt that occupational therapists focused more on available resources than on the impact of equipment on individuals' lives:

> ***Do you find the occupational therapists have been good at kind of showing you the options of what you could get, or do you feel that you've had to research?***
> *Nah, nah I don't think so, I mean all you need to do is you listen to what the occupational therapist says is available and then going on the Internet you can see a massive difference between what's really available. So again I think that's a lot of the services provided by occupational therapy are resource based rather than what's available. (Male, 25-50, mobility impairment)*

One participant had chosen not to access occupational therapists as based on her past experience she felt they focused on standardised equipment of little value to people with unique needs:

> ***Do you think that having an occupational therapist would have helped?***
> *Definitely, but, I don't know, I think you really do need to, as an occupational therapist, you deal with lots of different sorts of disabilities, and it does tend to end up as intercom, which is great, very useful, I have an intercom obviously, to open the*

> *door…grabrails, and various seats to sit on, which I cannot use anyway, it's too standardised really (Female,50-65, mobility impairment)*

In several cases, participants were simply unaware of the type of equipment available which could assist them with day-to-day living. For one participant, the council equipment team had been helpful in suggesting equipment and providing her with the opportunity to try it herself, which she found to be a very positive experience:

> *I didn't know what was available so I had to ask and then when they said oh what do you want for your flat I was like oh well I don't know what they mean…tell me what there is and I'll tell you whether I need it or not because there is a stick for everything…something that puts my socks on and I've got a special thing that takes my socks off and I didn't know that existed! So…they suggested a few things and we agreed them and then…they've got a lovely guy, a technician that comes round because I had it in two stages so they came round twice and sort of demonstrated everything and saw me use everything to make sure I was doing it in the right way and they're very very friendly and helpful and you can ask any question without feeling stupid so…that was a nice experience. (Female,25-50, mobility impairment, & long-term health condition)*

One participant had a more negative experience when attempting to access information, in this case regarding a wet room adaptation. This participant had pursued the issue for months, involving extensive work with adaptation services, with very little explanation of the process. In particular, the participant did not receive any clear advice about her financial eligibility which could have ultimately meant the assessment work was unnecessary:

> *In 2009 I started calling them, I probably rang them about five or six times and they kept sending me the same bits of paper. And I kept ringing them up and saying look I'm earning and I work full time. Can you tell me whether I'll be eligible or not for any services? And they would send me out the same bit of paper that told you nothing. It was just about this process. And then one day I got a phone call saying right an occupational therapist is coming to see you and I was like, oh, ok. 'Cause all the bits of paper had said you've got to pay two hundred pounds for an occupational therapist's visit. And I sort of said is that going to cost and they said no, you're on a list. So I somehow made my way on to a list somewhere. So in early 2010 I had an occupational therapist come see me and she started drawing up plans and all the rest of it for this bathroom and I kept saying to her nobodies assessed me financially yet. Am I actually eligible for this? And she said I don't know. I just give it back to somebody else, and you know this has been going on for months and months and months. So I've had a visit from a guy that did some preliminary financial assessments and said based on your savings your are eligible. Based on your earnings you're not eligible for other things. So I was like right, ok so am I going to get it? And they still don't know and it's still, I've had another, I've had a technical officer come round most recently in July a sort of surveyor guy who did some more detailed measurements and drawing up of plans. And I've had some bits of paper signed but I've still not had a full financial assessment. So I still don't know if there not going to turn round and say actually you're not eligible for any of this and it seems like mad….I just don't understand why somebody back in 2009 couldn't say to me yes you are or no you're not. (Female, 25-50, mobility impairment & long-term health condition)*

For some participants, their overall experience with equipment and adaptations was negative as they found that resources simply weren't available to meet their needs:

> *I've got a bath lift now but because we got the original cast iron bath, even with my bath lift it's beginning to get a bit harder because the old knees are packing up now, but I did want to, well council I tried to put in for a shower about, well must be five, six years ago, just don't want to know. The occupational therapist originally recommended a walk-in shower about, what three years ago? And the council agreed to it, then nothing, we just didn't hear anything after that. And when we went back to them about it and tried to follow it up, it was just like "no sorry, the funding's not there". (Male, 25-50, mobility impairment & long-term health condition)*

In these cases, lack of adaptations meant that participants struggled with day-to-day activities such as preparing food. One participant had been put on a waiting list for a bathroom adaptation but was unable to access adaptations to her kitchen to enable her to use it:

> *In my house the only room I can't use is the kitchen. Because they won't lower it to my standards, all the cupboards are up the top and I can't reach them. So if I want a cup of coffee or something I can't make one, if everybody's out I'm stuck. I've spoken to the occupational therapy department and they've said it will cost too much to make it adaptable but we are going to apparently get a new shower put in and the bath taken out but we've been waiting a year and a half now …I know the waiting list is long but I didn't think it was that long. Yeah and we would have liked the plug sockets raised to about here this level, you know waist level but they won't do it because it's going to cost too much money…They are a bit like the council its all about what they can't do not about what they can do (Female, 25-50, mobility impairment, long-term health condition & mental health condition)*

Similarly, another participant was also unable to access adapted kitchen equipment, which he put down to reduced budgets for council equipment:

> *There are certain things now that I could have had on the Council from them, they're actually turning and saying no, you've got to find that money elsewhere.*
> *Well, it's like I need a specialised dishwasher, the Council won't pay for that, because I can't lift properly, I can't have a proper oven, I've got to have a table-top one… but hang on a minute, the money has got to come somewhere else. So I've got like… because I'm an ex-serviceman, you know, the British Legion came out to see me yesterday to try and see if they can help me. So all them things that you used to be able to get off them, you can't, they're cutting right, right down and it's getting worse and worse (Male, mobility impairment & long-term health condition)*

A3.3.4.3. Provision of equipment and adaptations

Once participants had been assessed by occupational therapy teams, there was considerable variation in how well they felt the process of providing the equipment worked. One participant was particularly pleased with the speed with which he was provided with a wheelchair:

> *I was given a wheelchair, a manual one but when it came to it, when I have bad days I couldn't self propel. And then I got an electric one, but that was, I had to give that one up because one, I do have bad days and I'm a danger to myself and other people, and plus the hill I'm on is too, too steep for it.*
> ***Where did you go to for that? Did you source that yourself?***
> *No, I phoned up occupational health. I dealt with them before because my bathroom needed modifying and they had been round so I think they just knew about me and it just arrived. I was so surprised it arrived really quickly, and you know when I spoke to family about it they said, "What, you got it now?!" It was yeah, because Brighton and Hove seem to be fairly hot on things like that. (Male, 50-65, mobility impairment & mental health condition)*

Other participants experienced some delays in the provision of equipment. One participant was provided with some equipment quickly while other equipment was delayed until her occupational therapist chased it up:

> *It was quite quick it kind of came in waves so I got the first bit where I got some things for the flat that was really quick but then I didn't actually hear anything from anyone again for it must have been about four months and then this woman [name removed] she suddenly realised how long Id been waiting so she got everything done in about thirty seconds after that so yeah that was good…had to sort of wait a bit but when it started it worked well. (Female,25-50, mobility impairment, & long-term health condition)*

Another participant, who had recently moved to the Brighton and Hove area, was also dissatisfied with the speed with which the equipment was provided, but after a complaint was provided with equipment within three months:

> *At the beginning [November] when I came here I wasn't very well supported from an aids point of view and I complained to the OT department and by the beginning of January they sorted out everything. (Male,50-65, mobility impairment, visual impairment and long-term health condition)*

Several participants, who had accessed minor equipment and major adaptations, found that while basic equipment under a certain value could often be sorted out quickly, more complex equipment often took longer:

> *As soon as I learned where to go it was pretty straightforward. I've got my occupational therapist, I literally need to email her, to call her when I need to, she's brilliant and she has a conversation with me then she does all the council bit. For certain adaptations that if they're underneath a certain price they just give them to you, there's no questions asked, I think up to 500 quid, if I need a hand-dryer in the toilet they'll just come and fit it, the guy just comes, it's a two minute job and there's no cost at all. One thing that took a bit longer, I got a bed with a button that lowers it down, lifts it up, the back rest goes up and down, that took a little longer just because you have to go through the funding channels (Male,25-50, mobility impairment & long-term health condition)*

For another participant who experienced this variation, the biggest problem were not the waiting times themselves but the lack of information from service providers as to why they were waiting:

> *if you just want a grab rail or something, that's dead easy, within the Council, Mears will just come and do it, they've got their ordinary response team to do that, but other things do take a little longer, it's rather complicated. And they don't tell you what's happening, that's the problem. (Male, mobility impairment & long-term health condition)*

For the participant who was waiting for electric assistance on his door, although his experience of adaptations was generally positive, the barrier he now faced was the lack of coordination between council departments:

> *Adaptations have been wonderful, I mean I've got a level entry shower, I've got a closomat toilet, I've got mattress lifters and bed rails and everything I need really.*
> ***Do you have an occupational therapist who helped you sort that stuff out?***
> *I have yeah, that's another one that keeps disappearing. They do one job for you and then they vanish and [my OT] has done the last lot, I get on well with her, but we've sort of finished now. She's passed me over to the Council side housing because the last two projects are quite hefty. I live in a block of flats and there's fire doors and sometimes, depending which way the winds blowing in and things like that, I can't get through the fire door to get to the flat. And, so it needs some electric assistance on it, you know. It's got to go to their panel to say whether it's worth doing… The OT service is very good, but it's all too fragmented...I mean my front door also needs adapting, that will come under housing, but the communal door, which is only a matter of feet away, doesn't, it's separate, because it's in a communal bit (Male,50-65, mobility impairment, long-term health condition & mental health condition)*

For this participant, lack of information had also been a problem in the past, and he was concerned this could present a further challenge to the awaited work. Information provision from his current occupational therapist, however, had improved:

> *That's always been a problem with adaptations is things seem to just go into a black hole. They tend not to tell you what's going on, but with [my latest OT] it wasn't. She was perfect. On top of it all the time and said look this is what's happening, that's what's happening. (Male,50-65, mobility impairment, long-term health condition & mental health condition)*

One of the most common problems participants had experienced in regards to large-scale adaptations was the waiting times for work to begin. One participant reported waiting three or four years for an adapted shower while most others experienced waits of 1-2 years.

> *I had a bath that was…well not as long as my legs and I had a bar across it and I couldn't get in it, but as I say, I had to wait forever. Well, I think it was about three or four years before they came and put a shower in with the seat (Male, 50-65, mobility impairment & mental health condition)*

> *We had to put in a downstairs loo obviously so I have a little cloakroom downstairs with washbasin and toilet... that was reasonable, I think there was no delay from the*

> *point of view of the council, they got on with it, it's just getting the builder really to find the right time to do it. It was all very much more involved than I'd anticipated, it really was, you think just build this little loo, how long can that take, and it was, yeah, it was a year... (Female,50-65, mobility impairment)*
>
> *I find Brighton Council absolutely useless, you know and to leave me most of 14 months without the use of a bathroom is a bloody farce (Male, 25-50, mobility impairment, long-term health condition & mental health condition)*
>
> *It was in 2000 so, so quite a considerable time. It was about nine months, year from when the OT suggested it to when the funding was done. (Male,50-65, mobility impairment & long-term health condition)*

One participant felt that the wait was due to the fragmentation of the process which used out-of-house contractors:

> *I'm still going on with it, it's two years and counting. I moved because… well, partly because I was downsizing because my teenager has left home and partly because I needed to get rid of the stairs and the stairs into my property. And I rang the Council, explained and said "Can you help?" and they said "Oh, yeah, yeah, yeah, we've got all your details" and then I had an OT come out, because they've now done it as an out-of-house service and it's much worse. You have the out-of-house for the OT, then you have the people that are doing the building works and because it's gone out-of-house, the disabled facility grants have all got a lot more complicated too, and then the surveyors were all independent as well, so you have to go on a waiting list every single time and it's bloomin' annoying, you know. It should be by the end of the calendar year that I have the shower. (Female, mobility impairment & long-term health condition)*

Another participant, who had been forced to move out of his adapted council flat, still had to wait nine months for the adaptation that he needed:

> *Because of severe damp in my last flat, I was told by the Council it was uninhabitable and I'd have to move. I got a good end of the deal, but the one I moved into didn't have a wet room and when I said "Could I have one?" they said "You've got to go to the bottom of the list." But it turned out that, actually, no, they were wrong, because I'd been decanted and they had two weeks before to put a kitchen in, because there wasn't a kitchen in this flat… or a decent one, they could have done it then, but it still took me nine months to be able to get one that I'd already been assessed for in the other flat. (Male, mobility impairment & long-term health condition)*

Waiting times for adaptations could often have significant impact on participant's quality of life and need for support. For one participant, the delay in adapting a bathroom meant he was dependent on his partner for assistance with toileting, which he would be able to do without assistance once the adaptation was complete:

> *The only thing I would say on the downside of the adaption is the length of time you have to wait for them to be done. And it seems an awful long time. Like nearly two years. And I spoke to the guy that was doing the work and he said the quickest he knows that he's done is 14 months wait.*
> ***But you were able to manage in the intervening two years?***

> *Yeah, I have somebody help me and that so like I say I can only go to the toilet once a day. But the rest of the time I use the urinal and stuff and then my partner would empty it for me, but when it's done I'll have my independence back. (Male, 50-65, mobility impairment & long term health condition)*

One participant spoke of his frustrations of waiting for adaptations and struggling to manage with day-to-day activities in the meantime:

> *My case has been going on for… well, 18 months now...my kitchen has got to be completely ripped out and re-done because all the cupboards are all too high and it's not properly adapted, my wet room, everything's wrong in it... I got to a point that I got so frustrated and angry ...because it builds up and you think you've waited this long and then you get to a point and you can't stand waiting anymore because you feel like you're being shoved back, you seem to get one step forward and then you go two steps back all the time and that's how it seems to be going. (Male, mobility impairment & hearing impairment)*

Once adaptations finally started, experiences of the installation process were again mixed. For one participant in a council flat, his wet room was installed over the space of two days and he was very satisfied:

> *I've had adaptations done because I had to have a wet-room in there, because I couldn't get into a bath much. So I had a shower put in, that was all done under the adaptations…**I**t was actually amazing. They done it in two days, really brilliant, better workers than the Council workers because they use their own team, adaptations, and they're far better than the Council workers. (Male,50-65, mobility impairment)*

For another participant, the installation of wet room and kitchen was far more disruptive, taking six weeks and preventing him from accessing shower facilities during that time.

> ***How did you find the process of getting all those adaptations?***
> *It was an absolute, I'm trying to find an adjective that's not too bad. Just say you know it wasn't the best of things. When the builders turned up on the Monday morning when I said, well when you moving out? I said pardon? Well you've got to move out! You can't do this while you're living here. And I phoned up the Council and they said no you're not moving out. I said well they tell me I'm moving somewhere else! Oh no, no, no, no. We've got no where for you to go to. So I had to get the builders on and it was agreed that they would do, start work at 7, finish at 4 and they would have to take my kitchen, my cooker, my freezer and everything else out of the kitchen while they did the alterations. Then put them back in the evening and fix them up. And I couldn't have a shower for six weeks while it took them to do the bathroom as well (Male,50-65, mobility impairment & long-term health condition)*

A3.3.4.4. Ongoing costs:

One of the participants, who had received multiple pieces of equipment over the last decade living in Brighton, raised an issue regarding maintenance costs for equipment which had caused him considerable problems as an individual on a fixed budget. This participant felt that council employees had given the wrong advice regarding responsibility for ongoing costs:

> *My biggest complaint would be they've done the adaptations, I've got some automatic door openers what I use. When they break down it's a nightmare... my door opener's broken down and the company who installed the door opener system sent the bill to me, so for the last…two months probably? I've been phoning round Access Point, Community Solutions, Able 2, like four different places private and local authority, trying to sort it out. There's another two occupational therapists coming out next week to discuss it again, it's like, there's already been three out.*
> ***Do you know what the problem is, I mean have they told you why they're not funding it?***
> *Because they reckon that DFG they install or adapt your house. But after that it's your responsibility. And then you get conflicting advice. The first person I spoke to at Occupational Therapy, she said, 'oh right' she went, 'yeah you've got to pay that yourself.' Anybody else would have put the phone down and just accepted that. And I I was thinking 'this cannot be right.' So I had to go round phoning loads of other people to find out what the law was, then I got back to them and I says, 'you've given us the wrong advice' and I says, 'social services have got to pay for it.' But, it's still going on (Male, 25-50, mobility impairment)*

A3.3.4.5. Mobility Aids

Most of the interviews with participants focused on equipment and adaptations from council sources. In addition, some participants spoke about equipment sourced through other means.

Several participants used wheelchairs or scooters which they had sourced privately. Two participants used motability schemes to access this equipment and found it was critical in enabling them to get out and about

> *I've got arthritis in the spine and that manifests itself in the hips after I've been walking a little while, and that little while has got less and less and less as the years have progressed until it's down to about 10 yards and I'm virtually house bound. That's when I got [my wheelchair] here and since then the world's been opened up to me again and I can get out and about.*
> ***Did you find the chair yourself?***
> *Yeah, I went online. It's through motability. I couldn't afford to buy it cause I'm on you know, fixed income. I've got DLA. That's high mobility which is how I was able to get this and medium care. (Male,50-65, mobility impairment, long-term health condition & mental health condition)*

> *I do have a scooter … I got that through motability because I'm on high rate DLA, and they were, I was getting near on £300 a month, and then they decided to investigate me, saying, "Do I need a scooter, and we're paying you for," so I had to get one in the end. But it is useful because [my knee] has got drastically worse since I had an operation on it. (Male,50-65, mobility impairment)*

Another two participants have accessed mobility aids from the NHS, but found these didn't meet their needs and ended up accessing equipment elsewhere. One participant had been given a manual wheelchair but could not self-propel and had no one available to push the chair, and chose to give the equipment back and received a second hand scooter from a local charity:

> ***Have you ever been in contact with NHS wheelchair services?***
> *yes I got a wheelchair… I had a red one first but nobody could push me in it because it was so heavy and there's no way I can propel myself you know, wouldn't have the energy. So I've got, what happened then was I went back and they gave me a green one which is much lighter but you know its finding somebody,*
> ***The NHS wheelchair services they did they ever suggest an electric chair?***
> *No I didn't know that was an option. (Male,50-65, mobility impairment, mental health condition & long-term health condition)*

Another participant was given a walker from the NHS, but found this did not effectively meet her postural needs, and decided instead to privately purchase a walker

> *I paid for that walker because with the NHS one if you had it up high enough for me not to stoop it rattled like mad as if it was gonna fall…I thought I better send that back and…and buy one that….that you can, you know, have it up high. I got one from the mobility shop opposite the library. (Female,50-65, mobility impairment)*

A3.3.5. Impairment specific issues

The main groups of participants for which social care issues had a distinctive impact, i.e. in addition to the impact faced by all groups, were participants with mental health conditions and/or a learning disability.

A3.3.5.1. Mental health

For participants with a mental health condition, the issues raised around reliance on friends, family and neighbours for support with day-to-day activities had a particular significance. Several participants spoke of their reluctance to rely on friends, family and neighbours due to the stigma associated with mental health and the desire to keep their conditions private. In some cases this meant participants did not seek support when they needed it:

> *I mean everything gets on top of me when I'm in a bad space, including the space that I'm in, you know, becomes very claustrophobic and just, because I get completely overwhelmed and I don't know where to begin and just kind of look at everything and can't do anything. I mean, I've got a friend who usually does a shop for me but it looked as though he was going to go away for the rest of the year, for six months, so that was quite scary as well, just getting food in and things like that, and… yeah, I get sporadic help from friends but I find it really difficult, really difficult letting them into my*

> *space, including the space that I get into. I kind of want to keep that separate from my social life, you know, people seeing how bad I get (Female, mental health condition)*
>
> *At that particular point I stayed with some friends for a little while but the problem was when I was unwell it wasn't a good place for me staying at other people's houses, I felt like – it made me worse because I felt like I needed them and it wasn't their place to have to put up with, sort of help me and stuff like that – I'll just keep my distance (Male,25-50, mental health condition)*

In one case, approaching friends for support resulted in her receiving negative comments which made her more reluctant to ask for support in the future

> *I'm quite private about it really and there's only one or two friends that I've really shared it with. One of those, she obviously discussed it with her boyfriend because he was quite unpleasant to me about it. He started going on at me about how he hates his job but he still goes and he's never missed a day's work and all that. He obviously doesn't understand that I'm not well and that, but it's difficult when it's in your social circle, isn't it, to have somebody with that kind of attitude. There's only one or two people I've discussed it with. So I don't really get a lot of support from friends really. I've got one friend who, I see her sometimes but she's been preoccupied with her life so there's not a lot of support there really and with my parents, I don't tell them too much because I worry about them worrying. So, you know, I'm sort of looking after them in a way. (Female, mental health condition)*

Participants with a mental health condition tended to have a unique view of the benefits that could be provided to them by a support worker. As also discussed in relation to mental health services in the Health chapter of this report, regular support of this kind was considered by some participants to be important in helping participants avoid periods of crisis. One participant felt that simply having a point of contact for independent emotional support would help her to manage her condition:

> ***If you were able to access some kind of support, social care kind of type support, would that help you?***
> *Definitely, yeah. Absolutely. I think it's really important that you have someone that you can sort of report into in a way and just say, "This is how I'm feeling," and, you know, just somebody to sort of help you along really. I think it's helpful to have people who aren't emotionally involved with you...sort of independent from your everyday life, your social life and your family, somebody who's just there solely to help you with those kind of issues. Just somebody that's going to be there, you know. (Female, mental health condition)*

For other participants, it was felt that while it was sometimes enough just to have personal contact, support workers could also provided valuable practical support as needed to prevent participants becoming overwhelmed:

> *I have a support worker now and, I mean it's a bit weird because like a lot of the time, it's not been greatly helpful, half of it's just check-in really and when things are going well, you know, that's of little consequence really. But since I've had this problem with my housing it's been really, really useful, finding out things for me, he found out the phone number for Brighton Housing Trust. He helped me tidy one of the rooms in my flat and was generally really good, so yeah that's been really helpful. It's coincided*

> *that both people that are the most likely to help, who are a good friend of mine and my sister, were also moving at the time that I was having difficulties so it was difficult for them to help me. So it was really important that I had him to help me. (Male, mental health condition)*

One participant felt that often participants with mental health conditions could look well, but could still benefit from low levels of regular support:

> *I've looked into is there some kind of like, someone that I can pay to come in and things, but it's not so much cleaning as organising and de-cluttering and that's what I'd really like a support worker for. That's what my sort of fight was. But of course, they came round just as I was well and had a massage client, so I'd set everything up, the room smelled of oils, there were flowers and (Laughs), you know, they just sort of looked and thought, "She doesn't need any help." They hadn't seen under the bed and all the rest, but…*
> ***So did you get, you haven't actually managed to access any kind of social care support at the moment?***
> *No, I've got a Support, Time & Recovery worker. It's part of the transition teams. I think she's going to sign me off next week, I've had her for three weeks, but she hasn't been in this week so I've had a couple of weeks and I've been fine. (Female, mental health condition)*

A3.3.5.2. Learning disability

Four participants involved in the research had a learning disability, three of whom were living in a care home. These participants typically expressed positive feedback about situations where they had been given choice and control over their lives:

> *They knock on my bedroom door first. That is very, very important. And then they give me my med and ask when I want my shower. The wrong way of doing it is not knocking on my door first and then telling me I'm going to have a shower straight away. (Male, 50-65, learning disability)*
>
> *Yeah, I've got a new sofa in my lounge, new music centre, three tables.*
> ***Who chose the sofa?***
> *We chose it. Three of us went to choose it.*
> ***What, three of you who live there?***
> *Yeah, three of us went, I went to Ikea, I went and got the sofa. It's brown in colour, it's a brown leather sofa. I'm really chuffed with that. (Female, 50-65, learning disability)*
>
> ***And what do you think about your house?***
> *Quite nice. My bedroom's painted blue. I chose it myself. [My home manager] said, that's not my colour. I said, it is mine. (Male, 50-65, learning disability)*

For one participant, he felt it was important that he was involved in the running of his home, both through regular attendance at tenant's meetings and an opportunity to interview staff as part of the recruitment process:

> ***And are you able to do what you want in your own home?***
> *There are rules which….you have to keep to, like medication, shower and let the staff know if I'm going out anywhere. We have a tenant's meeting and we discuss any problems that occur, anything that needs doing, we talk about it at the meeting. It helps a lot because without tenants meetings you'd have everybody doing different things when they're not supposed to. (Male, 50-65, learning disability)*
>
> *I believe in interviewing staff before they start work. And at Westbourne…at Westbourne that didn't happen.*
> ***I see, ok. But does that happen where you are now? And it makes a difference does it?***
> *Er, yes. It does makes a difference in that you get to know the new members of the staff that are going to start work and we ask them questions. (Male, 50-65, learning disability)*

As noted in the chapter of this report on community participation, some of the participants with learning disabilities expressed a clear desire for more social contacts, while another was supported well to access social opportunities.

An issue raised by a participant with a mild learning disability, regarding the support received from her support worker, was that this was insufficient to do anything beyond basic administration and paperwork. This meant the participant was unsupported in key areas and experienced difficulty in managing her house and accessing social opportunities:

> ***So how often do you see [your support worker]?***
> *It was from 11 till 12 on Mondays and Wednesdays, but for two weeks I think it was she was coming to me at 10, leaving me at 11. I want to get some more hours, because I find now it doesn't give you enough time, like if you've got a bit of paperwork it doesn't give you time to do other things. It is certain things that I do need that little bit more extra hours I'd like to get now I mean, there's a lot of things I used to do when I was young that I can't do now, you know?*
> *I like to keep my flat clean and all that lot, it's the cleaning, because I like to be so spotless, sometimes it's not so a little bit of help, that's something else that I've really thought of now.*
> ***So how do you think your life would be different if you got more help from your Support Worker, what do you think that would mean?***
> *Yeah, it would, it would help me a lot, and also the garden, sometimes that's nice to have a little bit of help. (Female, 50-65, learning disability)*

A3.3.5.3. Hearing impairment

Most participants involved in the research who were deaf or hearing impaired did not access social care support regularly. The one issue that did emerge for two of the participants, living in separate council flats, related to problems with pager equipment to alert the participant that there was someone at the door, which did not work with communal entrances:

The pager, special pager system has to link with her front door, her own private flat door and the door for the communal door and the problem is for six months now they can't get it to work, they're saying it's not linking up with the communal door and she really worries, yeah, that if anything happened in the block of flats she'd have a problem, so six times the engineers been but it hasn't been sorted out yet, she's really fed up with hers, yeah. And his flat, the doorbell at the front... your own flat, private, works okay but the communal door downstairs doesn't work. (Male and female, hearing impairment)

A4 Appendix 4: Housing

A4.1. What are Housing services?

This section of the report is focused on participants' experiences of accessing housing services in the city. In particular, the research team wanted to know about how suitable participants felt their current living arrangements were as well as the kind of barriers people had faced or were currently facing to find a suitable home. The research team was also interested in participants' experiences of services provided by the council housing department, including management of council properties and other services such as provision of housing benefit.

Participants had a range of living arrangements including private ownership, Private shared ownership, private rental and council tenancy.

A4.2. Approaching the Topic

Researchers asked the following detailed questions about housing. Respondents were probed on their housing arrangements and how they had come to access their current housing:

- What do you like/dislike about your housing? We are interested in what you think about the property as well as the people in it.
    - Are you able to go where you want, and do what you want, when you want in your own home?
    - Is there anything or anyone that helps you in your own home?

A focus group was held for participants with a mental health condition, 45 minutes of which was devoted to housing issues.

A4.3. Detailed analysis

Participants were asked how satisfied they were with their current home and how well it suited their needs. As expected, there was a wide range of responses. Many participants' satisfaction levels with their home depended on its location. For some participants, quiet locations were preferred while others preferred the convenience of being located near shops and other facilities:

> *Basically I'm a little bit further out than I was, but the reason why we moved out here is that I hate noise, so I wanted to be somewhere ideally not quite as far out but was quiet. Beforehand I was living in a block of flats and that didn't really suit me at all. So yeah, I love living round here, I just wish it wasn't quite so far out, but I love the peace and quiet. (Female, 25-50, cognitive impairment)*
>
> *I live in Hove.*
> ***Okay. And what do you like about where you live?***
> *It's quiet. You can go outside on a Saturday afternoon, yes, sometimes people have got kids in their garden and stuff, but most of the time you go outside and there's no sound, and you're right in the middle of the city, but it's quiet. And I feel safe letting my cats out (Female,25-50, mobility impairment & long-term health condition)*
>
> *I love living where I live because you've got all the little shops so you can get your bottle of milk and your loaf of bread – all your provisions basically. (Male, 50-65, mobility impairment)*

One participant who was living with her mother was satisfied with her accommodation as it was close to the local hospital which she used frequently, but felt she would prefer a more central location in the future:

> *I think initially my mum had to get the house on health grounds because we were living previously with a family member in the centre of Brighton and it wasn't - it was just wasn't manageable, it was too cramped so we initially got it on health grounds because I needed to be quite near the hospital at the time so yeah, it's ok. I am happy; I think in the future I would like to move. I think where it is based you can't get around very easily without a car which obviously now is ok I have a car, so that kind of keeps me going but I think in the future I would need to think about kind of moving and having a little bit more of an easier trek into town, near social services. (Female, 18-25, mobility impairment & long-term health condition)*

For other participants, attractiveness of the property and the neighbouring area was most important:

> *I had a bungalow and it was rather big. It was alright when my husband was alive and that yes because he used to do gardening and that. But I couldn't do the garden and so I began to think, would I like a flat? Because I've never gone down that road, never thought about that road, no, no. So I thought well I would have to have a lift if I went above the ground floor. Anyway I looked at numerous flats, by golly! There were some flats out there that I wouldn't put my enemy in, let alone me! Oh dear me. And then I came across this one and it's so light and airy and so beautiful, absolutely, absolutely. (Female,50-65, mobility impairment)*

For several participants, the most important factor in the suitability of their current housing was the extent to which the house and the location met their mobility or access needs. One participant for example was "desperate" to move to a flatter location such as Worthing:

> *I just want to move, I want to get out of Brighton and move to Worthing. I just don't like Brighton and Hove any more, I just like Worthing, it's all flat. I live on quite a hill and, I*

> *mean, I don't want to, in seven years time I shall be 60, and I don't want to be on a hill. (Female, 50-65, learning disability)*

As will be seen later in this section, many participants were on the Council housing waiting list as they felt their current properties were unsuitable in terms of access, like participant 10:

> *I have applied for council housing because I'm finding I've got an iron staircase coming down from the back of the property that I'm finding more difficult to negotiate, especially in this slippery weather…treacherous in icy weather (Male, 50-65, mobility impairment & mental health condition)*

For one participant, the willingness of her landlord to make adjustments was critical in making her home suitable:

> *I've lived in some awful places but this flat that I've got now is lovely and I've got a really nice landlord so every time I've had sort of rails and things put into the flat to make it easier for me to get about, he's very good at saying yeah, do what you want… I mean the steps outside my flat are a little bit tricky but now I've got the rail it's easier but I was always living in either in houses where the rooms were upstairs or first floor flats and second floor flats and it just got too much for me in the end (Female,25-50, mobility impairment, & long-term health condition)*

For several participants, the main problem with access in regards to their housing was the lack of disabled parking. One participant was emphatic about this problem because many of the people living in his area needed disabled parking but there was little to spare:

> *It still wasn't enough for the area. But where I was, [name removed] there's about a hundred odd flats and seventy five percent of the people in there were disabled. (Male, 25-50, mobility impairment, long-term health condition & mental health condition)*

Another participant found the lack of parking made his home unsuitable as he lived on a busy road. However, he noted that even in his previous accommodation where he was allocated a disabled parking space, this was still a problem as it could not be reserved:

> *The other problem we have is when we leave there is no parking space for car. It is very difficult. You have to go around to find a spot. We are actually living in a main road, a lot of traffic and a lot of heavy duty vehicles and to stop and unload our shopping is a nightmare, it's very difficult. It is not only fast and it's narrow and for us to stop for five to ten minutes it is quite difficult. It would help very much if we had a disabled parking space. That would help a lot. But what happened before where we were living, although there was a disabled parking space it was unspecified for ourselves, it was for anybody. So still it was a problem. (Male, 50-65, visual impairment)*

Two participants also stated the safety of their property to be an important factor in how suitable it was for them. For one participant living in Whitehawk, both physical factors and safety concerns made her current property unsuitable:

> *You get people beating up old people, something they do sometimes. They haven't started with me yet, they damaged my car but they don't hit me…that's why I want a bungalow with a garden with a garage, so I can put the car away and I don't have to worry about the car. Because the car is my lifeline... Mainly, it's the three flights of stairs. It's the 22 stairs I have to go up and down that make me not go out at all. If I look at them and maybe I can make them down if someone helps me, steady one arm. But when I'm on my own going back up even just carrying my handbag it takes me for ever. I can't breathe when I get up the top, and I have to sit and get that back. If I don't drop with a heart attack first. (Female,50-65, mobility impairment & long-term health condition)*

For another participant, who had been the victim of a physical assault in Brighton many years previously, safety was also a primary concern, but he felt that his new council flat met his needs well:

> *I've been in private rented accommodation. I got offered this flat by the council last year, so I'm not going anywhere now. This'll do me. I didn't think I'd end up in a high-rise block, but I quite like it. It's easier to be anonymous sometimes amongst a hundred people than it is half a dozen. I've got no problem living here whatsoever. Neighbours are good and there's no trouble, and it's not like, you know, Moss Side or something. It's high-rise council flats, but they're well looked after, there are wardens about most of the time... I wouldn't say it was quiet, because of the traffic, it's very noisy and dirty because of the traffic, but yeah, I feel safe here. (Male, 50-65, mobility impairment & mental health condition)*

In some cases, participants were unhappy with their current housing due to disputes with and in some cases harassment by neighbours. For one participant, this was felt to be manageable and she was generally happy where she lived:

> *I've had a few problems with the neighbour down below. He's quite an odd bloke and he goes on about noises all the time. I mean, I know he's got his own problems, but I don't have a television, and I rarely play music, but he complained when I put on a fan heater when it was really cold. So we had a big argument over that but it's alright now. And in a sense I don't mind him because I know where I am with him, and he's not noisy he just gets a bit difficult and I have to say you know, look [name], you're being very unreasonable. (Female,50-65, mental health condition)*

Another participant had approached his housing officer for help with neighbour disputes, but felt dissatisfied with this process and remained concerned for his safety with other tenants:

> *I think this block is, there's a lot of people with mental health problems and I'm not quite sure how much of it is that or how much its getting old and cranky…I reported [a dispute with my neighbor] to the Housing Officer…and apparently he reported me, and that was all just, I found this one upstairs had been reporting lots of people for barking dogs which nobody else can hear, and noise that, was the wrong flat and all this that*

> *and the other. The one upstairs is just the block bully, I really think the Housing Officer's scared of him. They came to give me an interview about this bullying and, I gave her the list and said this is all the stuff that's been happening and I said you know I haven't really said anything before because things could be a lot worse coz he's directly up top. The Housing Officer said she would do an investigation, that was the last I've heard of that…That weekend when they both got at me, I just felt…I didn't like it at all because there's you know when I'm on my stick I only need a little push and I'll fall over. (Male,50-65, mobility impairment, mental health condition & long-term health condition)*

For other participants, disputes had made their current housing completely unsuitable, with one moving to a different location and another still on the housing waiting list to move:

> *I've had a problem with my neighbour. And had harassment from her right from the start she's been there a couple of years and there's always been a problem with the drains there sometimes the smell gets into her property and she's blamed me…And then there was a problem with the bins …I phoned [city clean] up and they said they would have words with her. I said hang on a minute, she's not a nice person she's you know quite a vindictive sort of person and 'don't worry don't worry' we have an answer to that we've got the anti social behaviour team…so I was ringing them up and explaining that I was getting a lot of harassment from her, you know. She was screaming and shouting at me in the street several times, she has the boyfriend hanging around you know, and his mates which you know the local area thugs you know. In April one of them was talking about kicking my head in. The [anti social behaviour team] put me on to the Police Community Support Officer, and he had to go and explain to her about harassment and you know it was a criminal offence and stuff. Then she changed her tactics and just started bad mouthing me all over the neighbourhood. (Male, 50-65, mobility impairment & mental health condition)*

Another participant felt that he had been deliberately targeted by other tenants and pressured to move because he was gay:

> *I got a Council flat I then had to move basically here, because...... Well, it was a strange block. A lot of the people had been there for ages, so they were really stuck in their ways. So, when I moved some of the other tenants suddenly realised another gay person's moved in. We'll get him out. And basically that's what happened.... and of course yes, I did get abusive. Cause I couldn't stand...they kept complaining about noise when I wasn't there. And obviously they kept diaries and made things up. Then when I'm told to keep diaries I thought, well no ones going to take any notice of mine cause you're taking notice of them…I did feel sort of....in that respect really let down cause the previous tenant was gay. They got him out. And then, two others next to them...now I don't know whether they got them out, or whether they just were going. But, it just, really homophobic basically, and....the neighbour every time I used to walk past he used to spit. (Male, 50-65, mobility impairment & mental health condition)*

Some participants felt that as disabled people, it was harder to move where they were unhappy with their housing or its location. As noted in the health section of the report, participants often did not want to move as it limited access to certain health providers. In the social care section of this report, it was noted that many participants had undergone extensive adaptation work in their current homes and as such did not want to move and start the process again. Other participants felt that expensive administration related to benefits and other services made moving too difficult:

> *We were going to move away because most of our sisters and daughters and that are up that way, then we kind of thought, well [my brother] had a full-time job and just the thought of kind of going, sorting all the benefits system out again and…It would have been a complete nightmare. You move from one place to the other when you've got a disability it's just so much paperwork it's unbelievable. But I was actually trying to, we actually did make a decision to go at one stage and just all the sheer volume of paperwork I just ended up saying "sod it, it ain't worth the aggravation". (Male, 25-50, mobility impairment & long-term health condition)*

A4.3.1. Social housing

Many participants in the research were living in or looking to move into properties managed by Brighton & Hove City Council.

A4.3.1.1. Waiting times

A common experience for many participants either looking to move or having recently moved into social housing were the long waiting lists to find a home. One participant waited 3-4 years for his current accommodation which he moved into in 2007, and put the long wait down to his mobility requirements:

> ***And how long did it take from going on the housing register to finding this place?***
> *Oh, I think, I'm not sure just roughly within 3 to 4 years I believe. Yeah, I think 3 to 4 years. Because I was looking for a particular requirement. There should a lift, there should be this, there should be that, you know. Perhaps, maybe not. This is the reason it took me so long. I don't know. (Male, 25-50, mobility impairment)*

Another participant, however, a wheelchair user who moved into an adapted home in 2009, found the wait was considerably shorter, but still lengthy at 18 months:

> *For me, it seemed relatively easy. The first part of the forms and all that was a struggle and getting put into the right group was a struggle. It's to do with like the group like the A, B, C, D's and all that stuff. And I was in group C. I was really shocked 'cause I had a phone call one day and they said, you're second on the list to view this property. Could you come down? So I had to come down from London and there was a lady before me and she turned it down so we got it. So in the end it was quite….it was about 18 months I think.*
> ***Right, ok did you feel you should be in a different category?***
> *I did feel that, I did and I tried to get up to group B and I had a support worker helping me and all that sort of stuff. But we stayed in C and it didn't turn out too bad in the end. (Male, 50-65, mobility impairment & long term health condition)*

For most participants currently on waiting lists for social housing, they had often been waiting for three years or more. This appeared to be the case for participants with a range of impairments and mobility needs. One participant with a mental health condition was still waiting after four years:

> *I am on the council list, but I've only been on it for four years and I only got Band C, so once or twice I've applied for things, but I mean, like hundreds of people apply don't they. And I'm not really considered priority. (Female,50-65, mental health condition)*

One participant with a visual impairment who had been waiting three years was able to find employment and a mortgage, and removed himself from the list after finding a home:

> *There was a time when I didn't actually have a permanent residence. I have my family I can fall back on to, and I did go on to the council list, but I just seemed to be on it for about three years and didn't go anywhere. I suppose vision impairment had some impact on it, but I kind of guessed, I decided that the best thing to do was try and get a job where I could actually afford to buy somewhere. So yeah, the housing situation for me is that I'm now mortgaged, which the mortgage isn't so good because it's a big mortgage so it means that I'm now frightened about losing my job, but I have a home and I'm supporting myself, so that's got to be good. (Male, 25-50, visual impairment & mental health condition)*

For other participants this was often not an option as they were out of work on grounds of incapacity or had taken early retirement. One of the participants mentioned above who had considerable difficulty getting out and about because of the stairs to her house, was in such a situation and had also been waiting four years, despite providing a wealth of supportive evidence regarding her need to move:

> *I've been on the council housing list for four years and I'm still, I haven't even seen a bungalow with them I haven't even had an offer of anything I bid for and I have bid for houses as well with stair lifts in and things like that or downstairs loos so at least I can live downstairs and just go up for a bath you know. It's not like I'm not trying to move…I've got the doctors letters, I've got the letter to my church, I've got the letters from my specialist all saying, you must give her a ground floor place because she cant manage, she is trapped. And it seems it doesn't make any difference so I'm going to try and find some bigger guns because otherwise I'll be throwing myself out the window I can tell you… I want to sit and enjoy life even if its sitting watching my own little bit of garden…lovely. In fact that would be ideal. (Female,50-65, mobility impairment & long-term health condition)*

Most of the participants on the social housing waiting list had been placed on band C, which participants felt meant they were given low priority:

> *They wrote us a letter and they put us on the [housing] list. You have to have a band and put in band C at the moment… I want a room for myself as well because of the musical instrument and things like that…my books as well because I am studying. My daughter sleeps with us in the same room because she hasn't got any room for her… I was hoping that I would be housed in a council house which met all my requirements, my needs as a disabled person. The fact that I am in Band C it is difficult to get anywhere. (Male, 50-65, visual impairment)*

> *I am on the waiting list …I joined the register to try and get a property for disabilities. I mean even with a medical condition you're still quite low down the list to try and get a property. I'm in Band C and Band D's the lowest cause the medical condition has pushed me up to Band C but I did my bidding over two weeks ago. It's normally all Band A's what get it.*
> ***How long have you been on the register?***
> *A year. (Male, 25-50, long-term health condition)*

For the participant mentioned previously who identified as suffering harassment from his neighbours due to his sexuality, the process of moving in 2003 was considerably shorter as he used the transfer process to find another home within two weeks:

> *It's just...just a happier place, quite honestly. Well I'm glad they....they put through the transfer. Put through really quickly. I got a phone call, saying come down now, cause we've got a place. So it was really...was within two weeks I think. (Male, 50-65, mobility impairment & mental health condition)*

Another participant, however, waited on the transfer list for over a year with no result, before being moved onto the social housing list in 2010:

> *I was walking relatively well until only about 18 months ago and then one knee quite seriously deteriorated. We had been on the transfer list for over a year – we were told they couldn't adapt this property any more at all so we said ok we'll get on the list and they gave us a banding. (Female, 25-50, mobility impairment)*

Participants on waiting lists for other sources of housing had also waited for considerable time to find a home. One participant who was unable to find housing through the council had to wait three years to find a shared ownership property:

> *We did own a previous house that we had some money from the sale. But because of all this benefits review the bank has said you had a mortgage with us for twenty years. Not touching you now. Haven't got the right source of income. Couldn't afford private renting 'cause although the income we've got is about eighteen thousand between the two of us, the rent on a two bedroom flat of fourteen hundred. You know that's actually more than we've got coming in. Council were simply not interested in housing. We'd fallen in that middle area. We had some money so they weren't interested, but not enough to actually do anything with it. I was disabled but not fully wheelchair bound so they weren't interested, and I wasn't over sixty five. So they basically said you can sort your own life out. So it took us three years to get a shared ownership flat. (Male, 50-65, mobility impairment & long-term health condition)*

A4.3.1.2. Allocation process for social housing

Many participants who had been placed on the social housing list either presently or in the past had experienced problems related to how housing was allocated. For some participants, it was felt that the allocation system had not taken into account their changing needs. One participant noted that his needs had been assessed eight years previously and felt that it did not reflect his current need:

> *I'm on the housing list but obviously getting something in Brighton and Hove is very difficult. You're basically whistling in the wind. It wasn't so bad back in 2001 but now in 2011 there's so many people coming into the city and people who need housing desperately – they have put me on a Band C. There used to be Band A, B, C, D, E and they lumped about 75% of the general population on Band C. To get onto a Band B its more medical and I last had an assessment about 8 years ago when I wasn't as bad as I am now so perhaps I should look at being more in the Band A category (Male, 50-65, mobility impairment)*

For another participant this situation was felt to be more critical, as after a year on the transfer list her needs had changed to the extent that she was now unable to get out of her house. However she felt this had not been taken into account and felt as if she was in a battle with the council to access appropriate support:

> *Then things started to get worse earlier this year so we wrote to them explaining this – they came back saying tough basically so I wrote back with a slightly strongly worded letter and yet so far it has taken 7 months before they actually contacted me. I never had so much as an acknowledgment letter from them. Something I didn't know until only last week when I got a phone call there's actually a Disability Housing Liaison Officer and they took 7 months to put me in touch with her. So literally I am having to kick and fight and punch the whole time.*
> ***And are you now in contact with the Liaison Officer?***
> *Yes and she has been very helpful. She's moved me up to Mobility 1 which is a fully adapted property - I can put bids on that and I would be prioritised very highly for that – brilliant – and at long last after many times of asking they're sending out a housing OT to say Oh, yes, you have got problems. But again, it's taken from the beginning of this year just to get somebody out – very, very hard work. They don't seem to want to listen to you or believe you – that's how it feels that you're pushed aside slightly it's like no, no, no just sit there and be quiet and it's really, really aggravating (Female, 25-50, mobility impairment)*

This participant felt that council housing staff did not understand the significance that an inaccessible house had on the lives of herself and her partner:

> *They don't seem to get what I am saying to them about how difficult things are because the other knee has now gone and I literally cannot walk – you know I can't get out to medical help, my doctors have to come out to here or dealing with phones or letters. I now need an electric wheelchair. They will not give me one here. Trying to get it into their head that this property is actually totally unsuitable for me and actually dangerous for me as I bounce off the walls as I am walking everywhere – it doesn't work. They just seem to think well why should we worry you've got a house – go away. They can't understand that my life has come to a full stop. You have got somebody who used volunteer – I can't do that. They've put me in prison. They have made life a lot worse and more dangerous for me and it's trying to get through to them that actually guys this is kind of important – you're strangling somebody – it's been very, very hard – incredibly hard (Female, 25-50, mobility impairment)*

The feeling that council housing staff did not properly understand disabled people's needs was also expressed by a number of other participants. One participant who had a mobility impairment but did not use a wheelchair, found that he was regularly suggested unsuitable properties while on the housing list despite making his needs clear:

> *I used to live here in Kemptown. Because there was no lift here, I applied, you know for a place with lift.*
> ***And how easy was it to, to find somewhere, somewhere different?***
> *Not that easy. I had to enter the housing register and then they offered me a few places which were not suitable for me. Either there was no lift or there were a lot of steps entering the area, you know. So I had to refuse, yeah…I gave them a list of my requirements for example there should not be any step. Number two, I need a lift. If this, not on ground floor. I mean, they offer me a place which was very, very steep and hilly. I said well I find it difficult. If I park, you know my car two block up the road. Its very difficult for me to climb up and down, you know. And then they offered me another place and again, about 21 or something steps. What they told me was its brand new, you know. It's a new construct. Well I said I'm not after a newly constructed one. I mean I can't cope with steps. And then finally they gave me the place I am in now. (Male, 25-50, mobility impairment)*

Another participant felt that the support he received was less than that offered to wheelchair users despite the fact he had a severe mobility impairment, and perceived this would affect his chances of getting housing:

> *What I could do with is a disabled bungalow because you can park inside but because I don't use a wheelchair they don't class you as severely disabled which is wrong…because a person can be severely disabled and have the same problems as a person in a wheelchair the only difference is you don't have a wheelchair. A wheelchair [user] can actually get out better than I can.*
> ***So you've found that's the major difficulty with the house?***
> *Its getting a property as I say I'm not wheelchair-bound. That can be one problem. They don't seem to account for types of disability they grade it in three gradings…they put me more likely into three because the other two are both wheelchairs and I don't use a wheelchair I'm not prepared to use one because why should I make myself feel even iller. You know, you start using a wheelchair and you go downhill even more. So yeah that is one problem with this council. (Male,50-65, mobility impairment & long-term health condition).*

One participant with a mental health condition spoke of experiences which had been recounted to her as a mental health advocate, where people's needs were not adequately accounted for when they were placed in social housing:

> *I know what's upset a lot of people's mental health is that they've been placed in places that wouldn't be appropriate for someone suffering mental health problems or, you know, physical disabilities. This isn't my story, this is another lady's story that she was kind of placed in an area that was experiencing a lot of social problems and it was really not doing her any favours, her children any favours, and she rang up the Council and said, "Look, it's really making me ill, I can't, there's so much going on, so many troubles, so many, you know, social problems," and the Council's response to her was, "Well, we like to put," I can't remember the expression, "we like to put the good with the not so good," kind of spread it out and she thought that was kind of a really bad interpretation from the Council. I think that quite often what can happen unless you rent privately you're just put somewhere that may not be the most appropriate...I mean*

> *I know someone less abled who's been put in a flat with three lots of stairs and no lift and it's kind of like, err, it's just not going to work. (Female, mobility impairment & mental health condition)*

One participant had experienced significant difficulty getting the Council to recognise his housing needs, as a result of his financial position. In this case, the participant reported that £4,000 worth of savings meant he was placed in the lowest priority group for housing. However this participant, who required an accessible property, was unable to afford to buy a property, and was excluded from council shared ownership schemes because of the low priority assigned to him. In this case, the participant had to wait three years to access a shared ownership scheme through a Private Housing Association:

> *They put us in Band D which they invented for basically go sort it out yourself. Um, yes we'll acknowledge you've got a problem but we don't want to know. And we did try for some shared ownerships and the rules on them you have to be on the Council list in Bands A, B or C. So several of them that were suitable, we weren't allowed to go for. Because the Council hadn't given us enough points so to speak. We went through and they said oh yeah, you qualify for what's it? Level 2 mobility or something. But because you've got over four thousand pounds in savings you're put back in Band D. So they've got these contradictory sets of rules. So you know they're saying well, go and sort yourself out, go for shared ownership. But then you can't qualify for shared ownership because this set of rules excludes you. (Male, 50-65, mobility impairment & long-term health condition)*

One participant also felt that council housing staff had not considered his general housing needs when he was looking to move from a property where he was experiencing excessive noise. In this case, he felt staff had failed to inform him about noise problems in the property he eventually moved to:

> *My old flat was absolutely noisy. It was right behind a pub. Every morning at 8 you would get bottles going in the bin waking you up and if you had your windows open over night the sea gulls would wake you up at 2, 3, 4, 5 in the morning. So…. They moved me in here. But they didn't inform me there was a previous history of noise. Which seems obvious and a damn sight relevant. They didn't inform me there was a previous problem of damp which they try and deny which I know for a fact they knew of. The amount of lies that they're actually telling to tenants and trying to cover things up…Environmental Health actually ask you to keep writing stuff down for three to six months to get enough evidence before they will actually act on it, if they act on it …I actually gave up two Council premises years ago for the same reason. I used to actually live in camper vans for quite a few years when I first came to Brighton…I mean I've been very tempted actually if they get me too annoyed I've been looking at other motor homes the last few days. (Male, 25-50, mobility impairment, long-term health condition & mental health condition)*

Where participants housing needs were not being met, therefore, this could have great significance for the individual, whether preventing them from going out or in this participant's case making them consider living in a motorhome. In other cases, where participants' needs were not adequately met, they were often forced to choose unsuitable properties which created additional problems. One participant for example felt that the problems with her previous home meant she had no choice but to accept a council flat in a tower block with faulty lifts which meant she was often trapped in her home:

> *Before I was here I was in Hove and I was stuck in the lounge, I slept in the lounge I ate in the lounge I went to the loo in the lounge I washed in the lounge. I did everything in the lounge, couldn't get out of the lounge and it got to the stage where I came so anxious and I don't know how I felt I just really really trapped I suppose…really trapped. I couldn't get out at all and this place came up and I took it because I needed the loo, that's the only reason I took it…because I was desperate for the toilet and when you've got strangers coming and emptying your commode and you're on your period and everything else I just felt I really need the loo and that's why I took this place… the only problem I do have is the lifts break down a lot which sometimes means they can be out for weeks and weeks at a time. Which means I'm stuck up here for weeks and weeks at a time (Female, 25-50, mobility impairment, long-term health condition & mental health condition)*

It was recognised by some participants that difficulties finding housing reflected a shortage of adapted properties. For one participant, it was felt that another part of the problem for people seeking adapted properties was the need to bid alongside other housing applicants who did not need adaptations:

> *They don't have in Brighton which a lot of areas do now, a sort of dedicated housing stock list for those properties that are adapted. A lot of other areas are getting that. They keep saying they are going to bring it in – it's not happening – they need to get a shift on and see that there's a difference. At the moment if there's an adapted property and say, I was to bid on it and somebody in an A band that doesn't need an adapted property they're more likely to get it. They can end up in an adapted property they don't actually need just because of that banding. And that's the frustrating part. (Female, 25-50, mobility impairment)*

A4.3.1.3. Emergency housing

Two of the participants in the research, both with mental health conditions had accessed emergency housing when they became homeless, one in 2010 and another over a decade previously. In 2010, the participant found that while the initial emergency accommodation felt unsafe, he was able to access a one bed flat on an emergency basis which met his needs well:

> *I found myself in a situation where I was homeless. I remember going to the council and I remember being directed to a particular place that was in a very loud place on the seafront…slightly like a prison, obviously security's important, but that was a bit intimidating and obviously the idea that there would be alcoholics, drug-users and other people that I would consider a risk to me, or at least intimidating to me at a point when I was feeling mentally very unwell and quite frankly needed to be in a safe, quiet, warm place not a loud, potentially dangerous place. So that was the first thing, when we looked into the situation a little further the guy actually turned round and said "for some reason," and I can't remember why, "you wouldn't actually meet the criteria for staying here anyway," which confused me. To be fair I had a point of contact and I*

> *could go back to the council people which is what I did and I was registered homeless, very quickly I was put into a one bed flat, a tiny little place and it was absolutely amazing to be fair, all of a sudden I'd gone from kind of being let down and panicking about where I was going to go and what I was going to do to being in a place that had a bath, a bed, water and so on and it did have some basic things… it was fine for what I needed. I think I was in the temporary accommodation for something like two months altogether which I was again very pleased and surprised I had that support and a place for so long while I was looking for somewhere else, Obviously they recognised that I was of concern so felt very looked after, it was really good. (Male,25-50, mental health condition)*

This participant, after several months in temporary accommodation, was offered a place on the home move scheme. However as with some of the participants above, he felt that his mental health needs had not been properly taken into account when offered a place. This meant he was unable to accept the home and had to move out of the area:

> *I was on the homemove scheme and because of my mental health condition and because of other circumstances I was quickly put into band A which was great… the homemove scheme is a completely different bag altogether – you get offered one place, if you turn it down for any reason, whatever, unless you've got an extremely good reason – you're knackered, you either take it or you're off the system. I went and looked at a particular place and it was miles away from town…it was up a hill. Public transport, I don't know where the nearest public transport was… bearing in mind I was still very unwell, was quite lonely at the time , had lots of things going on – to be shown a place so far away that had nothing in there at all, meaning there was no carpet, there was no bed, there was nothing – I mean it was an absolute shell. I said to the individuals that were supporting and helping me, who were very helpful – it wasn't their fault that it was the way it was, "How do you expect me to move into a place like this when I'm so unwell with nothing?"…they were saying things like "we can get you the 150 quid kind of free money loan thing, you can just have that, I've already spoken to my manager, you can have it," I'm like 150 quid will get me two foot square of rug, I suppose I could crawl up on that with a blanket but bless you, it's brilliant you're going so far and trying to help me so much but it isn't enough… it was a very difficult decision to make but in the end…I just couldn't do it. And the consequence of me rejecting that place was – I ended up going and staying with family abroad, I had to kind of run away from everything and I had to leave Brighton temporarily to fix myself in order to be in a position where I could come back and go back to work and it's fine now but at the time, as much as I was given all this help, at the crucial point when I needed help it was the wrong kind of help (Male,25-50, mental health condition)*

A4.3.1.4. Ongoing tenancies

For two participants with mobility impairments, finding a suitable home had not been a problem. Instead, they were able to stay in their current homes after tenancies were passed down from their parents:

> *I was very lucky. Most of my friends have called me many a name because when my father died they didn't transfer over to my mother. They gave her a brand new tenancy.*

> *And because she had a brand new tenancy it would be swapped over to me when she died. Where most of my friends, their parents had their leases swapped from the husband to the wife and then it can't go through the family anymore and so henceforth they've had to move out or been evicted. (Male,50-65, mobility impairment & long-term health condition)*

One of these participants, however, was only able to keep the tenancy after raising the issue with their councillor and local media. As a result, he was able to continue living with his brother which meant he did not need to access formal care services:

> *It took us months to fight to get this place off the council because when mum died, first thing they done is gave us an eviction notice. Literally mum had been dead a day and a Brighton councillor, a hand held letter "you're evicted". They wanted to put us both, split us up, put us both in bed and breakfast and we said "uh uh, no way, this is our family home since mum and dad have been here and we ain't giving it up for nothing". So went to the media and they backed down...they wanted to take us out of a two-bedroom house and put us in a one-bedroom flat each which would have cost them a fortune to do, plus it meant I would have been stuck in a bloody tower block somewhere with my disability, plus [my brother] wouldn't have been there as my carer, it was, it's like what the hell is going on? (Male, 25-50, mobility impairment & long-term health condition)*

Another participant with a physical and mental health impairment had also recently received a secure tenancy. For this participant, it provided him with reassurance and had enhanced his quality of life:

> *I've got a secure tenancy here now. I was lucky to be one of the last people to get in before the government changed it, so I have actually got a lifetime tenancy, which makes me feel quite good, and that's made a lot of difference to my life, it's made, you know, it has made a lot of difference. I know I'm secure and I'm okay. So whatever goes wrong, if I can't get up one day and I can't walk and whatever, it don't matter, do you know what I mean, it's just like, get used to it. (Male, 50-65, mobility impairment & mental health condition)*

A4.3.2. Private landlords

A4.3.2.1. Rental costs

As noted above, a key factor for one participant regarding the suitability of her property was her landlord's attitude towards making adjustments and adaptations. This also seemed to be the case for other participants in privately rented properties. However, one participant felt that while his landlord had made many adaptations, he had also taken advantage of the participants' reliance on these adaptations by putting up the rent:

> *I mean the landlord's always had to be consulted and sometimes he's like 'you're not doing that definitely not.'. But most of the time he's been kind of flexible, and he's*

> *helped, I mean he's done loads of adaptations on his own back, he ramped all the back garden for us...another problem about having a private landlord…because he's done some adaptations himself, and because I'm a disabled person, I think he's kind of like trying to exploit the system and he puts the rent up, you know he maxes it right up as much as he can. So I think we're probably about £50 a week short every week, of rent, even though we get discretionary housing funding as well. (Male, 25-50, mobility impairment)*

Experiences of landlords putting up rental prices by excessive amounts were not restricted to those participants requiring adaptations however, as several now faced significantly higher rents:

> *[I have a] very typical landlord really. Doesn't want to spend any money just wants to put your rent up all the time and my rent since he took over from my old landlady, since she died, since he took over he more or less doubled the rent. (Male, 50-65, mobility impairment & mental health condition)*

For one participant, the increased rent now meant that she had to move and now turned to the council housing department for support:

> *I've been living in Hove for the last few years and we can't afford to live there now, our rent's been put up to £1,000, it's gone from £675 to £1,000 so we can't afford to live there so yeah, I'm trying to get help from the Council to help us move*
> ***And how are you finding that?***
> *Well, avoiding, thinking about it too much, I'm meant to move on the 12th of September and that's not long and I haven't looked at anywhere yet, It's a bit anxiety provoking so I'm avoiding thinking about it too much, but I'm clearing the house out, that's what I'm doing in the meantime, and trying to raise some money and then I'll start looking, but it's not affordable for us to stay in Hove, there isn't any two bedroom flats that are less than £900. (Female, 25-50, mental health condition)*

Problems with increasing rents were a particular problem for participants on housing benefit, as this had in some cases also been cut. Although one participant had not been subject to an absolute cut, the lack of inflationary increase still made her financial situation more difficult and she worried about an increase in her rent:

> *I haven't had an increase in my housing benefit this year but I'm lucky because some people have actually had it cut. But, because I've been in the same flat for five years, I think was it regulation, is if you've been in the same flat and claiming benefits since 2008 you wouldn't be affected. But, by not affected that seems to mean not getting an increase either. I have signed up to be there until next May at the same rent, but the property agent keeps muttering about the fact, oh, you know, I could get fifty pounds a month more for that. And so, I'm worried next year he's going to put it up by fifty pounds a month, which is an awful lot when you're on benefit (Female,50-65, mental health condition)*

A4.3.2.2. Finding suitable rental properties

As noted above, many participants felt that as disabled people it could be more difficult to move home, whether due to differences in service provision, adaptation costs or lack of suitable properties. As a result, participants living in rental properties were often worried about the impermanence of rental arrangements, which could be a source of considerable stress and worry:

> *I am managing financially at the moment but you have always got a worry in the back of your mind because I am living in private accommodation where basically you could be given 2 months notice to quit your property. I'm not saying that would probably happen but it's always in the back of your mind that the place that you call home might not be your home. So it's always a nagging worry to somebody like myself as to what might happen. (Male, 50-65, mobility impairment)*

A common experience for participants claiming housing benefit was the difficulty in finding places to rent, as they felt that many landlords avoided renting to benefits claimants.

> *Most private landlords don't want housing benefit and this obviously indirectly impacts on people with mental health problems, and indeed other sorts of health problems, and you end up getting the last dregs of housing that the landlords are almost forced to accept housing benefit and, you know, you see signs in letting agents saying, No DSS, is quite common when I look for a place… it is legal to discriminate against people on benefits, which is just a preposterous situation. That needs to be a basic rule change I think. (Male, 25-50, mental health condition)*

One participant who left work when she became unwell, felt it necessary to lie to her landlord in order to keep her flat when she began to claim benefits. In this case the participant found the discretion shown by the council housing department to be helpful:

> *I've lived in the same place for a very long time, rented, again privately rented. When I became ill I ended up being on half pay so I had to claim housing benefit and that was an awkward moment because I didn't really know what my landlords would be like about it. So anyway I asked at the Council that I didn't want them to know about it but I still had to get them to write me a letter to say that I was living there and how much rent I was paying. They told me to say that I was applying for a bank account, so I did that and my landlord said, "Hm, I've never had to do that, what bank's that for then?", and it was really awkward, but I finally got them to, well when I first asked them they didn't do the letter so I wrote them a letter and just sent it and asked them to sign it. Then they did sign it and send it back so I gave that to the Housing Benefits people…I always pay my rent, I've never ever missed my rent. That's the thing, I've lived there a very long time and never missed my rent so really I can't see why they should be bothered if I'm claiming housing benefit or not, really. (Female, mental health condition)*

In some cases, participants were able to use parents as guarantors which enabled them to find rental properties

> *I have my mum as my guarantor which kind of clears that area, that problem, but I've just stayed with the same estate agents because, just that I don't want to go alone (Female, mental health condition)*

For several participants, the main barrier to entering the rental market was the financial layout required to make an initial deposit:

> *I've always rented privately, which I've had the same sort of problems trying to kind of come up with that thousand pounds, which is normally, you're guaranteeing a month's rent which is an absolute nightmare to be able to do. I've always had to use my dad as a guarantor. (Female, mental health condition)*

One participant felt that the multiple barriers to finding rental properties compounded with each other to make the process particularly difficult for benefits claimants. In particular she felt that cuts to benefits and increased rents had made competition for affordable rental properties very high, and had found no support from public services to assist her:

> *Someone has to do something about housing for people. It's just a nightmare, if you've got a council house that's fine, council flat that's fine, if you're not, the list is enormous, I don't know what you're supposed to do if you're in my situation, because council benefits are getting cut and cut and that's why I've moved, and I get an enhanced rate because I'm on DLA at a higher rate, but you know what if you're not... it's not sustainable, the amount's not sustainable and the competition for rooms is really hard, and I vaguely look like someone you might want to rent a room with, but you know, what if you don't? No one is going to give you a room, no flatmates are going to want to live with you...No one's ever offered me help, I have approached different charities and in the end I just got a room in Gumtree, I don't know how it happened, I just went to see this room and the landlord said 'what do you do' and I told him I was studying, which is actually true, he liked me, it worked, I was lucky, I just lucked out…it feels really, really stressful, it feels like you're, you're pretending, and it feels like if you weren't pretending you'd be homeless, it feels like a bit of a game really. (Female,25-50, mobility impairment & mental health condition)*

A4.3.3. Shared ownership

As noted above, one participant had obtained a shared ownership flat after being placed in the lowest category of the council housing list. This participant had subsequently experienced considerable problems in making his property accessible due to it's shared ownership status. The participant had difficulty accessing parking and other facilities due to a lack of provision for shared ownership tenants:

> *It took us three years to get a shared ownership flat. Which we moved into last year. But again we're in that middle ground with that. Building's got two halves. Council tenants and shared ownership. All the disabled facilities, totally including disabled car parking spaces, disabled adapted flats, disabled lifts, doors all in the Council side. Shared ownership side, nothing…There's what, four disabled spaces in the building? We're not allowed to use them because they're purely for the Council Tenants. None*

> *of them have got cars. But because there's spaces in the building we're having a huge problem getting a disabled bay outside the building. Again we've fallen down this gap and it's seems as, particularly in Brighton it's an all or nothing approach. You're either totally in a wheelchair on income support or its off your own back. (Male, 50-65, mobility impairment & long-term health condition)*

A4.3.4. Ongoing service provision

A4.3.4.1. Management of council properties

Several participants living in council housing properties felt that the council did not adequately maintain the buildings. As noted previously, one participant lived in a building where the lifts frequently broke down and left her trapped in her own home:

> *The only problem I do have is the lifts break down a lot which sometimes means they can be out for weeks and weeks at a time. Which means I'm stuck up here for weeks and weeks at a time which I don't mind so much if its raining and cold and miserable but when its beautiful sunny days and I just want to go down say the broadway down the bottom to the shops to have a look round or whatever I cant do it …they keep saying they are going to overhaul the lifts but then things come up that are more urgent then you get redirected. (Female, 25-50, mobility impairment, long-term health condition & mental health condition)*

Another participant felt that council were breaching their legal obligations as they had seemingly not serviced or changed her boiler since she moved in:

> *Well even to the council, when I went in there I said ohh at the boiler and they were talking '98 '99 the lady next door said ohh yeah they've been in since I been in here and that's 21 years, so that's illegal, they should be changed every 15 years and when I wrote and said excuse me I've got severe emphysema I need a move if you don't replace this boiler and all its stuff and all asbestos round it, all the mechanics told me it was round it that's why they wouldn't touch it. (Female,50-65, mobility impairment & long-term health condition)*

A number of other participants in council properties felt that doors and windows were in need of replacing but were still waiting for work to be done:

> *They don't seem to look after these properties that well…we're a forgotten area as far as the council are concerned they forget we exist.*
> ***What do you think is the reason?***
> *Don't know…they just don't care about it out here. Everywhere else they've got new doors and everything else done…we've got nothing…and then they turn around and say oh sorry we haven't got the money to do it. Pathetic… I've been waiting for a new front door for the past three years. I've got a gap an inch and a half wide top and bottom and about three quarters of an inch down the side. Supposed to be getting a new one but I'm still waiting for it. Done through the council, you have to tell them. They're not much cop. (Male,50-65, mobility impairment & long-term health condition).*

> *Your window's a problem...the fire service have actually recommended she's changed to PVC... the Council have said they're not yet set up for the costing for that, for her flats. But she can't open the window because of her disability, her arthritis as well is really stiff with the old wooden... is it double sash windows? Yeah, they're sash windows so there's lifting up as well, not good for her. Need to ask... big waiting list for repairs (Female, hearing impairment)*
>
> *Some of his doors are old wood and he wants it replaced, he's worried about theft and things, he'd like to have it replaced with some double-glazing but they haven't yet done it…he's saying about his flat door being wooden and he's worried about people being able to break in, he'd like the PVC, a bit stronger (Male, hearing impairment)*

Where participants had seen work carried out to their properties, some felt that the standard of work carried out by contractors could often be poor, although one participant felt it was variable:

> *Then the builders, the last lot that redone the bathroom managed to chip the bath in several places, managed to break one of the rails and had taken out all the wall and tiles to re do it. So they put two different hand rails in. And basically I think every contractor I've had here has been a bloody cowboy. Every single one of them. Not one single job has ever been done right. This time they took the whole…..cause the damp problem I'm having with the outside drain, literally took the whole bathroom out, new outside stack drain instead of an oval one, and three weeks after they'd done that the drain started getting blocked. They send down block busters. Block busters turn round and said it appears they haven't put the drainage in right. (Male, 25-50, mobility impairment, long-term health condition & mental health condition)*
>
> ***How's the council in general about the flat and stuff?***
> *Yeah they are alright, Mears aren't very good…the contractors for the repairs. Some work they do is really really shoddy other work they do is excellent so it's sort of like a mixed bag. (Female, 25-50, mobility impairment, long-term health condition & mental health condition)*

Participants also recounted negative experiences in dealing with council housing staff. For one participant, he felt that the council management of complaints had been quite poor:

> *The Council don't do anything about problems with flats. They just ignore it I mean I found the last few emails I sent which I've just sent to standard complaint's, the last five, six emails I have not had a single response to from the Council, the Housing Offices or from the Manager. This is why I send to standard complaints now and this is a stage two and if it doesn't get resolved this time I will sort it out by other means you know. Take it higher. (Male, 25-50, mobility impairment, long-term health condition & mental health condition)*

Finally, one participant felt that the council housing team did not take adequate account of her visual impairment:

> *Most of the time it's been good. The only thing I find frustrating that I have to mention my disability to the council all the time, to get exactly what I want. It just seems to me*

> *that they... Not all the council get all the information and it doesn't stay on their system. (Female, 25-50, visual impairment & mental health condition)*

*

The research team also explored participants' experiences of accessing regular services provided by the council housing department.

A4.3.4.2. Information and support with other housing options

One participant who had received information and support from the council housing team in relation to an eviction notice spoke positively about his experience:

> *My private landlord gave me an eviction notice recently which still stands but I'm hoping to get it sorted in the next week or two. I went to the Brighton Housing Trust who seemed very professional, came across really well, and since then I've been phoned twice by the City Council and they seem genuinely concerned about my eviction notice, the second call was unsolicited and just to see how things were going and it's been quite useful. (Male, mental health condition)*

Another participant expressed his frustration with changes to the way in which properties were advertised on the Home Move scheme, which he felt would have an unfair impact on people without access to a computer:

> *There's a thing called 'Home Move' which you contact or you can go to your housing office and pick up a book every two weeks which lists all the buildings that are available, all the houses that are available. Well, coming very shortly, that book is disappearing because of cost and waste, it's only going to be available online, libraries and whatever, but not everybody wants to use a computer or is able to use a computer So the Council, without consultation, have said right, if you can't use a computer, they will send you a regular update to your home, but it's going to cost you £10 for six months, which, again, is hitting the people who least can afford it. (Male, mobility impairment and long-term health condition)*

A number of participants, who had not directly dealt with the housing team, were unaware who to contact for information regarding housing options. One participant for example had experienced problems accessing information regarding sheltered housing options:

> *I would love to live in one of these accommodations where you have got your own independence in your flat but you have also got that people can look out for you. If you fell or you had a dizzy spell. You don't want to have to rely on your family because I would hate to have to leave Brighton to move back to where I used to live just to have my family supporting me – I find that terrible really. So I'd like to know about things but I don't feel I can find out information of whether I can claim these things or if I could buy a little flat using part of my savings so it's just a blankness really as to where you go for this help. (Male, 50-65, mobility impairment)*

Another participant, who had a moderate learning disability, had been looking to move for several years but lacked clear information regarding different housing options:

> *I had to go with a housing organisation because I'm an owner of my flat, but this government stopped other housing organisations from buying properties. And because I had my flat on the market and I had two people interested in mine, and because I had nowhere to go I had to take it off the market. There must be ways, I really don't know, of talking to somebody in the government, I don't know, to get me out of there. You know, I just want to get out of there. I only wanted to be in my flat for three years and I'm still there, seven years I've been there now, seven years too long (Female, 50-65, learning disability)*

A4.3.4.3. Other Council housing services - including housing benefit

Participants reported mixed experiences in dealing with council housing staff. One participant felt the Housing benefit staff had been supportive in helping her to fill in forms for housing benefit:

> *To be honest I've had really, really quite nice support from Housing Benefit, they've always been nice to me, cos when I moved I went down there, I wasn't going to, but I got really stressed with the form, they sent the form, fill out the form, I rang them up and I was crying, I just couldn't work out all the bits of the form which [name] would have done for me before, I just couldn't do it and I didn't have a PA, and I rang them and they said to make an appointment (Female,25-50, mobility impairment & mental health condition)*

Another participant, however, felt that council staff were rude and unhelpful when she experienced an administrative error with her council tax bill:

> *I find dealing with the council extremely stressful. The right hand doesn't know what the left hand's doing, and an example has been, I've been having a Council Tax issue with them, because their records were wrong, and I got 100% Council Tax, and it's, like, that's not my fault, that's your fault. So they sent me out this bill and I filled in the form and sent it away for them, and that was fine, and then they sent me a summons and I went, excuse me? And then I got a letter in the post from his boss saying, oh, we're terribly, terribly sorry, we've withdrawn the summons, and then the next day I got another summons for the same account, and it's, like, what do I have to do? And by the time you've spent 45 minutes on the phone with these people, you start thinking, I've no money, I'm sick and I'm dealing with this. What's the point? And phoning the council should not leave you suicidal. But I'm not alone in this, I think. As he said, I complained about a member of the council, and he said, I don't find that you were given any other treatment from anyone else. I said, probably not, but he was rude, obnoxious, deliberately obtuse and all of these things, and I think that probably is the average service, but that doesn't make it right. And, of course, the minute you say, oh, you're disabled, they start talking down to you. Not all of them, but a significant number. (Female,25-50, mobility impairment & long-term health condition)*

A third participant had also had a negative experience when applying for a disabled parking space outside her flat. In this case, she felt that the bureaucratic nature of the process for creating new disabled spaces had caused her significant difficulty accessing her flat:

> *The worst thing is parking outside my flat. That's the real nightmare I'm having at the moment. I'm trying to sort out a disabled parking space 'cause it's residents only parking. It's like something out of 1984...I applied to the Council for it and keep ringing them up and it's getting put off and put off and they said it might take up to six months and I got a letter six months later it said, 'We hope to meet in two months to discuss this.' Rang them back again after the meeting but they said oh it should be there in three months. So rang them back a few weeks later and they said oh it's been advertised 'cause they've got to obviously advertise them all and publish an application. And they said there's been a problem not with your application, but with somebody else's application. So they group them all together. So the whole thing is now put on hold and then it's kind of like it might be another four or five months now so you know and I'm kind of saying to them look, it makes no difference to my health condition when your meetings are. My health is still getting worse and worse and worse. I got a parking ticket the other day which I contest and I have to pay it. So it's just like you're in this bureaucratic nightmare and I just think you know if one person came and met me and said this is where you live, this is your parking, yes of course you need a disabled parking space outside your flat, here it is. You know after a sort of 11 hour day at work, I get home at about half past seven there's no parking anywhere. So it's really stressful because by that point my legs have had enough and don't want to walk anymore. I have to park you know, up the road and round the corner and walk with my bag and two walking sticks and you know. It's a nightmare. (Female, 25-50, mobility impairment & long-term health condition)*

As noted above, several participants mentioned financial problems they had experienced due to housing benefit being cut .One participant also criticised recent changes to housing benefit for single people under 35, which she felt did not take into account the needs of some disabled people for whom shared housing was inappropriate:

> *A single person is now 36, and that they're a single person now it's just gone ridiculously low so the only way they can possibly afford one flat on their own that they would have to share with someone else, which I think is going to cause huge problems for people that are physically less able and mentally less able, because you may have physical adaptions or mental health that you don't want to live with someone else. It's very private, and I think it, they're not incorporated that, they've not thought about that instance whatsoever. (Female, mobility impairment & mental health condition)*

A4.3.5. Impairment specific issues

A4.3.5.1. Physical impairments

For participants with physical impairments, the most common factors which determined the suitability of their housing where those relating to mobility and access, many of which have been mentioned above. One such concern for council housing tenants was the lack of adequate storage space for mobility scooters, as mentioned by one participant:

> *I'm finding now because what I mean trying to get this scooter storage done and I'm not getting any kind of one to one support from anyone…at the back of my front door it's a fire hazard. If there was a fire how am I going to get out if there's a scooter in front of the door late at night… it's not really being addressed by the council. The council are telling tenants they can't store them and charge them in the common lobbies. But on the other hand they haven't yet provided adequate storage (Male,50-65, mobility impairment, mental health condition & long-term health condition)*

Another exclusive concern of participants with physical impairments related to the accessibility of council housing offices. One participant felt that there was insufficient parking in the new housing office in Bartholomew place, while another noted insufficient seating in her local housing office:

> *You know Bartholomew Place? I've had to visit that quite a few times because I've been applying for council housing and I find they've taken four or five bays, parking bays out there, two for the electric cars which are never used and three or four for the city cars which are by the day cars sort of thing and left no parking, there's no parking. (Male, 50-65, mobility impairment & mental health condition)*

> *When you have an appointment you go to the ticket office and you pull a ticket and then you have to go to the next available person and tell them that you have an appointment... now there aren't, there are only chairs at one out of the four booths. They don't think that through, they don't think that through. It's like unless you're in a wheelchair it isn't obvious that you may have mobility problems. (Female,25-50, mobility impairment & mental health condition)*

Appendix 4: Housing

A5 Appendix 5: Transport & Environment

A5.1. What are Transport & Environment services?

For the purposes of this research, transport was defined as the many different ways participants travel around the city. This includes public transport, private transport, and walking (whether on foot or using a wheelchair or scooter) and cycling.

The research team wanted to know the methods participants used to travel around the city and why, in particular the opportunities and barriers to accessing various modes of transport. The research team was also interested in how services have been or could be made more accessible to participants.

A key point to note is the interdependency of transport services with most other services explored in the research, as transport accessibility influenced how participants could access their community, health services and employment. Many of these issues have been explored elsewhere in the report.

A5.2. Approaching the Topic

The research team asked several open questions regarding transport which were then followed up with extensive probing regarding participants' experiences with different modes of transport:

- How easy is it for you to get out and about in the city?
    - We want to know about any places you go to often as well as places you avoid
    - we want to know about any Problems you have accessing buildings (shops, community buildings, leisure facilities, pubs, cafes and restaurants)
    - we want to know how you travel around the city (on foot/bus/taxi/car)

Information on accessing buildings has been incorporated into the relevant sections of this report based on the type of building, with this chapter focusing exclusively on modes of transport

A5.3. Detailed analysis

This chapter is structured according to different transport services, including buses, taxis, private car, walking/cycling/scooting, and trains. In each section, variation between participants in different impairment groups is explored.

A5.3.1. Bus services

A5.3.1.1. General usage and satisfaction

When discussing general usage patterns and satisfaction with bus services, several participants noted favourably the physical accessibility of buses, which was felt to have improved in recent years:

> *And the buses are a tremendous plus, buses are really really good, and their accessibility is fantastic. That's a really positive attribute. (Female,50-65, mobility impairment)*

> ***How do you find the buses?***
> *Very good, very good. I mean excellent. I remember about twenty something years back when I came to Brighton oh, I had a nightmare to use buses. They had no railing, steep steps. And they were not lowering as they are now, and I tell you there was one, two, two three steps and I found it very, very difficult. Especially with shopping. But now it's very easy. (Male, 25-50, mobility impairment)*

Recent changes to buses, including the introduction of "talking buses" and new seating were commended by some participants, even by those without physical or visual impairments:

> *The new ones that we've got on the 6's are absolutely fabulous. I use the 7's as well and they talk…They're really interesting. They're better than some obviously that we've got already. They've got wider seating. Which makes it more comfortable to sit on. (Male, 50-65, learning disability)*

Some participants chose to use buses because of problems they experienced with other modes of transport, in particular the difficulty in parking when travelling by car:

> *I'll use the bus to go into Kemptown, the doctors because it is more of a hindrance trying to park your car because there's not that many disabled spaces in St James Street. There might be one or two spots that are always taken at certain times of the day so it's easier for me to get off the bus at the Steine, walk to the doctors, do the shopping at St James Street rather than have the hassle of taking the car. The bus stop is right outside the supermarket so I can carry a little carrier bag onto the bus. (Male, 50-65, mobility impairment)*

Various reasons were mentioned by participants as to why they did not use bus services. In one case, the main barrier was that the buses could sometimes be too busy:

> *I generally travel by bus, I have a bus pass. It depends how busy the bus is though… generally you can get a seat but it's a bit overwhelming if the buses are really busy. (Male, 18-25, visual impairment & mental health condition)*

Several participants chose to use other forms of transport due to factors relating to their impairment, for example the difficulty in walking to the bus stop:

> *I think the buses are great I don't have any complaints with the bus – but you have to walk to the bus stop – I mean sometimes I cycle to the bus stop and lock my bike up and do it like that (Female, 25-50, mobility impairment, long-term health condition & mental health condition)*
>
> *I've got a bus pass but at the moment it's hard to get there because I've got hills everywhere…that's a problem at the moment…I can't cope with hills. (Male,50-65, mobility impairment & long-term health condition).*

For one participant with a mobility scooter, he chose not to use buses as he was unable to take his scooter with him:

> *I do use the bus, I have a bus pass, only if it's places like where I can get a Two from round the corner, so it stops outside my blocks virtually and it stops just up the top here, so it's easy to come down. That's not so bad because I can walk down here but any further then I'd have to use my scooter. (Male,50-65, mobility impairment)*

Another participant was unable to fit on her local bus with her wheelchair:

> *I can't get on buses because my wheelchair is too big. One carer got me on once by removing my footrest but I have clonus in my legs and spasmed the whole journey and everyone in the bus stared at me all the way. (Female,25-50, mobility impairment and cognitive impairment)*

One participant with a mental health condition found that buses did not give him sufficient space, and felt claustrophobic so often chose to walk instead:

> *I was impressed broadly speaking by the bus service, by the frequency in particular. I would generally tend to walk most of the time unless I need to be somewhere for a particular time, because I can feel a bit claustrophobic and I feel as if I'm really helped by fresh air and having that space again from walking…a lot of the time I do feel quite sort of shut in really. I think I find myself almost then annoying others, where I'm opening a lot of the windows to try and get some fresh air because it feels very stale, and obviously, you know, it's not everyone's cup of tea to have a lot of the windows open. (Male, mental health condition)*

A5.3.1.2. Service provision

Participants were also asked specifically about their satisfaction with bus services. Many participants commented on the suitability and reliability of specific bus services they used. In a number of cases participants felt that waiting times for buses they used were too long. This could be a particular problem for participants with a physical impairment.

> ***Do you think the bus service is good?***
> *Most of the time it's ok but sometimes you stand around ten minutes and it doesn't come. It just annoys me sometimes especially if you go to the train station there is a time you have to catch the train…where I live only bus number 6 goes to train station but you stand and stand and stand and it not come…most of time I try to leave early…one hour or fifty minutes so I don't need to get panicked. (Female, 18-25, mobility impairment)*
>
> *I must say that they're not very regular as they should be. I'd say probably most days, fortunately I've got a seat in a bus stop, most days I'm having to wait between fifteen minutes and half an hour even if I've gone to catch a specific time I would say. But there are times when it's perfect but I would say more often then not there's a big wait. (Male,50-65, mobility impairment & long-term health condition)*
>
> *It's only places like where I have to go over to Hayward Heath then I have to get a bus in Brighton that can take up to an hour to, you know, because that is a difficult one to get hold of. But anything local's fairly easy. (Male,50-65, mobility impairment)*

One participant found the bus service in Bevendean to be particularly unreliable:

> *Where I live and that's Lower Bevendean. The bus services are, they say they will guarantee you three buses an hour but you don't expect three buses in two minutes. You know they all go round the estate. The first one's absolutely jam packed then the one afterwards is a little bit and the other one's running empty. And then they say it's not making a profit. …And you can't rely on them. That's why I have to get anywhere early to guarantee that I can get there because of the buses. I mean yesterday I went there to get up to the station and I waited 45 minutes for the bus in Bevendean but it's supposed to be a 20 minute bus service. (Male,50-65, mobility impairment & long-term health condition)*

Bus services serving council estates outside the centre of the city were found to particularly busy at certain times. One participant with a physical impairment found it was often necessary to stand where the bus was so busy:

> *They're pretty good up here, yeah, the 50's, or…*
> ***Does it go nearby here?***
> *Yeah, just round the corner. We find it easier getting round the corner because we go out early morning, by the time it gets round the estate I can't get a seat, I have to stand which I hate but there you go, that's life, make the most of it. But does kind of annoy me when you're, uh, well ten billion kids in pushchairs and they won't even give a seat up for you, I have to stand. (Male, 25-50, mobility impairment & long-term health condition)*

Several participants faced barriers to using the bus to access certain areas of the city due to the need to make multiple changes to get to their destination. This was a particular problem for participants with physical impairments who found it difficult to walk from one bus stop to another:

> *Buses and the free bus pass are great as far as they go if I need to, say, go to the hospital or something like that where parking is an absolute nightmare. But, yeah there's lots of places they don't go or you have to continually change bus...Generally they're great for getting on at home and going to one specific destination and then coming back that way. (Female,25-50, mobility impairment, & long-term health condition)*

> *Going to the Hove Polyclinic is, there's no way to get there without a very convoluted bus journey, so I just get a cab over there. (Female,25-50, mobility impairment & long-term health condition)*

> *I probably take buses about a quarter of the time you know when I'm fit. My partner will drive me round some of the time and I use taxis an awful lot because I find it quite difficult. Buses don't always serve everywhere that you want to go. It's alright if I'm going from my house into the centre of Brighton but if I want to go for instance to see [name removed] in Southwick there's no bus that I can take that would take me there. I'd have to go into Brighton and I've got to change buses, walk from one bus stop to another bus stop and then take another long bus journey from Churchill Square then walk from there…so that's quite difficult. (Male,50-65, mobility impairment & long-term health condition)*

One participant living in Hove felt that bus services travelling across the city were insufficient and had excessive journey times, and wanted to see an express route along the seafront:

> *I mean if I wanted to go to St James's Street from here it's 45 minutes on a bus. If I go in me car, it's 12 minutes, if that. Where if I go by push bike, which I occasionally do cycle sometimes, down Kemptown when it's a really nice hot day, even by push bike its…..20 minutes and I think what's the point of using a bus. I'm sitting on a bus for 45 minutes in warm weather, stuck in traffic… What they should have done years ago instead of doing all these buses, every bus route going down through Western Road which is a nightmare, they should split it up and put half of them from Hove, as a fast route that goes along the seafront with a bus lane and the other half on the normal. (Male, 25-50, mobility impairment, long-term health condition & mental health condition)*

Lengthy journey times were also an issue for one participant living in Portslade:

> *I can actually get from my office in Lewis via trains back to Portslade quicker than it takes me to get my bus from Portslade to Dean Gardens, which is like a 10 minute journey, I can actually do it quicker (Female, mental health condition)*

For many of the participants living in more central areas, however, bus services were felt to be good, with good coverage of the area:

> *It's a 1, 1A and 6 and course the 1 takes me all the way up to the County for doing my voluntary job. So that's very useful and taking me well, any part of Brighton or Hove that I need to go really and truly. (Female,50-65, mobility impairment)*

> *The buses in Brighton and Hove are brilliant. Out of the places I have lived in the past, Brighton and Hove has a very good bus service. You would rate it 9 out of 10. A very good bus service. Especially in Kemptown you have got three buses coming up St Georges Road 47,37 and 57 which go to Woodingdean Bristol Estate. (Male, 50-65, mobility impairment)*

A5.3.1.2. Driver attitude

Where participants had a negative experience with using a bus, this was often attributed to the attitudes of bus drivers. However, some participants felt that this tended to be the exception:

> *I find most of the bus drivers are very polite and they do have odd days and you've just got to put up with it, it's just one of them things to live with. (Male, mobility impairment and long-term health condition)*

One participant with a mental health condition felt driver attitude could sometimes make her journey an unpleasant experience when she was feeling unwell:

> *I'm alright on buses when I'm in a good space. If I'm in a bad space it's just horrible, it can be really horrible, a really negative experience. You know like you're saying, the bus driver, no hello. I mean, I do it when I'm in a good space, I'm so bloody cheerful to them and they're miserable, but I can do that in a good space, do you know what I mean? But otherwise it's just… when you're in a bad space you just look around and everyone looks how you feel. (Female, mental health condition)*

Two participants with mild learning disabilities felt that bus drivers could be rude or irritable, and in some cases lacking understanding:

> *Some of them can be rather irritable. I try not to take any notice when they're in that type of mood. I mean most of them are very polite but you do get the odd one. There was one incident where I gave the driver one pound thirty in loose change to get a ticket and he said back to me, that's the last thing I want at the moment. He was a bit rude. (Male, 50-65, learning disability)*

> *Last week the bus driver was rude. Very rude, yeah, and I'm waiting for a letter from the bus company to say about this bus driver. I went and told him before I stepped on the bus that my County Card was broken and that I was waiting for it to come in the post, and he sort of still pointed his finger to the machine on the bus, you know, so I just got stressed, a bit stressed from it, and I thought, you know, I'm just getting fed up with this Brighton and Hove bus company. (Female, 50-65, learning disability)*

Some participants reported experiences where they had been directly challenged by the bus driver in ways they felt were inappropriate. One participant recounted how she was challenged on how she used the buses:

> *There have been a couple of issues with kind of bus drivers, my mobility isn't great and I've used the bus pass to get from one stop to another that's too far for me to walk, and on one occasion there was a very angry bus driver saying that I should only be using*

> *my bus pass for long distance journeys and that it wasn't to be used for going from one stop to another and that he thought that he should charge me for that journey. Which…I phoned up the bus company and they weren't aware of any kind of regulations that permitted me from just going from one stop to the next one. But this kind of discussion was happening in the middle of a bus full of other people and just as I'm about to get off and as there's people wanting to get on, which was embarrassing, it was, I didn't feel I'd done anything wrong and I thought that was what it was there for, if I couldn't walk then that was there. (Female,25-50, mobility impairment, & long-term health condition)*

Another participant found that drivers sometimes did not want to assist him to access the bus in his powered wheelchair:

> *Well, 99% of the time, it's fine, you might get a driver who has probably had a bad day, and you do get problems with those, especially with the new system where they have to get out the cab to put the ramp down before you… if you haven't got a carer...You do get the ones who say "You can't come on here because we don't take scooters", if you contact Roger French, you can get one of those, which it says 'my wheelchair is approved for use on Brighton and Hove buses'. (Male, mobility impairment and long-term health condition)*

In the case of a deaf participant, he reported that a bus simply would not stop to allow him on with his son in a wheelchair:

> *On a Sunday they cut back on the buses, there's less of them, he wanted to go up to the car boot sale at the racecourse and there's a single-decker bus but he said he's not allowed on and why is he not allowed on and they ignored him. He put his hand out and it wouldn't stop for him because it saw the wheelchair. (Male, hearing impairment)*

A5.3.1.3. Concessionary schemes

Many of the participants included in the research held concessionary bus passes and had considerable experience of using this system. It was considered to be particularly useful for participants on limited incomes:

> *It's handy to say you get a higher rate mobility which means you get a disabled rail card and bus pass and all the rest of it which as I don't earn that much money it's quite helpful (Female, 25-50, mobility impairment, long-term health condition & mental health condition)*

For one participant, the scheme was useful as it provided recognition of her as disabled person and meant she could use priority seats if needed:

> *It's not really the paying for the bus as well, it's just for like you can sit in the seat at the front, although I don't even sit in the seats where they're for the disabled people because… I try and cause the littlest trouble as possible, so yeah… the only time I'd ever do it is if I was on a train and there was no seats, and then I'd like pull rank so to speak, I'd just say I can't stand up, and you need to do that (Female,25-50, mobility impairment & mental health condition)*

Two participants who were supported by carers or personal assistants when travelling were particularly critical that bus passes did not extend to assistants, unlike concessionary rail cards. For one participant the cost of travelling with a carer prevented him from using the buses more often:

> *Buses tend to be relatively helpful they can give me a bus pass but not to my carer. So I cannot do anything without my carer so my carer has to come with me everywhere I go, so if they give me a bus pass but they don't give a bus pass to my carer, they didn't give me a bus pass, they give me only half bus pass. (Male,50-65, mobility impairment, visual impairment and long-term health condition)*
>
> *Although I have got a bus pass but the person who is going to accompany will have to pay. It's free for him but…In Germany it's different they give two, the accompanied person. For that reason we don't go on the bus because of the money. (Male, 50-65, visual impairment)*

Another issue raised by participants was the fact that disabled bus passes could only be used after 9:30am, which could be a problem for people working or travelling early:

> *I have a free bus pass that I can use after nine, kind of annoying because I used to be able to use it before nine and it kind of bugged me that somehow it was almost as if I didn't have a right to be moving around Brighton before 9 o'clock, and maybe that the assumption was that most people with these passes are older people… Now I earn a wage so I'm not moaning about that too much, but it does cost more to get around. (Male, 25-50, visual impairment & mental health condition)*
>
> *Buses, the not before nine o'clock thing is weird. It's, like, I'm only disabled after nine, so that's kind of strange. (Female,25-50, mobility impairment & long-term health condition)*

However for one retired participant, this restriction was not considered to be a problem as it fit in with his personal schedule:

> *Yeah, I've had no problems with them because I don't normally get up early as well, half-nine bus pass, that's fine to me, so if I have to go anywhere that's, it's not bad. (Male,50-65, mobility impairment)*

A5.3.1.4. Impairment-Specific Issues: Physical impairments

Bus company demonstrations

Two of the participants with physical impairments lacked confidence with using their wheelchair on buses. However, on contacting the bus company arrangements were made to try getting on an empty, unused bus, both to assess the suitability of the participant's wheelchair for bus travel, and to give them confidence in using the service. This was a particularly positive experience for both participants:

> *Another good word for the bus company, they actually will, they gave me a test run so the guy actually came out, the supervisor I think he was, with a bus and we had a little trial with it with my wheelchair. Which I think is fantastic. Especially since mine was a little out of the ordinary, my wheelchair, and that basically gave me the confidence. (Female,50-65, mobility impairment)*

> *I went out with my support worker, I've got a real phobia with buses and I get panicky at the bus stop and I sweat and I run away basically….ever since I've been in the wheelchair I've had a problem. I feel like I get really embarrassed and anxious and stressed and It's like really hard for me. But anyway, I contacted Brighton and Hove buses and they arranged for me to go with my support worker to the bus depot on Lewes Road. And we waited on the front, the next thing I know, they're bringing this double decker bus around to get me on and take me around and they stopped seven…about six or seven times for me to get off and get on in the different ways the floors go and the ramps go and that. And it was lovely, it was perfect. (Male, 50-65, mobility impairment & long term health condition)*

Accessibility of bus stops

Another issue for participants with a physical impairment was the accessibility of certain bus stops. Where these were inaccessible, either due to steps or a lack of raised curbs to facilitate getting onto the bus, participants were unable to use them which limited their choice of destination:

> *I use the bus a lot and dear Mr French gets lots of letters from me too because at the polyclinic there's no high step to get on it and it's terrible to try and get on a bus there…there's not a raised curb there. (Female,50-65, mobility impairment)*

> *The bus stop at the top of the Swanborough flats up the hill…I got dropped off there once by a bus driver and I cant get off …its all steps and steep grass verge. I couldn't get off the bus stop so had to wait twenty minutes for the next bus to come along to get on the bus to get off at the next bus stop. I thought that was bizarre, who invented a bus stop like that? (Female, 25-50, mobility impairment, long-term health condition & mental health condition)*

No time to sit down

A major issue raised by several participants with physical impairments related to how buses were driven. In particular, the tendency of bus drivers to drive off before participants were seated meant they were concerned for their safety. In some cases this prevented participants from using buses:

> *Buses are a bit of a nightmare. Although I'm not actually in a wheelchair they're just really impatient to get off and they drive off while I'm still standing so I've just given up using them. (Male, 50-65, mobility impairment & long-term health condition)*

> *One reason I don't use the bus very often, maybe I'm lucky because I can drive, but is that I can only have one hand that I can use and the bus driver drives away before I get a chance to sit down. And I actually fell over once because I must hold my stick, I'm trying to hold one of the handrails and then getting off, I'm always terribly anxious because, quite often, I can't use a bell unless I stand up and then the stick comes into the problem again of getting a hand that I can use the bell. (Female, mobility impairment and long-term health condition)*

This was considered to be a particular problem for participants who had mobility impairments but were not wheelchair users. In some cases, participants' impairments were not obvious, however in others even where the participant asked the driver to wait, they were still not given enough time to get seated:

> *Things could be better for people with invisible disability issues…because I can't carry a stick or a crutch, but I kind of have issues of somebody that would, because I've got dodgy shoulders, so they move off too fast, I mean it's much better now because it's obvious when you're getting on that you've got a concessionary pass with the new machines. So it's not as if they don't know that I might need extra time (Female, mobility impairment and long-term health condition)*
>
> *If I use my disability card that should be some recognition of 'Okay, this person has a problem and I should wait', they don't ever wait, they're gone, and at full pelt, and they brake at full pelt. (Female, mental health condition)*
>
> *I know exactly what you mean about them pulling off, because I almost never get a bus now because of the trouble I have, but then on the occasions that I do, I say to the bus driver "Can you wait until I've sat down before you pull off?" And it's like 50/50 whether they do or don't (Female, mobility impairment and long-term health condition)*

Two participants spoke of experiences where the lack of time they were given to get seated resulted in serious injury, requiring visits to accident and emergency:

> *I got on the bus a few weeks' ago, and I said to the driver when I got on "Can you please wait until I sit" well, there were a lot of people getting on where I was getting on and what happened? I didn't even get to sit on a seat and the bus went forward, I couldn't see to hold anything and I just went and was injured and I had to go to hospital and a lot of internal injuries because the bus driver would not stop. And it was only one of the passengers said to me "Do you want an ambulance?"...and the bus driver had stopped at the crossing and then started off again, although everybody was shouting "Will you stop the bus?" Anyway, this ambulance came down and apparently went straight in front of the bus to make him stop and parked just there and everybody had to get off the bus because the bus was taken out of action...this bus driver was running late because it was about ten minutes late and that was why he shoved off and wouldn't wait. Anyway, when the ambulance drivers and the paramedic got on, this bus driver had to clear it, but he never even said he was sorry, which I thought was absolutely disgusting. (Female, visual impairment)*
>
> *There was one incident a few years ago when I had got these two carriers and I had got onto the single decker bus and as I was getting on I showed my – I have a bus pass with a little disabled sticker in it and unfortunately the bus driver didn't wait until I had got to the seat and he then took off while I had these two bags before I could get*

> *hold of anything and literally I fell backwards trying to save my spine and I broke my little finger which you can see is slightly broken and I was in such pain with that again, I had to go to A&E with it and the bus driver admitted that he was responsible for me falling over on the bus. But just something like that with what I already had was like an extra thing where this was bandaged up and that pain and the pain that I had it was like a double blow for me which lasted about 6-9 months. (Male, 50-65, mobility impairment)*

For two participants, the apparent tendency of drivers not to wait for people to get seated was felt to be part of a wider issue regarding the behaviour and driving style of bus drivers:

> *The drivers are much more friendly then they used to be, although I've had cause to complain a few times with drivers just sort of driving off without waiting till I'm even on the bus properly, sort of hurtling across the bus. Or, times when the driver doesn't stop by the bus stop because there are several buses and he'll stop sort of five buses down and by the time you get down there he's shutting his doors and I'm ending up banging on the door with my sticks and he just smiles at me and just drives off. And I had two times when he smiled at me and he couldn't move because he was in traffic jam but he still wouldn't open the doors. And I was almost in tears with rage outside and the [expletive] just refused to open the door and he hadn't even stopped at our bus stop, you know. So that incenses me. (Male,50-65, mobility impairment & long-term health condition)*

> *I know they've now adapted them, that buggies and wheelchairs can use them, which is fantastic and that wasn't around when I had my first child, it was awful, but buses, they drive like lunatics, they've got automatic braking systems and they get great joy out of braking really, really hard. They never wait till you sit down, and they've got a sadistic personality some of the bus drivers. I've seen one watch this little old lady, who was very less able, trying to make it for the bus, waited till she was nearly there and drive off. I've gone through red lights, I've had a bus accident that screwed up my only arm I can use properly. Just every day it's like being on a ruddy rollercoaster (Female, mental health condition)*

One participant who was a wheelchair user recounted more positive experiences where drivers had ensured he was secure before moving, but perceived it to be an issue for others:

> *I've had a couple of drivers that have said to me "Are you okay?" "I'm in place…" I've said "Yes", but it does happen, I've seen it happen quite often and it is a big problem. I've recently heard of somebody having a very bad accident that had gone up the stairs and because the driver had suddenly set off, they flew all the way down the stairs again, she'd ended up in quite a bad way. (Male, mobility impairment & long-term health condition)*

Ramps

For participants who were or had been wheelchair users, a key barrier to using buses was the reliability of access ramps, particularly those using an automatic system. For one participant living in Hove the failure rate of ramps was felt to be excessive and prevented him from taking his son to school:

> *You know I'd like to take my son to school some more and sometimes the assistants don't drive. I'd like to just get on the bus and take him to school, it's only along church road, but it's like when I've tried to get the buses it's probably 75 percent failure rate, it's like the ramp isn't working, it's a nightmare. So that like puts us off, especially if we've got to get him to school at 9 o'clock, what do I do, start waiting for a bus at like 7 o'clock? I'd like to jump on a bus like everyone else and just take him to school like all the other parents, that's impossible… I ended up, the last time I tried to get a bus was coming from Brighton, and I kept on going to the next bus stop waiting for the next bus, just keep going, keep going, keep going and I made it all the way home, there wasn't one bus that was working. (Male, 25-50, mobility impairment)*

Some participants noted that this issue had improved to some degree recently following the introduction of manually operated ramps:

> *The new system where they have to get out the cab to put the ramp down before you… those do not fail, that's the thing, where the powered ones, you sit there and it comes out and goes back, comes out, goes back, and you're stuck there. (Male, mobility impairment & hearing impairment)*
>
> *This year Brighton and Hove have actually got 21 new buses, which, to their credit, the ramps actually work, no problem. There's still a lot of old buses that have still got these ramps that come out, I tried to get on one the other day and the guy had tried his best and it just wouldn't… it came out and then it shot back and everything. (Male, mobility impairment & long-term health condition)*

Wheelchair spaces/Priority seats

Another issue for wheelchair users was the perceived limited availability of wheelchair spaces, which were often occupied. Some participants accepted the first-come first-served system:

> *When I did use a wheelchair I used to go on the buses, but sometimes you couldn't get on because either the ramp wouldn't work or, they had five prams on. And so I wanted to see what the position there was and basically was first come first served. So I thought, well that's ok. (Male, 50-65, mobility impairment & mental health condition)*
>
> *There's things like drivers don't know how to use the ramps and ramps that don't work, buses that come with people already on in wheelchairs or buggies so I can't get on. (Female, 25-50, mobility impairment, long-term health condition & mental health condition)*

Others felt that the policy towards prams and buggies was less restrictive than towards wheelchair users:

> *We're subject to statutory size limits, but those buggies…I mean, well, someone got on, it was bigger than my wheelchair. Now, I don't see why, considering they're*

> *carried as a courtesy, the bus company can't limit size, if they gave twelve months' notice, no one would have an excuse for having the wrong size buggy. (Female, mobility impairment & long-term health condition)*
>
> *Some buses are full up as well, he's got a wheelchair again and they're allowed one wheelchair so sometimes there's four prams on a bus and you can't get the wheelchair on the bus and they're only allowed one wheelchair. They had four or five prams all lined up, but if there's one wheelchair then he's not allowed to put another wheelchair on. (Male, hearing impairment)*

A similar problem was reported by participants with mobility difficulties who needed to access priority seats at the front of the bus during busy periods:

> *When it comes to transport...oh god....if I get the wrong times, as I do my exercise walk down Sutherland Road, come to the big Gala bingo bus stop. Oh, if it's three o'clock, three thirty and all the old people have come out - nightmare. Just don't even try and get on a bus…I have checked this out so I do know, I do know where I stand. The priority seats on the buses are legal for disabled people only. It's courtesy for....for old people. It's all it is, but they're not enforceable which is a really silly situation. (Male, 50-65, mobility impairment & mental health condition)*

Several participants with mobility impairments also experienced problems using priority flip-down seats at the side of the bus, due to the strength of the spring mechanism:

> *The ones on the side are useless. They're useless because I try to hold sticks. Rucksack on back…and though…nothing to hold on to. A recipe for disaster. (Male, 50-65, mobility impairment & mental health condition)*
>
> *The other physical thing about the buses, which I can't manage, are the seats that you have to put down to sit on…I can't see a way round that because I know people with prams or chairs are able to use the space, but the seats are… unless you've got the hand to hold the thing down, you end up on the floor quite easily. You know, because it's quite strong, they spring back up (Female, mobility impairment & long-term health condition)*
>
> *I have to use so much strength to move the seats (Female, mental health condition)*

Attitudes of fellow passengers

For many participants with physical impairments who needed to access priority seats or wheelchair spaces, the main problem using buses appeared to stem from the attitudes of fellow passengers. In many cases, other passengers were reported to have refused to vacate priority seats or made hostile comments to participants using the seats, which was attributed to a misunderstanding as to how they should be allocated to both elderly and disabled passengers:

> *There's some helpful people but I do find a lot of them are quite rude as well. In my experience anyway. You go on a bus, say, and …having a disability it's always best to*

> *sit at the front and you get a lot of the elderly people say, who are able to go to the back, and they just wouldn't give up their seats. (Female, 25-50, visual impairment & mental health condition)*
>
> *I've given up trying to sit down, partly because of the abuse you get from other passengers, because they go "Why are you sitting in the seats for the elderly?" and I say "Well, they're for the disabled as well" and then they start having a go at me. (Female, mobility impairment & long-term health condition)*

This was particularly felt to be a problem for participants with invisible disabilities, e.g. mobility impairments which were not immediately evident:

> *There have been…a few comments if I haven't been able to give up my seat for someone else, or other people not thinking they should have to give up their seat for me, and it's not all the time I need, I need someone to. But I think in many respects I'm younger and I don't necessarily look disabled. I have the walking stick and movement can't always be great, but I think in many respects if there's someone older than me, not necessarily a huge amount, but there are certain looks and comments about me having to move out of the way for someone older than myself or, kind of huffs and tuts and puffing out of the chest and kind of not necessarily saying anything, but their demeanour, there have been a few issues of that. (Female,25-50, mobility impairment, & long-term health condition)*

One participant felt that one solution to this problem might be to raise awareness among other passengers as to how seats should be used

> *They have their posters up you know for trips away and stuff like that….could they do something like you know, are you a priority seat hogger… or something like that? Something nice… cause I think they do an awful lot of good but …just…again gently prodding. And basically the answer I got back [from the bus company] was um, well the people that would be aimed at wouldn't read it anyway so there's no point. (Male, 50-65, mobility impairment & mental health condition)*

Some participants using wheelchairs reported negative experiences with other passengers when sharing the allocated spaces:

> *They let me on the bus and there was like a couple of wheelchairs and pushchairs and they were a bit reluctant to move to let me in that one place that you can go on. And I was just getting embarrassed and I wished I weren't there. (Male, 50-65, mobility impairment & long term health condition)*
>
> *I think the worst problem I have with buses is prams and students, I find the students sometimes can be very rude, they bang you all over the place when they're getting in because they stand right in the middle of the gangway and other people can't get past. You get women or mothers coming on with some prams, some of them are very polite, but then there's others that are not, they don't care, you know.… and they're sort of giving you a really dirty look and it's very aggravating. (Male, mobility impairment & hearing impairment)*

For other participants, a key issue was felt to be the behaviour of other passengers when embarking and disembarking from the bus, which made it difficult for participants with mobility impairments:

> *What always happens to me is, everybody swarms round me, even if I'm there first, by the time I get on, I then have to shift pushchairs and little old ladies and things, I mean I think the wheelchairs should get on first. On aircraft, they load the families first, but we need to talk to the bus company so there's a protocol and the guys then know what's needed from them and expect it. (Female, mobility impairment & long-term health condition)*
>
> *The drivers and things were fine and even now cause as I say I've given up the wheelchair, given it back because I want to exercise my legs more regardless..... the one thing that's not consistent with them is when you try to get off the bus... I don't know why people feel they have to get off quickly when people are getting off. Cause the bus is not gonna go anywhere, and can they just wait a bit? Again it's awareness. And some drivers say wait to them, and you know they get off and wait. Sometimes it's me saying will you get off the bus please. And they look at me and they breathe in. And I say, no, all the way! (Male, 50-65, mobility impairment & mental health condition)*
>
> *On the buses you get bashed by peoples bags they're carrying on their back. I used to go right at the back and sit at the back so at least I didn't have anyone pushing from behind me or mobile phoning behind me, they are all over there you know. Where I could sort of cope with them, put me bag there and my stick 'I'm here, I'm sitting in this bit'. But yeah, otherwise glad I've got the car. (Female,50-65, mobility impairment & long-term health condition)*

A5.3.1.5. Impairment-Specific Issues: Visual impairments

For participants with a visual impairment, the main barrier reported to using buses was the difficulty in identifying the correct bus. One participant spoke favourably about his experience using talking bus stops, as well as an I-phone app to find bus times:

> *Generally speaking the bus service here is really good, we have a lot of buses in Brighton. I was using the Reactor Key System, you know, the little talking bus stops, but part of me is that I don't really like drawing attention to myself, so standing at a bus stop and suddenly an announcement comes out you feel a bit self-conscious about it… What I do now, the Brighton and Hove bus company do an app, and with my iPhone 4 I have voice-over on it and magnification, so I now have a real time application. So when I get to the bus stop I know how long it is going to take for the bus to arrive, so I actually know more than people who haven't got that because there's not a real time bus stop there. (Male, 25-50, visual impairment & mental health condition)*

However, other visually impaired participants found it difficult to identify bus numbers when embarking on a bus. One participant with a guide dog also had a problem at busy bus stops where buses stopped some distance from the actual stop:

> *I catch the bus, from the bus stop, there are about eight or ten buses that come to that stop, and of course then there's the stop only twenty yards down the road and then*

> *there's another stop, and they just come one after the other and stop behind each other and sometimes the bus I want could actually be almost back down at the next lot of pedestrian lights, it then comes up and it doesn't stop, how did I know it was down there? And yes, I mean some of the drivers are really good when they shout out 'it's a number such and such' because what's the point of me getting on and saying 'what number are you', oh no, actually this one doesn't go the way I want, just to get off again and then there's somebody behind you who doesn't understand why you're getting off, often they don't even notice the guide dog I've got to be honest… recently the number six bus has sometimes has those talking stops, which are very helpful, I like that. One of the things I, my idea for the 21st century which we supposedly are in, would be that …when buses open their doors it actually says, spoke, 'this is a number one' or number seven or whatever it was (Male,50-65, visual impairment)*

For one visually impaired participant, the anxiety related to identifying bus numbers prevented her from using buses altogether:

> *I don't actually go on buses because of my health condition. You know, because obviously of knowing where the stops are. And then, also, even though they've got these talking bus stops, not being able to see what number the buses are and having to rely on the public. You're having to put your trust into a lot of people then,.with the visual impairment. How do I know that person's genuine? I mean, there's all sorts of people out there. It sounds negative but you've got to be so wary. (Female, 25-50, visual impairment & mental health condition)*

Participants with visual impairments also experienced problems with bus company staff who they felt did not adequately communicate problems with bus passes which they attributed to a lack of disability awareness.

> *The only gripe recently with regard to the buses was with the bus pass they introduced a swipe system. Firstly my bus pass that I did have didn't have a chip in it so it wouldn't swipe, and I experienced a reasonable amount of unsupportive behaviour from drivers, saying 'Well you need to sort that out' or 'It doesn't work'. .. I felt they weren't describing very well where to put the card, swipe the card, they would just point out to it…Now I understand that drivers probably, on certain days, get really irritated by the amount of questions or silly questions they're being asked, but I don't know what Brighton and Hove put in place, but some very simple awareness training would have been so helpful. I found that a couple of the drivers, a few of the drivers over that period of time were quite irritated that I was asking them to tap in a number to get my pass. So that would have been an example of where some decent awareness training would have made that experience, yeah, not made me feel like an idiot or disabled, you know. (Male, 25-50, visual impairment & mental health condition)*
>
> *A few days' ago, I was on the bus with a lady and we was actually waiting at the bus stop near where I live and the bus went by that we needed. On the way back from the destination, we actually got on the bus and I was standing there like a complete lemon not knowing what's going on and then the bloke didn't explain to me that his ticket machine was broke until later on. And then I put a complaint in when I got home and, anyway, I got a free Daysaver. (Female, visual impairment)*

A5.3.1.6. Impairment-Specific Issues: Hearing impairments

As with many other services explored in the research, the key barrier faced by participants with hearing impairments to using bus services related to a lack of accessible communication. Experiences of deaf and hearing impaired participants were recounted to a sign language interpreter at the focus group and are reported in second or third person perspective. In some cases, participants' experiences related to information on bus times, which was found to be improving in some areas:

> *Okay, you find the buses easier now with the sign, you can read when the time bus is coming, so it's much better, before there were nothing but the bus signs are much better now that they've done this. Not all of them unfortunately, not every bus stop, he knows it's expensive but it's in the future maybe they could spread it, it's useful. (Male, hearing impairment)*
>
> *She uses the texts as well to find out when a bus is arriving, that's useful the text messaging for bus times (Female, hearing impairment)*

As with participants with a visual impairment, one deaf participant had seemingly received no accessible information on changes to the bus card system which left him confused when using the bus:

> *He's not sure what he's doing with the student bus card system on the bus… there's a new system on the buses, it's confusing again, no information explained to them (Male, hearing impairment)*

Problems for participants with physical impairments when communicating with fellow passengers was particularly difficult for a deaf participant travelling with a wheelchair-user:

> *Sometimes he tries to ask them to move the pram sideways so he can get the wheelchair on and they say they can't move and he can't talk, because he's deaf he can't communicate with the people, he's asked, "Please can you move so I can," and he's showing you now how he does it and they get cross sometimes with him. (Male, hearing impairment)*

A5.3.1.7. Impairment-Specific Issues: Other impairments

Finally, one participant with a cognitive impairment found noise on the bus to be her main concern, but used personal adaptation strategies to overcome this problem:

> *I use the bus service a lot. I prefer not to, I prefer to walk where I can, because it's fine if I get, what is it, a Saver ticket, where you can jump on and off buses, but I do find them a bit noisy sometimes. You know, I can't stand it if somebody's there having a loud conversation on their mobile phone or they've got their headphones on playing really loudly, or you get people who don't want to sit next to each other but they still want to have a conversation across the bus. So all of that, I hate that kind of level of noise. General murmur, you know, a couple of people having a general, reasonably*

> *quiet conversation is fine. So I do bring my iPod, so if it's noisy and it's not suitable for me to get off then I'll put those on. (Male, 25-50, long-term health condition)*

A5.3.2. Taxi services

Many of the participants in the research were regular users of taxis in the city. In many cases, participants had positive experiences of using taxis and did not identify any specific barriers:

> ***How do find the taxi companies that you use?***
> *Yeah, I've had no problem with them. (Male, 50-65, mobility impairment & mental health condition)*
>
> *I've never had a bad experience with any taxi driver. (Male, 50-65, learning disability)*
>
> *I use a lot of taxis again that's what I use the DLA money for is to pay for taxis. So yes, lots of taxis lots of driving (Female, 25-50, mobility impairment & long-term health condition)*

A5.3.2.1. Cost

The barrier apparently preventing most of the participants from using taxis was the cost, which many participants felt was excessive:

> ***Do you use taxis?***
> *No not usually, it's so expensive. (Female,50-65, mobility impairment & long-term health condition)*
>
> *Taxis are expensive as well. Particularly down in Brighton, my god! Your taxis are extortionate down there. That would be something…maybe the council could consider maybe reducing prices for disabled taxis. I don't know maybe I'm naive but they do seem particularly expensive down your way the taxis. (Male, 18-25, visual impairment & mental health condition)*
>
> *Don't use taxis very often because if you get to Brighton Station they're about £3 before you get into them. So unless I've got a big case with me because of work, sometimes I carry a big case of stuff, I'll do it then because I can claim it back. (Male, 25-50, visual impairment & mental health condition)*

Often participants were on a limited income and simply could not afford regular taxi journeys:

> *I use buses. If it's a short journey. If it is a long journey I might take a taxi. And then that will fall into my finances that are quite stretched so I try to minimise going out a long way quite a lot. (Male,50-65, mobility impairment, visual impairment and long-term health condition)*

> *Normally get a taxi when I go to into Millview because there's no buses to go there, without going all the way to Hove and all the way back and stuff like that, and generally they're not unfriendly, but it's ridiculously… it's three quid once you get in, you know, and it's like 'Really?' I know fuels gone up but, you know, it's my week's wages just to get down the road, so it wouldn't be my first port of call. (Female, mental health condition)*

While some participants received taxi vouchers, it was felt that these did not go far enough

> *You are given £70. And I was calculating only going to the Beacon, it is going to cost me £70 for one month. And then I cannot use it for anything else. (Male,50-65, mobility impairment, visual impairment and long-term health condition)*

> *I get taxi vouchers but they don't last long(Female,25-50, mobility impairment and cognitive impairment)*

A5.3.2.2. Vehicle Suitability

Often participants' experiences of taxis depended on the availability of vehicles appropriate to their access needs. Two participants using wheelchairs found the provision of accessible taxis to be sufficient and received support from drivers to access the vehicles where necessary:

> ***So when you have to use taxis, what's that been like?***
> *It hasn't been too bad. When you're booking the taxi so long as you tell them you've got a wheelchair then normally they supply a big taxi that caters for the chair. So yeah, hasn't been too bad. I've always found them pretty good, unless you get an ignorant driver which you get everywhere, very helpful, helping getting me in and out of the taxi and stuff like that. That's happening more and more in the last few years, they've managed to get much better. Obviously the council, the council obviously sets some pretty stringent rules down because three or four years ago there was nothing really in terms of assistance I've found, but now they have to be able to help people. (Male,25-50, mobility impairment & long-term health condition)*

> *I've had a few taxis yeah the taxis are fine 'cause they've got ramps. As long as you get the accessible taxis like London cabs that sort of thing and then they've got little ramps to go up for you and then it's fine. Sometimes the ramps are a bit steep so you have to go back up and vroom! And they sort of have to push you 'cause you're like spinning on the top so, but they do give you a shove in. (Male, 50-65, mobility impairment & long term health condition)*

Several other participants who used larger powered wheelchairs experienced more difficulty in finding suitable vehicles:

> *The problems with a taxi is getting a taxi that can accommodate the height of my wheelchair. The last time we used a taxi was from Worthing and as usual i'd be reclined right back then the next 3 days I was in agony, and I think the time before that*

> *was probably a year ago so just put off altogether using taxis. (Male, 25-50, mobility impairment)*

> *I can't sit upright, so I'm always lying back, this is about as high as I can go, at the moment, I can't get in the taxi. (Female,50-65, mobility impairment)*

> *I've always used taxis. I don't now cause I find it difficult to get in and out of so called adapted taxis cause they're not. They're just ordinary taxis with a ramp, and you get up there and you've got to get in. I'd rather use a bus. In most cases they're just standard London cab with a ramp that comes out. So you've got the door, when you're quite a big person as well, I've got to get down to get in and then you're sitting…you can't turn round in them to sit facing the driver, or away from the driver. You're crossways, which isn't very comfortable and not very safe (Male,50-65, mobility impairment, long-term health condition & mental health condition)*

One such participant, while able to enter the vehicle, found that he was inadequately secured when travelling in his power chair:

> *I think the worst thing is, you've not been strapped up. (Male, mobility impairment & long-term health condition)*

One participant found that the ramps into accessible taxis were not always suited to her wheelchair, and she often had to wait for a suitable vehicle:

> *The problems I have with the taxis is they very rarely have available the single ramp because my wheels are different widths they can't use the double ramps… It's got to be one big long single ramp. I have had to wait recently around fifteen minutes for a taxi which isn't good when you've got a bag full of frozen food and it's a hot day!...sometimes I phone up for a taxi and they say no wheelchair accessible taxis available. So I have to phone up and cancel doctor's appointments at short notice (Female, 25-50, mobility impairment, long-term health condition & mental health condition)*

Other participants using accessible vehicles also found that availability could be limited, particularly at certain times of day for example during the early morning school run:

> *In a couple of incidences where I have to use taxis regularly to somewhere else, I've always found that they turn up ten minutes…well, fifteen minutes later, so I'm having to book before. For me, if I've got a meeting at half past nine, I have to say "Right, I want you there at quarter to nine" they'll be there… nine o'clock to get you there on time, so that is one of the biggest problems I find…And that is one of their nightmare times of day though, with special school runs (Male, mobility impairment & hearing impairment)*

> *Taxis told him off because when he's ordered he's got the wrong taxi and the taxi driver is not happy about dealing with a wheelchair and a disabled boy into a small taxi, but the big taxi is never available for you. (Male, hearing impairment)*

For some participants, wheelchair accessible taxis were particularly difficult to use. This included participants with mobility impairments as well as one with a guide dog:

> *I find this idea that all new taxis have to be these wheelchair accessible taxis that's fine possibly for that disability but for me getting into one of those I have to walk in which means I have to be bent over which I can hardly do or rather I have to be un-naturally bent over and then it's a long way to try to walk back into the taxi to the seat. I find them almost impossible… what I have to do is go in on my knees and sort of shuffle on my knees to the back on the cab and lift myself up onto the seat…I'm not worried about dignity; I gave up on dignity many years ago! (Male,50-65, mobility impairment & long-term health condition)*

> *I find the saloon car better than those London taxis because you have to bend to get into them. And also they send you a ford transit van round you know, mini bus sort of thing and I can't, I find them very hard to get in to those. But a saloon car it's easy to get in and easy to get out for me. (Male,50-65, mobility impairment & long-term health condition)*

> *London taxis are great, the ones I hate are the ones which are described as wheelchair accessible vehicles because they might be great for wheelchairs, they're horrible for people of a certain size with a dog trying to get in and out, and you're bent double and the trouble is you're meant to put the dog out first and by definition, by putting the dog out first you lean out before you step out and then everyone starts to grab you and goes 'oh my God, he's going to fall', and then you're not in control because somebody else is trying to grab you because they think you don't know what you're doing, so I don't like those (Male,50-65, visual impairment)*

One participant who had difficulty using wheelchair accessible vehicles was a regular user of taxis and had stipulated requirements to the taxi company, but still had difficulty obtaining an appropriate taxi:

> *I can't use the Hackney cabs because they're too painful and if you use a firm regularly and you're on their books, you can say "Look, can you just send saloons" they will, because I've got an account with one of them and that works quite well... it's fallen down in the last year or so, what I've been finding recently is, quite often I'm getting not the saloon cars, I'm getting the big minibuses arriving...the operators send it out as 'saloon car only' and what happens is, any driver can pick it up, but they're only supposed to pick it up if they're a saloon car, but they're just ignoring it because they haven't got any work. And then the drivers get quite abusive and what I've found is, I've had one that was so abusive to me recently that I actually reported it as a disability-hate incident and then I got one of their controllers abusing me on the phone, so I reported that as well, and since then their attitude towards me has really improved (Female, mobility impairment & long-term health condition)*

A5.3.2.3. Driver Attitude

For a number of participants, the attitude of taxi drivers was an important factor in how they characterised their experience of taxi services. A number of participants reported positive experiences with taxi drivers who had been particularly helpful:

One participant had a less positive experience and made a complaint to the council, but was satisfied on receiving a refund for her journey:

> *One driver was quite rude towards me. He just didn't want to help, didn't want to assist.*
> *And generally... And then it got taken to the council. I mean, the good thing is that I got my money back. And I was happy with that. I just wish it would have been dealt with quicker. You know, but I've just... I've realised that things take longer.*
> ***So did it take quite a long time to get it sorted?***
> *I'd say about a couple of months. (Female, 25-50, visual impairment & mental health condition)*

Two other participants in the research were guide dog users, and noted an improvement in awareness among taxi drivers of the legal requirement to carry guide dogs. However, one participant attributed her recent negative experience in a taxi to the driver's resentment for taking the guide dog:

> *Taxis have changed tremendously...they used to refuse to take you … and they try to avoid taking you, they do their utmost, but they will not, I can name the times I've been refused and again, that's, I can deal with that better than probably others so that's easy. (Male,50-65, visual impairment)*
>
> *I haven't actually used one company because they discriminated against me and my guide dog twice, one time after another…not wanting to take my dog....And what I also find now, that hasn't happened recently, but what I have found is, I don't know whether there has been some awareness training, but a lot of drivers know that they have to take a guide dog now, but if they don't want to, they'll make my journey as unpleasant as they possibly can. I've had windows open so I've been getting wet or cold, I had one driver who just kept spitting out of the window…and I just found it amazingly unpleasant and they'll take a longer route to… and I know my way round, you know, I think they're trying to put a few miles on the journey perhaps, I don't know. And I've also had quotes from an office when I've said that I've got a dog then I find that the actual cost is four or five pounds more than I've been quoted and my only assumption is that they're putting that money on because they have to take my dog. (Female, visual impairment & long-term health condition)*

For two participants, problems with taxi driver behaviour had more serious implications. One participant with mild learning disabilities had been the victim of a serious sexual assault from a taxi driver. Another participant had experienced sexual harassment from a driver:

> *I had a couple of problems with the taxis. One of them was generally based upon,.. I sat in the front and the taxi driver basically puts his hand on my knee. I reported that to the firm. And all they did was just didn't send him. (Female, 25-50, visual impairment & mental health condition)*

A5.3.2.4. Impairment-Specific Issues: Hearing impairments

One deaf participant had experienced problems accessing taxis by text, and had found the service to be unreliable:

> *Sometimes [text messaging] doesn't work and the taxi company response is that their signal is not very good 'cause the messages don't get through in time, so then the deaf person is saying is the taxi coming, isn't it coming? (Female, hearing impairment)*

A5.3.3. Private Cars

For many participants, the main mode of transport they used was their private car. This was for a variety of reasons, including many of the barriers mentioned above as well as aspects of their individual impairments or health condition. One participant found using a car suited her best due to breathing and mobility problems she faced when using public transport:

> *Because the car is my lifeline, I couldn't stand and wait for buses and even now the easy ones with off and on and all of that there's so many people that use sprays and deodorants and even do it on the bus. I was on the 1 bus and they were spraying their perfume and all that, I had to get off because I can't breathe. (Female,50-65, mobility impairment & long-term health condition)*

One participant with an anxiety condition found that having a car gave him the confidence to get out and about:

> *I have a motability car which I got on the DLA, paid for by DLA and that gets me out and about. Usually I come into town and park up New Road and have a little bit of a stroll around, what I can manage you know.*
> ***And would you find it hard to get out and about if you didn't have the mobility car?***
> *Yeah because since I had this accident I do find, was getting panic attacks and things it did affect me that way. The fact the cars there and park it up and go for a little stroll someone and sit down and know the cars there you know two minutes three minutes five minutes away and I can get to the car and get home (Male, 50-65, mobility impairment & mental health condition)*

For several participants, the car meant participants with mobility impairments could access their destination with minimal walking involved:

> *It helps me because you can do things but living in Brighton and Hove I don't use it as much especially with the price of petrol I might use it say once or twice a week if I visit antique or boot fairs. If I can go to them I can park the car up close to where I am going to see rather than parking half a mile away I am actually on the spot. (Male,50-65, mobility impairment & long-term health condition).*

> *Having a car helps I think. Before having a car it was an absolute nightmare and it made my life quite hard and I think you don't really appreciate how difficult it is until you have an easier option given to you. But before having a car it wasn't very easy, where I live there were steps, the bus journey was too long, it was just a nightmare of*

> *getting into town, going shopping. I mean I used to have to do sort of a shop and I remember afterwards, I couldn't manage the bags, I had to get a taxi driver to help… I remember like the day after doing all of that I used to just ache and I couldn't get up and down my steps and often that would mean that I miss college or university because of such a tiny episode of something that's an everyday occurrence.*
> ***So how does the driving improve that?***
> *It improves it massively. (Female, 18-25, mobility impairment & long-term health condition)*

In some cases, participants found the use of a personal car reduced their dependence on unpaid carers for support:

> *If I didn't have the car and adaptations on the car then I'd be so isolated if I couldn't get from A to B by myself, come to work. And when I came out of hospital while I didn't have the car it was driving me and my wife crackers, if I wanted to go to the bank I'd have to ask her to take me to the bank, if I wanted to go somewhere else I'd have to wait for her and ask her – so she couldn't get on with her daily housework and everything else because I would sit there waiting for her to take me somewhere. But now I've got the car it allows me to come to work, if I didn't have the car I wouldn't be able to come to work because you can't be getting a taxi everywhere. (Male,25-50, mobility impairment & long-term health condition)*
>
> *The blue badge has made my life so much easier, because you cannot park anywhere nowadays, so yeah, it has made my life easier. I can go and do what I want for myself instead of having to ask other people to go and do it and this, that and the other. (Male, 50-65, mobility impairment & mental health condition)*

Several participants had accessed adapted vehicles through the motability scheme. As with other participants, cars had given them greater independence and enable participation in employment and their local community:

> *I do depend a lot on the car to get out and about. I don't really go on buses anymore…I've got an adapted car … I've got hand controls and a steering knob thing with it so, which is fantastic. I've had that for about 18 months now. It's brilliant. (Female, 25-50, mobility impairment & long-term health condition)*
>
> ***And in terms of your motability car – how long have you had it?***
> *Two and a half years, due to go back soon. That has made such a difference that just opened up my life again. I mean at the moment I find it difficult to even get to the car so it's a bit annoying but when I was able to oh, it was wonderful – you could actually go places – it was super as I was getting worse and we were getting very housebound, that's made such a difference that really does just to be able to get in and go. (Female, 25-50, mobility impairment)*

For two of the participants who were wheelchair users and had problems using buses and taxis, an adapted private vehicle was a more suitable mode of transport. However a challenge for these participants as non-drivers was finding someone to drive the car:

> *My regular carer drives and we go all over the place. It is great... I have a Motability vehicle but I am often with carers who can't drive. (Female,25-50, mobility impairment and cognitive impairment)*

> *I think people like myself would probably have the transport, I certainly had an adapted car, I just needed a driver. So that's just the sort of thing, it doesn't relate to me now, but it stopped me looking for work. (Female,50-65, mobility impairment)*

An important factor in making the car a suitable mode of transport was the availability of disabled parking badges which allows participants to park near to their destination. Most participants in the research held a blue badge which made parking easier:

> *I'm thankfully able to now have a badge so that has helped hugely in terms of attending hospitals, especially around here, I mean the parking is awful as it is and the hills are terrible so, you know, thankfully having that has had massive improvement, sort of on my quality of life and getting to places really. (Female, 18-25, mobility impairment & long-term health condition)*

> *Having a blue badge, that makes such a difference because then you can literally get so close to things that again it's not a struggle (Female, 25-50, mobility impairment)*

> *I can park easily because of the disabled parking badge. If I didn't have that I couldn't cope, I just couldn't cope. (Female,50-65, mobility impairment & long-term health condition)*

The process of obtaining disabled parking badges was generally seen to be straightforward by most participants:

> *Getting the blue badge wasn't a problem, fill in a form, tell them what's wrong with you, they give you a blue badge. I think I got that before I got the disability allowance. So there was no problem there (Male, 50-65, mobility impairment & mental health condition)*

Lack of disabled parking, however, was a key barrier reported by participants using a car to get around the city, which in some cases led participants to travel elsewhere to access facilities:

> *We don't go shopping very much in central Brighton 'cause there aren't any disabled parking bays available except for Churchill Square. And they're normally always full. So you tend to go to Hove a lot or Worthing because there's better facilities there in terms of parking. (Male, 50-65, mobility impairment & long-term health condition)*

One participant chose instead to use a combination of car and bus to get around the city, in order to avoid the difficulty finding disabled parking

> *I drive to the nearest bus stop to my house because there is a distance between my house and bus stop. I drive to the nearest bus stop. I park near the bus stop and then I use buses to town or other places. And then I do shopping and then go back to bus stop and then take my car. (Male, 25-50, mobility impairment)*

Parking was a particular problem for one of the few participants without a disabled parking badge:

> *Parking is a nightmare 'cos I don't, I've never tried but I don't think I'd qualify for a Blue Badge and although it would be convenient I don't really want to go down that road at the moment. But yeah getting into Brighton is a bit of a pain. So we don't go in very often really. Parking is expensive anyway isn't it? Incredibly expensive. But I get around to other places and that. Go to Worthing and East Crawley if I am forced to go shopping that's where we go. (Male,50-65, long-term health condition)*

Several participants who used disabled parking badges yet nevertheless experienced problems with parking, felt that disabled parking spaces were often abused by non-disabled people, either without a disabled parking badge or with a badge that did not belong to them:

> *A lot of people have cars but the point is, I just feel that there's some people without disabled badges that are parking in disabled bays. (Female, 25-50, visual impairment & mental health condition)*
>
> *At Withdean stadium the one big problem was parking, was a big issue, you clearly had blokes who had borrowed their mum's disabled badge, the amount of blokes that parked their car then ran off into the crowd you knew they just weren't, and none of these stewards checked badges so there was never enough parking. (Male,25-50, mobility impairment & long-term health condition)*
>
> *It was lots easier back a few years ago in terms of parking space, in terms of visiting shops or shopping centre. Now you don't dare to go to shopping centre, because there is no parking space. I mean there are some designated areas you know for disabled parking, but all taken, or not all, most of them taken by people using blue badges that do not belong to them. Is either their friends or something you know. I did notice on several occasions that lots of these drivers, they were very, very healthy and they could walk you know, more than fifty yards no problem, and then I had to wait sometimes for about 10-20 minutes to find a space. Yeah, and this problem is very visible now, you know in Asda car park in Hollingbury and especially in the Marina. (Male, 25-50, mobility impairment)*
>
> *If you're in the centre of town it's really hard to find [disabled parking spaces] empty it really is and that really, really winds me up when you see people that you know that's not their badge and they are using it. That really winds me up. (Female, 25-50, mobility impairment)*
>
> *I do have a problem with big shops and people who aren't disabled using the bays. Now I know that they're now monitoring them in some shops, but I think that still is a bit of an issue in general terms. I mean, if I go into Brighton … I just think there's a big issue about non-disabled people using disabled parking bays… I just see them getting out of their cars and they don't have a thing, and I think 'Why are you doing this?' (Female,50-65, mobility impairment & long-term health condition)*

One participant recounted a case of institutional disabled parking badge abuse by a local care agency

> *There’s my personal assistant who applied for the job about two months ago she asked me whether a blue badge comes with the job? And I was like, ‘nah’ and she went, ‘well can you tell me how to apply for a blue badge?’ And I was like, ‘why do you want a blue badge?’ and she went, ‘because it’s a nightmare parking outside the home where I work on a night and outside my house.’ And I was like, ‘nah, nah, you cannit apply for one’ and she went, ‘because the residential home where I’ve worked for the last three years’ she does nightshift every now and again, the home owner issued the staff with the blue badge, each. So she was obviously using the clients entitlement to DLA to apply for a badge for the carers who worked at the home so she didn’t have to pay the parking fees where the home was. And a little bit of an incentive so they could use the blue badge you know, so it was like aye well no wonder there’s no disabled parking about if all the care staff in the residential homes have got the blue badge! (Male, 25-50, mobility impairment)*

However the perception of abuse was itself identified as a problem for participants with mobility impairments which were less evident, who had experienced verbal abuse from members of the public where they were perceived to be abusing their disabled badge

> *I was once parked on the London Road in a disabled bay, and I was getting out of my car and I wasn’t using my stick because the shop I was going to was literally less than 10 yards and I was walking out the car, and some guy turned round to me and said ‘Oh, so you’ve got a blue badge then have you?’, meaning that I wasn’t disabled … because he shouted it as an insult, and I was really shocked. I realised that the reason that he was saying that was because I had no physical sign of being disabled (Female,50-65, mobility impairment & long-term health condition)*

In some cases, participants attributed parking problems to inadequate provision of disabled spaces:

> *They are absolutely crap on disabled bays in Brighton. There’s not enough. This road has got one and it’s right up the other end by the lights, that’s it. If I go out in the evening, I’ve got one hell of a nightmare getting parked back cause there’s not much spaces. (Male, 25-50, mobility impairment, long-term health condition & mental health condition)*
>
> *We tend to rely on the car which we did buy outright a few years back. But it’s finding somewhere suitable to park is the big problem because where there were disabled bays, they’ve now turned into loading bays and skips and bus stops. (Male, 50-65, mobility impairment & long-term health condition)*
>
> ***Do you find it easy enough to park in the city then?***
> *Not really, no, it’s a bit of a nightmare, but after a while, like you get to know where the places are. So there are places where I go regularly, like venues I go regularly or shops I go regularly, and I’ve learned where the parking spaces are near them…what frustrates me is that there aren’t actually many disabled parking spaces, I just don’t think there are enough, and they’re not really near the places I want to go to…I mean, I don’t know if you know The Dome? I do go to that area quite regularly, and there’s three disabled spaces right outside. They are never, ever empty. Ever…I mean, a review of where the bays are and where people need them would be great. (Female,50-65, mobility impairment & long-term health condition)*

One participant experienced a particular difficulty finding disabled spaces of adequate size for his large adapted vehicle:

> *Having a van, I sometimes find it difficult getting the van in disabled parking bays, you know if it's, because I need to open the back doors to get out so it's kind of like you need quite a length and it's like a lot of disabled parking bays cannit accommodate the van basically. (Male, 25-50, mobility impairment)*

Conversely, several participants who used disabled parking badges did not consider parking to be a major barrier to getting out and about. These participants parked in a combination of disabled parking bays, pay-and-display bays and double yellow lines, and found provision to be adequate:

> *It's quite good, because you can also use the park and pay ones er, so if you can find one of those you can park there. (Male, 50-65, mobility impairment & mental health condition)*
>
> *If I go to the supermarket or in to town or anything. You can park near enough right next to where you want to go. Without a blue badge bay of course you can park on the yellow lines. You know, which is so much easier. (Male, 25-50, mobility impairment, long-term health condition & mental health condition)*

A5.3.4. Walking/Scooting

Many participants travelled around the city in wheelchairs and scooters. For these participants, key barriers to getting around the city related to the quality of streets and pavements. In particular, participants identified problems with dropped curbs throughout the city. In most cases the main problem was seen to be the gradient of many dropped curbs:

> *The main difficulties I find are these dropped kerbs…actually there's one right at the end of your road up there. Montague Place and Edward Street. On that corner…'cause when I go to the hospital, it's got a dropped kerb but then it goes down and up steeply. Really and my wheels spin 'cause they can't get a grip. And there's lots of those around Brighton… If you stick to the main route like down to the seafront or up to Western Road they're all lovely and flat. But if you go anywhere outside the centre they're a bit difficult (Male, 50-65, mobility impairment & long term health condition)*

In addition, dropped curbs were found to be inconsistent in many areas, with a drop on one side of the road and not the other:

> *There are places you get stopped where there's a ramp going up, when you get to the other end of the street there isn't one going down so you've got to turn around and go all the way back again. (Male,50-65, mobility impairment, long-term health condition & mental health condition)*

The consequences of insufficient drop curbs was for some participants an inconvenience in travelling round the city. For others, the combination of dropped curbs and cracked and broken streets could cause participants considerable pain when travelling around the city, often preventing them from going out:

> *Some of the kerbs, you know, they're just ridiculous, bumps, pavements are all uneven. So the time you went, I have to take painkillers before … terrible where they've got trees on the pavements and the roots have gone underneath, so when you go over on a scooter you've got to take the hill and then go down like that, you know. That kind of thing is worse and especially when people leave their bins out there at the same time, you've either to get out and, off and move the bins yourself, which I wouldn't do because I wouldn't want to be hurt myself, or I have to go onto the road. (Male,50-65, mobility impairment)*

For one participant, the lack of dropped curbs was compounded by streets in her local area which had been broken due to the placement of trees on the street:

> *I'd like a dropped curb outside the flat so I can get to the shop over the road, at the moment it takes me seven minutes…I have to go out of here down to the crossing cross over there and then come all the way back…It's stupid. But they could put a drop curb this side a drop curb that side and I could get over there and back in a minute. And also the pavements are also all rickety and uneven and they're cracked and they've got roots sticking out from the trees and I'm going along bump bump bump bump and my back is killing me. (Female, 25-50, mobility impairment, long-term health condition & mental health condition)*

For another participant, dropped curbs were a risk to his safety and he spoke of an incident which could have been far more serious:

> *I had an accident just up the road. I was out looking at drop curbs and I went up this, this drop curb and there was a funny camber on it and it skewed the chair off and down on to the road, throwing me out and uh, a couple of passer bys helped me back into it just as a bus came round the corner. If we'd have been seconds later you know, it would have been a lot more serious. (Male,50-65, mobility impairment, long-term health condition & mental health condition)*

Several participants however noted that some newer dropped curbs were often of good quality, particularly in newly renovated areas of the city:

> *A lot of drop down curbs in Brighton are excellent. (Male, 50-65, mobility impairment & mental health condition)*
>
> *Where they're good, they're good. The new one it um, the junction off Church Road and Jubilee Road, New Road, brilliant, absolutely brilliant (Male,50-65, mobility impairment, long-term health condition & mental health condition)*

One participant who had approached the council about the issue reported that he had been told there were inadequate funds for dropped curbs, but felt investment was urgently needed, in consultation with disabled people:

> *The Council…they say they haven't got any money, but I know it's a different pot. The government puts all this funding for cycle lanes to give cyclists safe journey across the city. That's a lifestyle choice. This isn't. We ought to have some of that pot to make sure we've got good quality dropped curbs… And any new ones and any that are in very bad repair should have input from a disabled person. I mean, which won't cost anything cause we'd do it for nothing, you know. (Male,50-65, mobility impairment, long-term health condition & mental health condition)*

In contrast, one participant reported receiving a very positive response to his request to the council for more dropped curbs:

> *When I got the wheel chair a lot of Southern Road hadn't got dropped curbs and I phoned up….knowing that the budget probably had been all accounted for and spent. But, within a couple of weeks, well less than a couple of weeks they were doing them, and I know they do it in conjunction with BT and whoever's doing works anyway, but they've done… all the side I live on has drop down curbs. (Male, 50-65, mobility impairment & mental health condition)*

Experiences of problems with broken streets were not restricted to wheelchair and scooter users. One participant with a visual impairment reported a fall in the street due to this issue:

> *I feel unsafe, say like if I'm going down the road, because I have fallen in the street. Not because of me not using the cane properly, more because of the, the kerbs. There's lots of cracks. And at one stage I have actually snapped my cane. (Female, 25-50, visual impairment & mental health condition)*

In addition to problems with dropped curbs and broken streets, some participants also experienced problems accessing certain areas of the city due to the age and design of buildings. This theme also emerged as a key barrier to community participation earlier in this report.

> ***Getting around the city – what's that like?***
> *Not too bad, round the Lanes it's pretty tough just because it's so old down there. Churchill square's easy because it's so smooth and flat, it's no problem. But the Lanes, the doors are very narrow; they're not going to be widened just because buildings are so old. (Male,25-50, mobility impairment & long-term health condition)*

A5.3.4.1. Street furniture

Another barrier identified to getting around the city with a scooter or wheelchair was street furniture, such as advertising boards, rubbish bins and various street posts. In some cases this was made worse where bikes were changed to street furniture and blocked the pavement:

> *I went up North Lanes once with somebody and there was just you know, A-boards, tables, chairs and other people in scooters coming towards you, prams coming towards you. So I got on the first junction and turned left. And then, there is I can't remember the street you know where Infinity Foods is, there is a corner just by there, I*

> *went as far as there once and I was stuck… and somebody had parked a bike on the post on a corner so this thing went half off the pavement. (Male,50-65, mobility impairment, mental health condition & long-term health condition)*

Often limited space on streets was made worse by a combination of street furniture and other vehicles:

> *Going along Eastern Road to the hospital is not always easy because sometimes they put one of the black communal bins right over a ramp. Yesterday a big lorry was parked over a ramp down in Ship Street (Male,50-65, mobility impairment, long-term health condition & mental health condition)*

One participant who was a regular scooter user found this to be a particular problem but felt that the situation had improved to some extent more recently:

> *The worst thing is people sticking signs out in the middle of the bloody pavement for a shop and I'm always having a go at the Council about this, and even I go and move the signs myself, move them out of the way, and then they come out and I'll say, "Well, excuse me but this is a pavement, that's your area, this is our area, shouldn't be on there," you know. So we've had a good thing on that and they tightened up on that quite a deal. (Male,50-65, mobility impairment)*

The issue of street furniture was again a problem for participants with visual impairments. One participant who used a guide dog was often required to walk on the road against traffic due to street obstacles. This participant was also particularly critical of the shared street system in new Road:

> *You get New Road which is just the most bonkers idea out, you're walking down the middle and a taxi comes at you or and one comes from behind at the same time… the other things which are bugbears are all the A-boards on the pavements, we've got such narrow pavements and particularly around Ship Street you get the cars about always parking on the pavements, people always think if there's room for them to get through therefore anyone can get through… but when you're walking with a guide dog, the guide dog works on the width of the two of you, they will not say 'oh look it's a bit narrow, we can squeeze through', and therefore you have to go out on the road, you know, unnecessary danger every time... (Male,50-65, visual impairment)*

A5.3.4.2. Crowds

A key barrier for some participants walking around central Brighton was simply the large crowds in areas such as Churchill square and Western Road. This could be a problem for participants with mobility difficulties, and also for participants with visual impairments.

> *There's one area I do not go because I hate it up there, that's Western Road, Churchill Square. It is a nightmare, but when we're always up that end I just hate it because they just barge past you, see you struggling and people just barge into you, and it's many a times we've been up there and I've kind of had to move out the way because*

> *someone's barged into me, nearly had me over. I just detest the area, hate it up there. (Male, 25-50, mobility impairment & long-term health condition)*

Two participants felt that this problem was compounded by a lack of awareness among the general public of people with visual impairments using white canes:

> *You're walking down the street and although I've got the white cane people just still walk into you. That's what I don't like. But, I guess, because it's a city, you're going to get that. (Female, 25-50, visual impairment & mental health condition)*
>
> *Walking round town is not a problem but the people down there don't move out of the way or anything like that …I don't think you guys know what a white stick is down there…it seems to be alien to most people in Brighton. So people make it difficult to get about. (Male, 18-25, visual impairment & mental health condition)*

A5.3.4.3. Crossing roads

One participant with a visual impairment who used a guide dog felt some areas lacked accessible crossing points. Although this participant spoke favourably of crossing points with vibrating spindles, he found this provision to be invalidated by poor maintenance and insufficient consideration of visual impaired users when designing new streets:

> *Crossings, they're wonderful but you know, all the crossings where you rely on the spindles to turn… they are very poorly maintained and the other factor is they've got a lot better in Brighton, I have to say, but there are still problem areas. The junction with Hove Street, there's nothing to help you cross the road there, there's a green man but there's no spindle, the reason, 'ah well that junction has a filter on it, therefore it wouldn't be safe to give you a spindle', and yet, I know every seventh time the lights change it's safe to go. So why can't a spindle do the same?... the one which I can't do any longer is the top of Grand Avenue and The Drive, because they reconstructed it, I have no idea, it was a nightmare to cross anyway, but at least I knew that if the cars were turning right I could walk across because it was still, it was safe, now they've changed the whole layout and the spindles don't work there…and the other thing they did is build that diabolical cycle lane where you step off the pavement and then you've got step up again... I wish these planners actually had to walk with a guide, or work with a guide dog, or any other form of disability. (Male,50-65, visual impairment)*

A5.3.5. Trains

Several participants were regular users of train services to travel to locations outside of the city, and many spoke positively about assistance they received from platform staff:

> ***Are the trains accessible?***
> *Yes, they're very caring, and I always think that everyone else has to stand, but I can sit, I always have my place**…** very good. I've been out to Chichester and Eastbourne,*

> *just things I can do as a sort of retired and active in my mind person (Female,50-65, mobility impairment)*

> *Trains, they're quite good...I've been all over the country. For the most part they're fine, the underground they can be very helpful... it's usually finding the right platforms, I usually ask for assistance to get on, I don't need it to get off (Male,50-65, visual impairment)*

Some participants had experience of using assisted travel schemes. One participant found this scheme to be particularly helpful when he was travelling long distances with luggage:

> *I happened to ring Great Western and I said I want to make a journey. And she said no problem. She worked it all out. Someone at Brighton station, takes your luggage, puts the ramp down, makes sure you're on, in the right place, puts your luggage away, phones through you're on the train, where you are, when you get to the other end there's somebody there with the ramp to get you off and it's brilliant and its free and they plan the journey for you. (Male,50-65, mobility impairment, long-term health condition & mental health condition)*

Another participant, however, reported platform staff were not notified of a request for assistance when booking travel through the one-stop travel shop in central Brighton:

> *The trains. Yeah we keep getting—because sometimes we go up and see family and we keep booking assistants and they keep saying oh you haven't booked an assistant. … we go to One stop travel down the Steine to book the tickets and ask for assistance for wheelchair user etc etc. They put it on the computer screen and then when we get to the station its like ohhh…it's not on our list and they can't help. (Female, 25-50, mobility impairment, long-term health condition & mental health condition)*

One participant who regularly used the assisted travel service found that occasionally platform staff did not provide assistance to get off the train as requested:

> *Brighton, most of the time, they do get it right, but on the odd occasion, they do get it wrong, but I find that this problem of either forgetting to take you off, is a really bad nightmare, especially if you've got to be somewhere by one o'clock or whatever. (Male, mobility impairment & long-term health condition)*

This participant also recounted a negative experience travelling to Birmingham and back, where scheduled assistance to assist with disembarking the train did not happen, leaving him stranded on the train until it reached the end of the line. The return journey was also problematic as he did not receive appropriate assistance when his journey was rerouted

> *I'm a regular traveller up to Birmingham and my last journey was all hell let loose. And, unfortunately, one of the boxes blew up or something, so we were late, but I was supposed to get off at Clapham Junction and they forgot to take me off, so I ended up having to go up to Victoria and then coming back round that way. And when I mentioned it to one of the guys when I got back to Clapham Junction, he said "Yeah,*

> *we're always having problems with them from Brighton" it seems a constant problem and it's a frightening experience.*
> ***And in that situation, had you booked the assisted travel?***
> *Yeah, everything's been booked and everything, because I always book long journeys, because, obviously, with changing over trains, and the other thing was that on the way back, I had to get off at Milton Keynes. The manager wouldn't allow me to get a taxi… anyway, they managed to get me on another train and ended up at… what was it… Euston, and I was completely lost because I don't know London at all, hardly well. And I had to get somebody to take me to a bus stop where I could catch the bus back to Victoria (Male, mobility impairment & hearing impairment)*

For one participant, a key issue with accessing assistance on the train to avoid being stranded was the fact that alarm systems for calling assistance had been deactivated:

> *You have to press the alarm on the train, that's the only way to get attention. And one of the problems there is the alarm in the disabled area, which is there at a low height so people in wheelchairs can reach it, is always locked, the only person that can unlock it is the guard and the guards don't unlock them because they make out… whenever you question them about it, they say "Oh, kids always mess about with it." (Female, mobility impairment & long-term health condition)*

A difficulty for one participant using the train was the cost of train travel which he found to be excessive. For another participant, the concessionary rail card allowed him to use the trains more frequently:

> *Trains are pretty rubbish to go anywhere, expense wise anyway. Luckily I don't need to travel on trains anymore for work, so you can find off peak rates. (Male,50-65, long-term health condition)*

> *The trains are alright, they're not too bad at the moment because I've got my Railcard as well which is handy. My Railcard cost me fifty four quid for three years. And it gives a minimum of a third off each ticket. For carers as well... we get a lot of use, saves us both a fortune... we used to go to Worthing and that by bus but since my Railcard it works out cheaper for him as well, so we use the trains a lot more. (Male, 25-50, mobility impairment & long-term health condition)*

A6 Appendix 6: Employment & Volunteering

A6.1. What is Employment & Volunteering?

This section of the report examines participants' experiences of employment and volunteering. For these services, the research examined participants current working status, whether employed or unemployed, actively seeking work or not. It also explored participants' experiences of looking for work, including barriers participants faced to employment and opportunities that were available to overcome these barriers, and for those participants in work, their experiences in the workplace including attitudes and adjustments made by employers. The research team was interested in hearing about both good and bad practice from employers.

A6.2. Approaching the Topic

During the interviews the research team began by asking general questions about what participants got up to in a typical week and how they occupied their time. Many participants mentioned employment and volunteering activities at this point in the interview. The research team followed up this information with probing questions regarding how participants had accessed work and volunteering and their experiences.

The proscribed questions in the interview guide did not include questions on employment and volunteering, as a later event was planned which was later dropped from the research proposal. However considerable information was nevertheless gathered which is included in this section of the report.

A 45 minute focus group was held specifically for participants with mental health conditions on employment and volunteering issues.

A6.3. Detailed analysis

A6.3.1. Working Status of research participants

One point to note when characterising the participants in this study is that they are not necessarily representative of disabled people in the general population. More information on the selection of participants is available in the Methodology chapter of this report.

Participants who were employed fell into two main groups. Firstly, there were those participants working very low hours (less than 4 hours per week) on a part-time basis. Secondly, there were those participants working full-time or part-time more than 16 hours per week. These participants tended to have had impairments for a substantial part of their lives and were able to manage their conditions adequately while working. Impairments of employed participants included long-term health conditions such as severe asthma, mobility and visual impairments, cognitive impairments such as dyslexia and Asperger's, and mental health conditions which were managed with medication.

Participants who identified as unemployed but looking for work also tended to be those with long-term impairments which they had had for most of their lives. Two participants in this group had given up previous work due to sickness during periods of depression but were currently managing their impairments with medication and sought employment in the future.

Participants who were unemployed due to incapacity fell into several groups. The largest group was those participants with impairments which caused pain and fatigue, and those which were fluctuating on a day-to-day basis. These participants felt that the unpredictable and impairing nature of symptoms prevented them from being able to keep regular commitments to work. Another group of participants had moderate to severe learning disabilities and although two were volunteering, none were seeking paid employment. A third group of participants who were unemployed due to incapacity were those with multiple health conditions where a large proportion of their time was spent managing their symptoms. Only two participants identifying as unemployed due to incapacity felt that some work could be sustained (e.g. by working at home or with more support starting work).

Several participants who had pain, fatigue or fluctuating conditions participated in volunteering work, but these tended to involve less than 5 hours per week, or longer hours on an ad hoc basis or from home when the participant felt well enough. One participant with multiple impairments which did not cause fatigue or chronic pain had been signed off work indefinitely but was currently taking part in extensive volunteering work.

Another group of participants who were not currently working were those who had taken early retirement. Participants in this group tended to be those who had developed mobility impairments or chronic pain later in life.

The majority of participants we spoke to had held some form of full-time employment at some point in their lives. The exceptions to this were participants who had moderate or severe learning disabilities and one participant who had multiple, fluctuating health conditions all her life.

A6.3.2. Significance of work/volunteering

Most participants saw employment as an ideal to which they aspired if they felt capable to work. In terms of volunteering, many participants noted specifically the benefits that it could bring.

For some participants, the benefit of volunteering was in helping the participant to cope with their impairment or health condition:

> *I do the volunteering here to keep me out the house because it wouldn't work with me and my wife everyday, morning, noon and night together and it'll drive me crackers and that's not me anyway, I just couldn't… it takes your mind off what you're going through. If you didn't do it you'd probably spend most of the time just moping around the house, so this does take your mind off things (Male,25-50, mobility impairment & long-term health condition)*

For participants with mental health conditions, volunteering was seen as a key source of indirect support which in some cases enabled them to avoid periods of depression:

> *For several years I was doing voluntary work and that's fantastic because that's like you're getting support but it's by the way, do you know what I mean? It's not, "Right I'm going here for support." You don't necessarily notice the support you're getting on a daily basis but you sometimes look back and think, "Oh well that was good," you know. That's wonderful, again I'm still in contact with a lot of those people as well, which is really good. And again, it gave me structure for my week as well, I knew where I was expected to be at a certain time, I felt like I was actually doing something. (Male, mental health condition)*

For other participants, volunteering was a key source of social activity which helped to avoid feelings of social isolation. As noted in the section on community participation this was a concern for several participants:

> *I volunteer at a shop in Brighton Just usual things, tidying the clothes, make sure good clothes, bad clothes in a basket… I enjoy it because I know a lot of people there (Female, 18-25, mobility impairment)*
>
> *I want to try and do two or three days a week voluntary work somewhere, because at the moment I know I go down town on the bus and we go for days out by train and that, but I get a bit bored sitting in front of these four walls and the telly all day. ... kind of working in one of the charity shops or anything to kind of get me out just to relieve the boredom (Male, 25-50, mobility impairment & long-term health condition)*

Another benefit the participants attributed to volunteering work was in providing them with future employment opportunities. One participant with a long-term health condition reported being employed in a full-time capacity following a successful volunteering placement:

> ***How hard have you found it to find work and does your health present any challenges to that?***

> *I've been quite fortunate I think, I've put myself out there and not let my condition determine what I'm going to do which has been helpful so I think I've always been fortunate, I've volunteered in the community which led to job opportunities through people that knew me and my capabilities (Female, 18-25, mobility impairment & long-term health condition)*

Similarly, one participant reported securing regular part-time work as a music group facilitator following an initial period of volunteering work:

> *I do a music group for learning difficulties which I get paid for … I volunteered for a little while and then I said I wasn't going to do a music group unless they paid me to do it (Female, 25-50, mobility impairment, long-term health condition & mental health condition)*

Another participant similarly started in a student role with another organization which subsequently led to full-time employment:

> *When I finished my training with Guide Dogs they weren't able to place me in a job, so I went and found one for myself, and I've been there since 2000 as a student, and then as a paid employee (Male, 25-50, visual impairment & mental health condition)*

For one participant, volunteering was important not for any direct employment opportunities provided, but rather in enabling them to prepare for re-entry into the workplace as their health condition improved:

> *At the moment I'm trying to rehabilitate myself back into a normal sort of routine really, so I try to sort of replicate a sort of working life, even though I'm not working, so that if I ever get well enough to work I'm in that mode. So I get up and start my work if you like and carry on until five, and then, like a working person, I say 'Right, this is my time now' (Female,50-65, mobility impairment & long-term health condition)*

Participants also saw volunteering as important in itself for supporting the community and fellow inhabitants of the city:

> *I like helping other people, always have, and haven't been able to do much good in the last year with other things so it's nice having this again. (Male,25-50, mental health condition)*

A6.3.3. Barriers to employment and volunteering

The majority of participants wanted to work where they felt capable of doing so. However, a number of barriers were identified to participating in work.

A6.3.3.1. Impairments/Health Conditions

While not a “barrier” in the social model of disability sense, many participants who identified as unemployed due to incapacity, felt they were unable to work as a result of impairments and health conditions that caused pain, fatigue or fluctuating symptoms. Most participants in this group had felt unable to continue in existing employment due to the symptoms:

> *I took some time off work and one month led to two months – two months led to about six months where I was just continually having physiotherapy – on lots of pain killers – had acupuncture, all things relating to pain and treatment and then six months led to nine months and the Civil Service, my employer, decided that it wouldn’t be a good idea for me to go back to work full time as I would be taking so much time off work due to the pain and the work that I was doing would just exacerbate the condition I was under, really. So I took what was called Early Retirement in my early forties in the job. (Male, 50-65, mobility impairment)*

> *The neuropathy, the arthritis, the chronic fatigue and the MS affect me day to day. I mean you’re probably aware of the…the brain fog syndrome…I wake up in a daze and it takes me a long while to get going in the morning. And during that time I bump into things. I slur my words. I can hardly move. When I do get going, I can’t really grip anything ‘cause I’m always dropping it. And the thing that does affect me as well is the fatigue. I’ll have like a couple of hours of mobility to do something then I have to lay for a couple of hours. As I call it, flat battery syndrome. I do try to do as much as I can with that…But it does limit…the amount of work I can do. So at the moment I’ve retired from work… I was aware that there’s no way I could carry on working. (Male, 50-65, mobility impairment & long-term health condition)*

> *The wheelchair can cause problems for me because when I went into the wheelchair I lost all of my confidence. And I really haven’t got it back yet. But the worst part of my condition is actually the fatigue. Because I can’t go through a single day without having to sleep, usually in the afternoon…I had to give up work and I desperately miss that, I really do. (Male, 50-65, mobility impairment & long term health condition)*

> *I like doing work but because of the illness I have…my fibromyalgia when its wet cold and raining my body stiffens up and I can’t go out because I’m in too much pain (Female, 25-50, mobility impairment, long-term health condition & mental health condition)*

Participants felt that even if they felt capable of working, employers would not want to employ them due to the limitations that their health condition placed on their life:

> *So ok you find me an employer who will take me on for 2 hours a day before I have to lie down. Now you find me someone who when I have one of my bad heads, I’m off for 5 days – I’m out of it, forget it. You find me somebody who’s going to be ok if I have to take pain killers and then sit there goggly-eyed – I really would love to go back to work … I would love to do a couple of hours a day just to get out, back with people again but it’s so unrealistic. (Female, 25-50, mobility impairment)*

One participant who was concerned about recent reviews to Employment and Support Allowance felt that she simply would not be able to function effectively if forced back to work:

> *I would love to go back to work, in some way, because you know what, I'm good at it, but everything I do makes me poorly and some days I can't do the basics, so how is there going to be the capacity …four or five nights a week I go to bed at, between four and seven pm and I'm never not in bed for more than twelve to fourteen hours a night and then I rest in the day, and I try not to, and the pain just reaches a level, and then the only thing that's going to happen is I'm going to have to take more medication to kind of calm down the pain, 'cos everything flares up and so I'll just be whizzing around with side effects… I'll be bloody awful when I've got to go work then wouldn't I… I mean my weeks are dominated by sort of symptom management and I haven't been able to sustain any regular commitments (Female,25-50, mobility impairment & mental health condition)*

One participant who had become self-employed to work around his impairments found even this could not be sustained with his worsening health condition:

> *I started a small firm… but after three or four months in the business I was really ill, couldn't get out of bed, and my whole back locked up solid, and that went down the tubes, and it cost me an awful lot of money. Ended up with me going bankrupt actually... I thought I could go out and work three days a week, four days a week, make my own time, make my own appointments, work around my illness, but I still can't, because I'm bad every day, so I can't do it now. (Male, 50-65, mobility impairment & mental health condition)*

Some participants with mental health conditions had also found it difficult to sustain work due to repeated periods of depression and the consequent need to take extended sick leave:

> *I'm sort of classified as rapid cycling so I have three or four events of depression a year…I was, well I still am a teacher but in effect ….it was not compatible with my profession basically. In a sense I've been paid off by colleges and in effect I've been made redundant really… My last period of employment I had it was tutoring which I thought might you know, have less of an impact if I get ill. But the problem with me is if I'm ill then that tutoring is discontinued so that wasn't good either. I enjoyed it but I did it but then I had a bout of depression so I was out of it for about two months…Cause it was a new term they basically finished the contract so that was me out of work again. (Male, 25-50, mental health condition*
>
> *Bipolar itself has meant that I've had to give up work. And I've had about 3 breakdowns in the last 5 or 6 years and I find the more I have them the more anxious I become after. I don't really get back to what I was before. I'm alright as long as things are going quite well, but I get really stressed over things, little things in family, a big bill. (Female,50-65, mental health condition)*

A6.3.3.2. Benefits disincentive

Two participants felt that the benefit system could in some cases be a barrier to work. However in both cases participants still wanted to access work. One participant felt that any attempts she made to test her capacity for work by volunteering could be used against her in future benefits reviews, even if it worsened her condition:

> *I was thinking yesterday, I was thinking 'God, how much I'd really, really like to get back to work', and I was feeling frightened of doing more voluntary work because…I know that I'm going to be assessed for ESA, I know that if I say I'm going to do voluntary work they're going to sort of strike me off, and put me back onto Jobseeker's. Also I know that the information they collect could affect my Disability Living Allowance…I'm kind of afraid of doing more voluntary work in case it looks like I'm better than I am. …the whole system actually puts in lots of disincentives, and my primary aim is to get well and get back to work, but I'm fearful of that. I mean I've heard stories of people who've actually started doing part-time work and then because they're doing it it's assumed they're better…even though I could lose benefits I'd still prefer to work, you know, but the problem for me is working could make me sicker, so there's that kind of balance to get (Female,50-65, mobility impairment & long-term health condition)*

Another participant who had recently started a job and was supporting a family found that she was not financially better off, however still felt other benefits from employment outweighed any lost income:

> *The benefit calculation, which they keep portraying is a better off calculation, (a) isn't a better off calculation and shouldn't be put out as such because how it works out that you're better off, by the time you actually take away what you lose from stepping off benefits, like your travel to work, your children's school meals etc., you're actually financially not better off, and also they should be portraying it as in not just financially better off, there's other things that you're better off from returning to work. So it was a big, huge shock to me, it's kind of 'Oh you'll be so much better off', actually no, I'm not financially better off, I'm worse off, and luckily it's a really good job that I really enjoy (Female, mobility impairment & mental health condition)*

A6.3.3.3. Lack of support/awareness

For one participant with a mobility impairment, a barrier to engaging in employment or volunteering was her own lack of awareness of adjustments that could be made and the reluctance to ask for support from a potential employer:

> *I'm retired, I did actually apply at my local surgery [for work], they are digitising their medical records, they do need people and they do take people on, but I do think the problem is, being in a wheelchair I can't use the specific rooms they use, they need to adapt a room so I can actually use the computer and so it's all tricky… mostly they are setup with monitor screens which I can't really get close enough to, a typical workplace. That kind of adaptation I can't expect them to do that just for me, for a part-time job. (Female,50-65, mobility impairment)*

A6.3.3.4. Lack of suitable jobs

For some participants with mobility impairments which were quite static, it was felt that the main barrier to work was the lack of jobs which did not require physical work. Two such participants perceived this - both came from an ethnic minority background:

> *I had some offer but I couldn't do the jobs - like serving, selling, door to door selling and you have to work 8 hour, 10 hour. I am just looking for a part time office job - it doesn't matter which, if I can sit down at the computer. (Female, 18-25, mobility impairment)*

> *I cannot do heavy job, I cannot do a job which requires running or walking or standing. It should be sitting position. (Male, 25-50, mobility impairment)*

For some participants, the main barrier to employment was a lack of jobs available

> *I worked as self employed but this is not working well because I work every three months or so as a pianist. (Male, 50-65, visual impairment)*

One participant had also experienced difficulty finding a volunteering position, which was appropriate for her access and communication needs:

> *I can’t do any volunteering. I have tried several charities but none of them could give me something to do (Female,25-50, mobility impairment and cognitive impairment)*

For one participant, the poor economic climate was felt to restrict his choices, and perceived barriers to employment meant he saw no option other than to accept a demotion.

> *I nearly lost my job two years ago and I probably, with losing a seniorship, probably, if I hadn’t been vision impaired, I would have gone ‘Oh stuff this, I’ll go and find a new job somewhere else, I’ve been here for nine years’, but I have a mortgage and I kind of felt like I, shall we say, cheapened myself a little bit and said I was just going to stay here and I’ll deal with the lower wage, just because I’ve got a job. So it is quite frightening to think that the opportunities maybe missed for people to work because of cutbacks. (Male, 25-50, visual impairment & mental health condition)*

A6.3.4. Support needed to help people work

Participants who were in work or felt capable of engaging in some form of employment or volunteering were asked what kind of support enables or would enable them to work or volunteer.

A6.3.4.1. Support to find employment

One theme to emerge from the research was the importance of appropriate support to find employment, and the barrier that the lack of such support could create. One participant with a mobility impairment felt that appropriate support had not been forthcoming when he contacted the job centre. This participant came from a BME background and previously in the interview had identified a language barrier when communicating over the phone:

> ***And have you ever been seen by someone at the Job Centre?***
> *Yes there used to be a woman in the job centre. She was dealing with the disabled enquiries. I did have a few meetings with her maybe four years ago, five years ago? But I think, that position is I don't know, dissolved…And every time I phone them and say I want to talk to discuss my needs they give me the central number in Worthing. I rather prefer to discuss it face to face. Rather than over the phone.*
> ***So what kind of support would you like to see?***
> *Well perhaps helping find a suitable job for me for example or maybe give me some advice how to set up my own counselling profession as a self employed job. (Male, 25-50, mobility impairment)*

Several participants had accessed support to find employment in the past. Two participants identified the support they had received from an employment service to have been useful to help them find employment:

> *They're great, because I've been to the same unemployment adviser …she's been very good, because I've needed an additional support recently, she's been interactive and doing that. (Female, mental health condition)*

> *Well, what she actually done with me, she filled my application forms out, CVs and everything and I got three job interviews and three job offers straight off. (Male, mental health condition)*

One participant with a mental health condition had accessed support from an employment support provider which she found useful in not only assisting with her job search but also providing talking support which helped her to prepare for employment:

> *I was working with [an employment support provider] and I know that people have had mixed kind of reviews of that, but that was good, you know, just having someone who was kind of interested in me going back to work, someone that I could talk that over with who kind of understood where I was coming from. But then they lost their money or whatever and I don't know who is available any more, it's like I've got to go down all that again (Female, mental health condition)*

Another participant however, also with a mental health condition, felt that the support from the same provider had been of limited value as he was looking for specialist employment as a teacher:

> *They're supposed to give you advice but if you're in a specialism they can give you support but they can't really give you advice…I used to go there and say well this is what I've done blah, blah, blah. He'd say oh that's great. So in a sense he was letting me be… independent which was the direction that he's trying to get people to go in I suppose. (Male, 25-50, mental health condition*

In some cases participants felt that support schemes to find employment simply did not offer the type of support that was needed. One participant who had been optimistic about the Employment and Support Allowance process felt that more emphasis was placed on proving the severity of her impairments than on finding employment

> *ESA, for me I thought 'Oh that sounds quite good actually, that's what I want', I want some support, but this summer has all been about proving how ill I get, which has made me ill. So that's been time wasted in which I could have been trying to get back into work, and now I'm doing that on my own, I'm doing bits and pieces, but I'm again thinking 'Right, where do I go and get the support now to try and get into employment?' (Female, 25-50, mental health condition)*

One participant felt that schemes supporting disabled individuals to find employment should focus on enabling the individual to pursue their broader goals, but felt that the emphasis in the scheme she accessed had shifted towards finding any form of employment:

> *When I first joined the scheme there was a Return to Work and Learning Advisor, and I really like that it was learning also because I felt it was more holistic and more interested in what I wanted for my future, not just stick me in any job, and they've now taken that away because of government funding. It's just about jobs, and I think that causes big problems because it's not holistic and not just about the person, it's just finding a job. (Female, mental health condition)*

A6.3.4.2. Ongoing support/mentoring

A key theme to emerge among participants with a mental health condition was the perceived importance of ongoing support to enable participants to remain in employment once they had found it. One participant felt that ongoing support could prevent people falling back into the benefits system:

> *For me it's about getting support to stay in employment, because I find that it's pretty much, you can get some, well it's not really help it's more just kind of pushing you into it and wiping their hands clean, and then if you sink you're buggered, and then you're back in that loop again, you know, being on the benefits again. (Female, mental health condition)*

One participant felt that ongoing support could help participants to deal with difficult workplace situations, particularly where their condition had not been disclosed to other colleagues:

> *When I start work I'll have these things might arise that I'll need to deal with but I won't have the once a week going to talk to somebody about it, I'll now be needing to just get on with finding employment and working and maybe not saying that I have a condition and maybe just, I don't know, if I have weird behaviour how my co-workers will see that or deal with it, it would be good if I could find some support in place for when that happens, it might be possible, I don't know. (Female, 25-50, mental health condition)*

One participant with an autistic spectrum condition felt that ongoing support had been invaluable to her when experiencing problems in her employment:

> *A couple of times when my boss, who means well but has just wound me up so much that I've been stressed out. He's one of these people that tries to help too much, and when you're trying to do something that can be really annoying. If you've got a deadline you're just thinking 'I've got to make this deadline, I've got to make this deadline', and he just keeps butting in…on two occasions I walked out because I was so stressed out anyway, then with him giving me grief, well-meaning or not, I just had to walk out. So I've been in the car park and phoned up ASSERT, 'I'm in the car park!' [laughs], and also I've got a very good friend of mine who doesn't work … he's come to get me a couple of times when that's happened. So it's very useful to have somebody who can come and help you when you're sort of like in a car park all stressed out, 'Argh! I'm going to kill somebody!' Crying 'Oh I can't cope!' (Female, 25-50, cognitive impairment)*

For one participant, it was felt that support should also be available for an independent body to liaise with an employer on an individual's behalf, to enable them to address any issues and make adjustments to enable the individual to remain in employment:

> *I think that it would be good to have somebody who knows about your problems, who could liaise with your employer and discuss the best ways to make it easier to return to work, and to help you when you're at work, there might be things that could be adjusted so that you don't become so ill that you can't work. I think that it would be a good thing if you went to your doctor and you're referred to somebody who'd be able to actually liaise directly with your employer and discuss it if you wanted them to…if you're not very well, sort of you're depressed or something like that, it's quite difficult for you to stand up for yourself… If you're finding things very stressful at work there might be something that could be adjusted…it could be your hours, or the duties you do and that kind of thing, there might be ways that things can be changed…I think, on a personal level, that if there had been something like that then it would really help me, and if you're trying to return to work there's a way of helping you go back with that kind of help. (Female, mental health condition)*

Participants with mental health conditions who identified a need for ongoing support in employment felt that this was best provided by people with knowledge and understanding of their condition:

> *I'm a woman on Incapacity Benefit and Disability Living Allowance, and I don't want to be on these benefits, I want to get myself off of them and I'd like to just talk to somebody who has an understanding of the particular issues rather than just going to a job centre, just that there be somebody with specific knowledge to help and support. (Female, 25-50, mental health condition)*

One participant specifically identified the peer support model as a suitable template for the kind of support that was needed:

> *Something along the lines of the Peer Support Model I would suggest, because I think you need people who you trust and you can build up that rapport with, so that you can be completely open and honest with them, and then I think you can deal with the*

> *issues step by step… it needs to be people who are really skilled in that, you can't just have people who have got a couple of leaflets*
> ***Whereas the Peer Support Model of being supported by somebody that's also had their own mental health issues is one that you feel would work?***
> *Yeah, because again the emphasis is on drawing the strengths out of the person, again, as my Peer Support person would say, working with what's strong rather than what's wrong. Again it's a huge thing, if you place that emphasis on that person's strengths as you're going through the process… then obviously you're in a better position if you're getting affirmed like that then to deal with the difficulties that are involved. If you're not getting affirmed then the process very quickly can be overwhelming, suddenly you're having to justify how unwell you are, the way that you are, and then suddenly you just think 'I've just got to walk away, it's not helpful' (Male, mental health condition)*

A6.3.4.3. Advice on self-employment

Several participants looking for employment felt that one potential route into employment was becoming self-employed. These participants felt that support with the process of setting up your own business was something which could be of value to them:

> *I wish I could set up my own practice in Brighton…I understand there are a good number of ethnic minority living in Brighton who need counselling. But, I don't know how to be heard, how to convey my message to these people. I'm a bit lost here. (Male, 25-50, mobility impairment)*

> *A lot of disabled people would like to start up their own businesses and have no idea because that is the ideal for any disabled person is your own business. Because then you can work from home, you can adapt around your conditions and how you feel and it fits in but I don't think people realise…they don't realise how or if you can. (Female, 25-50, mobility impairment)*

One participant had managed to identify a source of such support and intended to access it in the future:

> *I'm thinking about going to self employment … But this year 'cause I've had three bouts of depression it's sort of taken a back seat but…. I spoke to [an employment service provider], they were saying if you could prove you could get a regular income from it, they would help give me somebody like a coach to actually help me with a business package. …But that was like 18 months ago I just haven't even got round to it really. (Male, 25-50, mental health condition*

A6.3.4.4. Getting back to work

One form of support which participants felt could enable them to access employment was an appropriate occupational health mechanism among employers to enable participants to get back to work after extended periods of absence. One participant who had taken time off for depression found that a supportive return to work process was critical in enabling him to retain employment:

> *But the one good thing is you do have the occupational health nurse, she is the voice of reason and the light in an otherwise dark place sometimes because you're very aware you've been off for six months and there's a whole load of pressure on the medical people to get me back to work, there's a whole load of pressure on the occupational health nurse who's representing the employer to get me back to work there's therefore a whole lot of pressure on me to get back to work and I'm just saying, "I'm not sure if I'm quite ready if I go back now, what if it goes wrong I could go back six months, I don't want to do that," so there's very hesitant kind of steps, small steps but she helped to do it in a really good way where she made it clear it was inevitable, the sooner I do the better but it doesn't have to be the way I'm catastrophising it again when I wasn't very well I wasn't capable of really approaching it with the right attitude, she was really good (Male,25-50, mental health condition)*

Another participant who worked as a teacher found that return to work arrangements could vary widely between schools, but that a gradual return to work was helpful where it was offered:

> *In schools what you find if you're ill in schools, if they can't get somebody in as supply staff...someone coming in as supply, then other members of staff get extra pressure for having to produce cover work. So you return to piles of homework that aren't marked that you don't know anything about …you go back to work and you're not feeling too good and you just feel obliged to do it… one thing that does happen, some schools do say right, it might be a good idea that you cut your timetable down to what, half for the first two weeks to get you back in to the swing of things which I think that's very beneficial (Male, 25-50, mental health condition*

A6.3.4.5. Low-hours volunteering/employment

In many cases, the type of support participants felt would enable them to secure or retain employment related to practical factors such as hours and working patterns.

Several participants felt they would be capable of doing occasional work or volunteering where positions were made available for less than five hours a week:

> *I couldn't do a days work but I could do 2 or 3 hours in an afternoon when I am feeling well like reception work – I don't want to sit in front of a computer screen all day. (Male, 50-65, mobility impairment)*

> *I only do the odd bit of voluntary work every now and again because I can say like do three hours one day a week knowing that the next couple of days I can write off. A couple of half days a week is the maximum that I can do. (Male, 50-65, mobility impairment & long-term health condition)*

> *It would be nice if they maybe had…because I know they do advertise jobs on the website, but maybe these little jobs there's some way they could say its maybe suitable for a disabled person, something simple locally and only about three to five hours a week. (Female, 25-50, mobility impairment)*

For some participants, hours needed not only to be limited per week, but also flexible to accommodate their fluctuating health conditions or impairments:

> *I just want something that's part-time where I can go and do an hour flexi time or something… Because I can't do a nine to five…I'm not well enough to do that. But I'd just like to do something for an hour or two but I can't be consistently well every Friday at two o'clock and it really is a bug bear because how am I going to get an interview if I put that on an application form that my illness is unreliable and inconsistent (Female, 25-50, mobility impairment, long-term health condition & mental health condition)*

Even where participants felt they could manage more hours per week, many felt that part-time positions and flexible hours were still important to enable them to access or retain employment:

> *I think I'd need them to be quite flexible. On the internship that I'm starting in a couple of weeks, hopefully, they said they'll be quite flexible with when I can do hours, and if I can't make it in on Friday then I could come in on Wednesday and that sort of thing. (Female, mental health condition)*

Similarly, two participants currently in employment also found that reducing their hours had enabled them to stay in work:

> *I've had to reduce my hours at work because of the impact of taking too much on which obviously leads to anxiety in the future. (Female, 18-25, mobility impairment & long-term health condition)*
>
> *The guy I was working for for the first three years I was diagnosed with this I was working full time… he called me into the office and suggested that I go part time because I was winding up in hospital every winter. He had other employees buggering off and I was staying there doing their work and of course its making me ill…and he suggested going part time, which I did (Male,50-65, mobility impairment & long-term health condition).*

A6.3.4.6. Sickness/Flexible working

Where participants experienced higher levels of sickness due to their impairment, it was felt that differential treatment of disability related sick days was beneficial in allowing them to maintain employment:

> *Work has been great. They've really worked round what's been wrong and been very supportive. When I first got diagnosed I was unable to work for a while and because I was sick quite a lot they put me into a special sickness category, so basically any sickness I have with this condition is discounted and I don't get called into the office and get a telling off… Initially I didn't work as much and they had their own health*

> *services so I was under their health services and was monitored all the time. If I was feeling too tired then they'd make other adjustments. No early mornings and stuff like that. So they've been very, very supportive. (Male, 25-50, long-term health condition)*

A6.3.4.7. Accessible Working Environments

For several participants, a key aspect of support to access employment was the provision of suitable working environments. Several participants felt that employment which allowed them to work from home was more accessible to them:

> *I would like to work but I am frightened of being put into a job that I don't like and also not having a boss that's empathetic. You know, so it's not for the fact that I don't want to, it's just fear. If I had to, I guess I would have to find a job from home, working at home, because one I've got the facility there and two, I can stop and start when I like. (Female, 25-50, visual impairment & mental health condition)*
>
> *And they're very good here because I can work from home sometimes and I can access all my directories and so on and all my emails. (Male,50-65, long-term health condition)*

For other participants, where working from home was not an appropriate or desirable option, importance was placed on the accessibility of the working environment. One participant benefited from working in a new school and scheduling arrangements which allowed them to minimise walking between buildings.

> *I've got my own classroom and most teachers have to move all round the building but I know that they're really good with timetabling me in my own room so I don't have to move around too much… the office that I should spend a lot of time in is right down the other end of the building as is the sixth form area where I should spend time. But people just come to me you know. People don't mind doing it…they haven't really made adjustments but I'm quite lucky. It was a brand new school so all the facilities were all really good. They've got a lift, there's a disabled loo just down the corridor from where I'm at. (Female, 25-50, mobility impairment & long-term health condition)*

Another participant had benefited from a desk assessment both at home and his workplace to ensure his workplace was accessible:

> *I've got a parking space here so I can get here okay, they've got me a desk for home and a chair and they've got me all the access I need and so on and quite a sympathetic Line Manager and so on. (Male,50-65, long-term health condition)*

For one participant with Asperger's, the working environment was made suitable by selecting an appropriate working space:

> *Just my Line Manager knows, his Line Manager knows and his Line Manager knows, and then one friend knows, and nobody else from my department knows, and I have to say they've been really good. I mean, I haven't asked for very much, but they reorganised the office, because I was working in an enormous, ridiculously huge, open-plan office. I mean, people with Asperger's don't really want that kind of thing,*

> *too noisy, too many people around you, but they were really great, they went to a lot of trouble to make sure I got a seat so I wasn't in the middle, so I was as far away as possible… and sort of little things like if the fire alarm goes off I don't hang around where everybody else hangs around, because I find that sort of enforced socialisation, small talk thrown in, really awful. So I'm allowed to just sort of do circuits around the block and keep checking. (Female, 25-50, cognitive impairment)*

A6.3.4.8. Technology

For participants with visual impairments, the most important aspect of support to enable them to access and retain employment was the provision of assistive technology for using a computer:

> *I couldn't do my job without the resources that were provided for me by Access to Work, and interestingly, although I worked for an organisation that specialised in working with people with sight loss, they're not always that forward about sorting out bits and pieces with accessibility… for a long time I managed without equipment and then I can't believe how I actually managed without a CCTV, now the equipment provides for me, allows me to do my job. Without my CCTV, without the speech magnification on my computer, without the talking phone I've bought myself, it would be really difficult for me to engage in the kind of work that I do. (Male, 25-50, visual impairment & mental health condition)*
>
> *I have a job as a professional and I rely on my computer, it has JAWS software, OpenBook, something called J-Say which is an interface between JAWS and Dragon Dictate, so I can speak to the computer…I did have some specific training to try and get me more proficient or totally proficient on the internet, which I had managed to miss out on the loop on that, I had some very good one to one training. We had to pay the first half and the second half the government paid 80%.(Male,50-65, visual impairment)*

A6.3.4.9. Support workers

Another source of support to access employment mentioned by participants was provision of support workers, which one participant with a visual impairment benefited from:

> *I do have a support worker for now eleven hours a week, it just increased from eight to eleven hours a week, and she is incredibly helpful because although I can access the files on the computer we are very paper based, and my cases are the biggest because I'm the antique in the office and a lot of my work is in large lever arches etc and there is nothing more frustrating than scanning through about a hundred pages to find the one you wanted to read, and by the time you get there you've forgotten why, so it's much easier having somebody there who can actually flick through things and basically be your eyes on a paper based file, and that's, she comes in and does that and that's really very, very helpful, I don't think I could manage without that. (Male,50-65, visual impairment)*

A6.3.4.10. Support with adjustments

For two of the participants in employment, support from an individual or organisation in identifying appropriate adjustments had enabled them to access or retain employment:

> *I've been referred to the Occupational Health people, which I don't mind, you know if they come up with any suggestions that's fine. I know it's a process to go through. And I don't think it's so unmanageable that I would ever look at termination. I've seen them before actually, it was quite good. I mean I have to be referred there but he knows that I'm under quite good care with my own doctors and Consultants and so on, so there's not much he can add really. So I mean that was a good, good thing. And if he can come up with some brilliant idea, all the better. (Male,50-65, long-term health condition)*

For one of these participants, this kind of assessment, which in his case came from an external organisation, gave him more opportunity to explore the range of support available and maximize his potential, than he felt would have been the case if the assessment was unsupported:

> *I had at the time a woman from Action for Blind People, which is now a subsidiary for RNIB, and she came in for me and did an assessment, then a reassessment when I changed my job role. For me that was good. When I was reassessed it was a very successful reassessment and I got much better equipment and updated equipment, and it was helpful and it helped to adjust to the changes in my sight. A colleague of mine who was struggling with an old machine, he got reassessed, and at that time they were doing self-assessment, which was nowhere near as helpful. It's much better having somebody who can sit with you in a room, who's got a certain amount of knowledge, and the biggest reason for that is that most people that I know with a disability who work will try and play down their disability. (Male, 25-50, visual impairment & mental health condition)*

A6.3.4.11. Other adjustments

Finally, the participant with Asperger's identified barriers to employment for individuals with autistic spectrum conditions due to the selection process for most employment positions, and felt that an extended working interview could provide the opportunity needed to access employment:

> *The whole process for you to get a job is based on an interview, and if you don't do well in the interview, doesn't matter how competent you might be at the job, you're not going to get there, and of course, if someone's on the autistic spectrum, communication isn't their strongest point, doesn't mean they can't communicate, when they need help they can ask for it and whatever, but it means that they might not communicate in the same way as other people. It's a massive, massive barrier to autistic people getting work, I think... especially people with Asperger's, is they're usually brutally honest and in an interview, when people say 'Oh can you do this or have you experience of this?' the whole point is you're supposed to gloss over it and make it sound like you have, even if you haven't, whereas natural reaction is 'No I haven't done that', and that's the end of the conversation, which isn't a selling point.*

> *So it is a massive, massive barrier, and I do think that employers need to look at the way that they get people to prove that they have the skills to do a job and not base it 100% on a half hour performance. (Female, 25-50, cognitive impairment)*

A6.3.5. Bad practice

Several participants in the research identified negative experiences of work and employment, which revealed barriers to employment and volunteering created by employers themselves:

In some cases, participants recounted experiences where employers or volunteer organizations had ended contracts held by the participants, who felt more could have been done to enable them to stay in work:

> *I used to work a company in Lewes. They made me redundant.*
> ***All right. Do you feel they could have given you more support?***
> *Yes. The owners of the company are a bit spineless, so they were never very good at putting their money where their mouth was, unfortunately. They couldn't wait. They were, like, just get rid of her. I'd just started in a new department and everything was great and it was all going well and then suddenly it wasn't, but I know that there's another woman at the company that's had an ongoing illness, and she's had to have surgery on her back and stuff, and they are desperately trying to get rid of her, but they can't. So, yeah, I was not surprised. I was on statutory sick pay for a few weeks and then they said, oh, by the way, when are you thinking about coming back, and I went, oh, well, I was thinking about March. They were, like, okay, because we were going to make you redundant. I was, like, okay, I shan't bother, then. (Female,25-50, mobility impairment & long-term health condition)*
>
> *I've lost a job, that was quite a long time ago, and I was working as a children's entertainer at the time, and I rang up about work and she said 'I'm not giving you any more work', and I said 'Well why's that?' and she said 'Well I've heard something about you'. And I never rung back again, but I know that that was a mental health thing, and that was really horrible. And then there's once that I disclosed it on an interview, on an application form, and I know I didn't get it because of that, and they're the only two times, and now I will never tell anyone, I'd never tell an employer, ever, ever, ever, because of those experiences. Because then I applied for another job straight after that, didn't disclose it, got it like that. (Female, mental health condition)*

One participant who volunteered for an organisation supporting people with learning disabilities reported being asked to leave after developing a mobility impairment. This was many years ago yet appeared to have influenced the participants opinion of her employability:

> *I did voluntary work with [people with learning disabilities]… I used to make cards and help them with their craft work …I was alright even without a stick in those days and then all of a sudden when I was coming down to the building … one of them saw me with… a stick and they didn't say leave but they indicated because of me being slightly wobbly perhaps with my stick. That's when it started and that's about fifteen, fifteen, sixteen maybe seventeen years ago.*

> ***Ok, and did you feel that you needed to leave or….?***
> *No, no I didn't no. No I didn't really. I was quite upset to be honest (Female,50-65, mobility impairment)*

Several participants also recounted experiences where they felt volunteers or employers had not offered them positions due to their impairment or health condition:

> *There was another project I think it was launched in 2003 or 2004. It was for helping asylum seekers. I'm a little bit disappointed you know with the management, because I was trained as a volunteer and then everything's finished. I was meant to mentor these asylum seekers and it never happened. I mean I'm pretty sure it was, it was related to my disability. I couldn't find another reason. My English was far better than lots of people who were volunteering there and got mentoring. My education was much higher and my experience living in Brighton, was more than people in the group and there was only one difference between me and them. They did not have any disability and I had. And all of them they had got some mentoring or mentors…I did talk to the project manager, and I said what is happening with this? He said you know we're trying to find a suitable mentor, client for you. But it never happened. (Male, 25-50, mobility impairment)*

For one participant, what she felt had been repeated experiences of such discrimination meant she no longer disclosed her mental health condition to employers:

> *I've had a lifetime experience of lying to get jobs because that's the only way. You know, and I think some employers are very, very good employers and very open to mental health and disabilities and are quite willing to work with you, and I think there's still quite a lot of employers where you are not going to be seen as an attractive candidate. (Female, mental health condition)*

Several participants identified disagreements with individual managers as reasons for leaving employment in the past. One participant felt bullied by his boss regarding changes to his working arrangements which he had not been consulted about:

> *One of the reasons I gave up work is I virtually had a break down because I'd been bullied by a boss, you know. Just change of circumstances, change of boss, job change completely and I'd had difficulty hacking it. (Male,50-65, mobility impairment, long-term health condition & mental health condition)*

For one participant it was felt that revealing her cognitive impairment led to a change in attitude of her manager who she felt discriminated against her by undermining her managerial role:

> *I only had my diagnosis about five years ago, which is quite common, especially in women, you know, people with Asperger's have a late diagnosis because it's only fairly recently that people have become a bit more aware of it. I told my Line Manager at the time and she suddenly decided that I was completely incapable of communicating. She'd obviously read up on the internet what the traits were and decided that I had all of them, despite the fact that I'd worked with her for two years and she didn't have any problems with my performance beforehand. Basically I was in charge of a team and she started giving directions straight to my team mates and missing me out…she then*

> *decided to make reasonable adjustments without discussing it, like taking jobs off me and stuff like that. You know, it was kind of like out of nowhere and she suddenly did these things, and I ended up having a nervous breakdown, I was off work. (Female, 25-50, cognitive impairment)*

Another participant identified a similar experience in a voluntary position, where it was felt that the volunteer manager went too far in making adjustments by excessively limiting the responsibility given to the participant:

> *Voluntary work that I've done recently. I mean, [the employer] knew where I was coming from because I'd met her at a mental health centre, and doing some voluntary work for her, but yeah, completely going overboard in really underestimating what I was capable of, and in the end I felt so patronised I left. It's like I would turn up, and say I was five minutes late, she'd already have someone in there to take my place, like I wasn't turning up or something. I said that that's not the sort of person I am, if I say I'm going to be there I'll be there. And it was just kind of very, very patronising. I know it was coming from the best intentions but it was kind of never really giving me too much to do. In the end I felt like this isn't challenging me in any way whatsoever, and yeah, I had to leave in the end. (Female, mental health condition)*

Conversely, for one participant, she felt that not enough was done to take account of her mental health condition following an assault at work:

> *I didn't get any supervision and I'd been attacked by a patient, and I'd disclosed that I had this mental health problem and no one sort of gave me any support. (Female, mental health condition)*

For several participants, issues arose around reasonable adjustments they had specifically requested from their employers. In one case, the participant's job role had changed and the employer refused to make adjustments to make the position more appropriate:

> *I worked at my employers as a business trainer, and when we had the recession they got rid of my job, and they put me in a call centre. I was then suddenly… all my whole job changed, everything about it, you know. I won't go into details, but it was quite humiliating for me really because it was like I'd been demoted, but it was only because my job had been got rid of. So that was all quite stressful for me, and then working in the call centre was really stressful and I had to do things that I didn't feel comfortable with, it just didn't suit me. I tried to do it for a while, and that's when I became really ill. Yeah, so I asked them if they could put me in an admin area, and I know there was admin work going but they wouldn't move me into it, and I think that if I didn't have to deal directly with the public on the phone I could gradually get myself back to work, but I'm not capable of having people shout at me down the phone…Before I was off my manager actually asked her manager if I could be moved, you know, independently of me, because I was doing my best to try and look like I was coping with it all, but she knew me quite well and she did ask if I could be moved, and they said no because they needed me in the call centre. (Female, mental health condition)*

In another case, the participant requested disability related sick-leave against her manager's wishes. While the employer's human resources department made the adjustment, this later affected the working relationship with her manager

> *When I first joined back in 2009 I explained that I would have a number of health appointments, they were fine of course but one of the managers who recently came in to post wasn't very helpful and said that I would have to take it as annual leave holiday and toil - make up the hours. And I said I just can't do that, it's in Cambridge, it's a day off, I can't take it as annual leave, I don't see why I should, it's not my fault that I have this and actually alongside sort of arguing about that there was, from HR, they documented basically the equality act and that I could have the time off at the discretion of management, paid, because it was a long term health condition. So I sort of fronted her with that and I then heard through the grapevine that actually she was pretty annoyed about this and I think that upset me because her response was "Well I don't see why she has to get paid for attending hospital appointments," and I thought that was a bit off (Female, 18-25, mobility impairment & long-term health condition)*

For another participant, the speed with which the employer made reasonable adjustments was felt to be inadequate:

> *The Occupational Health woman, who was just really patronising, she thought it was perfectly reasonable for it to take over a year to have reasonable adjustments put in place…So they were awful, I wouldn't want to work for them again. (Female, 25-50, cognitive impairment)*

Finally, one participant recounted a negative experience he had had when returning to work after a period of sickness related to his mental health condition, which demonstrated the variation in approach to reasonable adjustments that can exist between different occupational health staff within a single organization:

> *I had a different experience when returning to work, because I'd been unwell, said that I was unwell, and then they had a very good HR person, and she put together a very good Return to Work Plan … she was very empathetic, she took time to listen. The unfortunate thing was that then, just as we'd gone through this process, she had to reveal that she was leaving the position. So she wasn't able then to take forward what we'd worked out together… Then it kind of then went badly wrong because the person who followed didn't pick that up at all, I don't think it was their approach, well I'm assuming that they didn't endorse it. The Line Manager then didn't do anything that she'd agreed to on the Plan, even though the employer had paid for private occupational health (Male, mental health condition)*

Appendix 6: Employment & Volunteering

A7 Appendix 7: Crime & Safety

A7.1. What is Crime and Safety?

This section of the report explores participants' experiences and perceptions of crime and safety. The focus of the research on crime and safety related to how safe people feel in the city, and their experiences of using emergency services. The research team wanted to know about factors which made participants feel safe or unsafe, and how safe participants felt in different areas of the city (e.g. centre and periphery). The research team also wanted to hear about participants' experiences of services provided by the police and fire services in the city.

For most participants, crime and safety did not appear to be a current priority based on the amount and quality of information participants shared with the research team about these issues. However participants in some areas of the city had more problems than others with issues of safety.

A7.2. Approaching the topic

The research team asked the following detailed questions about crime and safety in the interviews:

- How safe do you feel in your neighbourhood?
  - Have you ever experienced crime?
  - Have you ever experienced bullying, intimidation or harassment?
  - Have you ever contacted the police/fire service/community safety team? If you did, we want to hear about your experiences
  - How safe do you feel in the city centre?
  - What makes you feel safe or unsafe?

Researchers probed for more detail on factors which made participants feel safe or unsafe and perceptions or experiences of crime.

A7.3. Detailed analysis

A7.3.1. Perceptions/Experiences of Crime & Safety

Many participants felt safe in the area in which they lived, which they attributed to not having experienced or witnessed any problems when out and about. Two participants in Kemptown felt relatively safe, although the first participant had suffered verbal abuse which could potentially be categorised as a disability hate incident:

> *I've never been threatened like, I've been called a nutter, and stuff like that you know, when you've been in Millview you're a right nutter, but no one's ever hurt me or attempted to hurt me in any way. So, yeah, so I'm not frightened to go out at night at all. (Female,50-65, mental health condition)*
>
> *On the whole I think very good natured, I have not any trouble, and I go out late at night. (Female,50-65, mobility impairment)*

Similarly, a participant living in the Coldean area also based his perceptions of safety on whether he had experienced any problems:

> ***Is it quite a safe area? Do you feel quite safe here?***
> *I'm a bit stressed out at times err yeah its…I don't really know. I've never had a problem round here. (Male,50-65, mobility impairment & long-term health condition).*

Another participant living in the Kemptown area, however, felt less safe, as he was aware of previous problems in the area:

> *I know there's been problems in St James's Street. If I do go out in the evening it's probably no more than 200 yards from my home and very public areas, you know. But don't take chances. (Male,50-65, mobility impairment, long-term health condition & mental health condition)*

One participant living in the Queen's Park and Craven Vale area felt safe, which he attributed to living in a busy area where he could feel anonymous as opposed to a target:

> *I feel safe here. First time I have felt safe for a long time, I feel safer here than I have done anywhere else... I didn't think I'd end up in a high-rise block, but I quite like it. It's easier to be anonymous sometimes amongst a hundred people than it is half a dozen. (Male, 50-65, mobility impairment & mental health condition)*

Some participants noted improvements in their local area which had made them feel safer in recent years. One participant attributed this to the presence of a police community support officer in the area:

> *Hollingdean I think is safe, well we've grown-up here...Parts of the estate are pretty rough. But this area where we are, it is pretty quiet. You used to get a bit of trouble a few years ago, we used to have a gang of kids coming around like throwing stones. They used to live in the first block here a few years ago. But don't happen half as much as it used to, it's a lot better than it was... there is a PCSO, a Police Community Officer that wanders round the estate. I think she's actually helped things a lot as far as the kids wandering around causing trouble...As far as we're concerned we've not really had any sort of real aggro here at all. We've had like kids wandering around trying to break into garages down the road there and we get the occasional stupid comment from the kids. (Male, 25-50, mobility impairment & long-term health condition)*

One participant in the focus group for people who were deaf and hearing impaired felt his area of Whitehawk had improved, but was aware of ongoing problems elsewhere:

> *A long time ago Whitehawk was bad, it's much better now, there used to be lots of people doing damage and neighbours doing things but it's now stopped...where he is, where he is he's very lucky, he feels but Old Whitehawk it's very bad, still a load of cars racing, Police coming and then it gets worse and worse at the moment up on the hill (Male, hearing impairment)*

For some participants, feelings of safety appeared to have relate more to personal feelings of vulnerability (i.e. concerns about going out in the dark or in crowds) as opposed to perceptions of a specific area:

> *In winter time I don't like going out when it's dark. Um, security reasons basically. But nothing ever has happened to me (Male, 50-65, mobility impairment & mental health condition)*
>
> *She's too frightened to go out in the afternoon, too many people, but in the morning it's fine and she goes out shopping quickly and then she gets home and then she feels safe at home after the morning. (Female, hearing impairment)*

For another participant, his main safety concern came not from other residents but from visitors to Brighton:

> ***How do you feel living in Brighton?***
> *Generally very safe actually, very rarely do I hear of any crime. The one thing that does concern me is that Gay Pride seems to have a crime rate that's untypical of Brighton and I know that there are certain areas or the area of Gay Pride where the cars kind of drive and park and I've heard stories of friends being mugged by some guy that's come down from London for example (Male,25-50, mental health condition)*

For some participants, however there were real safety concerns about certain areas of the city, which made people feel unsafe when out and about. A common theme to emerge was fear of groups of drunken people in the centre of Brighton.

> *I was over at a bar over at Regency Square with a couple of friends, they said what are you doing now? I said I'm going home. Then I realised it was half past nine. It was Friday night. I thought, sugar! I've got to go past the bottom of West Street. I don't really want to go anywhere near West Street if I can avoid it. As we went past the bottom of Regency Square, by the war memorial there was a gang of yobs yelling and bawling and jumping up and down and what have you and I just went on by, but then I kept conscious of them being not far behind and I thought hmm, I did then feel nervous and I walked up the side of the Metrics corner and round the back. Came up Churchill Square and got a bus home and I thought that's something to remember. Not be in town on a weekend and come across that bit. (Male,50-65, mobility impairment, long-term health condition & mental health condition)*

For several participants, this perception of the centre of Brighton as a place for groups of drunken people created a barrier to them visiting the area:

> *I avoid the centre of Brighton on a Saturday night so I can't really talk about crime and whatever in that way (Male,50-65, visual impairment)*

> *I won't come into Brighton unless I have to. I don't feel safe in Brighton, especially at night, I don't come in at all at night. I just think it's all over Brighton, especially along the seafront because I like to go along the seafront at night, you know, get nice fresh air, relax and chill out but there's so many idiots and all the pub bars down there, it's just not safe, you know. And somebody that's on a scooter is an easy picking. (Male,50-65, mobility impairment)*

Some participants living in the area around St Peter's Church also felt particularly unsafe in the area. For one participant, groups of drinkers made him feel unsafe in the Level, close to where he lived:

> *I feel alright. Although going onto the Level you know, it is a bit intimidating in the summer when you get these hordes of beer can drinkers (Male,50-65, mobility impairment, mental health condition & long-term health condition)*

Another participant living in the same area felt it to be unsafe as he had witnessed problems with drug dealing and violence on an ongoing basis:

> *The area we're in at the moment. It's a bit rough. There's a lot of alcoholics and drug dealing going on. So it's, it's an area that we're wary of. I feel obviously more vulnerable now that I walk with a stick and need my partner's help. If I was wondering out on my own and it was getting toward evening, I would probably think of a reason not to do it. Where we were before in Hove was a much better area. There weren't any drugs or alcohol problems or stuff and I would have been ok there at night on my own. ..we've seen lots of assaults and intimidation... outside our window every night, there's a shop on one corner that's open 24 hours selling alcohol and there's a youth hostel on the other corner and every night there's punch ups. (Male, 50-65, mobility impairment & long-term health condition)*

Some participants had also been the victim of crime in the areas in which they lived, which made them feel more unsafe. One participant living in central Hove had his car vandalised outside his house and felt that police were not doing enough to address drunks loitering in the area:

> *The only thing living on this road is the amount of idiots you get go up and down this road on a Friday night that are pissed out there 'eads. That's why I have the camera on me car.... Normally it's about two-ish on a Friday night... I've had odd things like my tow boot cover was took off the car and thrown in the road which I've found and picked up. You do get them sometimes you know you get yobs I've had ones before now, got a bloody paint pen and graffiti on the back window, which makes me laugh cause one little chemical and I just go wipe it off. .. Idiots basically you do tend to find that in Brighton as well... the local police are never around when they're bleedin' needed and the other thing down here that annoys me is the amount of pissheads that sit down that toilet down there. There's forever always one sitting on there drinking, pissing it up, crashed out, stoned out their head. I've reported numerous times to the police and they've shifted them on and now I've stopped reporting they just leaving it again, letting*

> *it carry on (Male, 25-50, mobility impairment, long-term health condition & mental health condition)*

One participant in her 60s living in Whitehawk, identified major safety concerns in her local area. This participant had personally experienced vandalism to her car:

> *You get people beating up old people, something they do sometimes. They haven't started with me yet, they damaged my car but they don't hit me. You just walk along and you've had it keyed. Somebody has stood by the front door sometime or other and picked paintwork off the door handle. They've shot an air gun pellet in the bonnet; somebody has taken some sort of metal instrument and gone (scratching noise) because there's a great big scratch in the middle of the bonnet. All sorts, you know, my windscreen wipers have been broken, your mirrors are broken. (Female,50-65, mobility impairment & long-term health condition)*

Through her involvement in a local church, this participant also had indirect experience of harassment and vandalism to properties of local residents in the area:

> *You know you've got to look quite strong when you're out. I mean I go to church there so a lot of the children know me round about and whatever but there are some still that you wouldn't want to walk by unless you had to. Coz you know honestly they do, they harass one of our parishioners who keeps getting bricks through his windows. So much so he said to the council leave all the downstairs ones boarded up now, can't be doing with it. So, you know, go like that every time I hear children go by waiting for the next brick to come in. They kept mending them, I said why can't you put bullet proof stuff in there, it would be worth it for him... Yeah yeah, we've had Jamaicans move in, lovely people, and they've had pictures of dead bodies chalked on the path... (Female,50-65, mobility impairment & long-term health condition)*

This participant attributed the problems with crime to children of drug-users and felt "troublemakers" were often housed in the area by the council:

> *They just move all the trouble makers it seems into Whitehawk area and either let them sort it out among themselves or quite a lot of people move around, move around, move around you know. You won't find very many that stay in Whitehawk...there's some children that have learnt not to have any respect for anything. And unfortunately I know it's the drugs that the parents took, heroin heads and they haven't got a stop button. They just think that's funny and laugh you know. You couldn't even say I'll come to your house and do it to your dad's car because they wouldn't care, they wouldn't even see what the consequences were. We get quite dumped with quite a lot of that you know, and some of the nicer ones run away and we try and stay sometimes to try and make it a bit better. (Female,50-65, mobility impairment & long-term health condition)*

Two participants in the research recounted experiences which could be potentially categorised as disability hate incidents or hate crimes, although these terms were not directly used. For one participant, his experience was characterised by verbal abuse from a member of the public, which had been traumatic but had not impacted on his feelings about the local area:

> *There was a van parked outside on double yellow lines as I was going up the street.... I was on a very slow day that day, walking wise, and I watched and I thought, well he's been in the van for ages. And there's nothing coming down, there's nothing coming round so I started off walking. I wear a high vis thing so, hardly inconspicuous. And I got just to his van, and he starts reversing. So, I hit...hit the van obviously, and he stopped. And he was just going to drive off. I was stunned by it. I said, aren't you going to apologise. Well he said "Well, you shouldn't have been there." I said well you shouldn't be here because this is a double yellow line anyway. So he reversed out, but he stopped and came back....and then started his verbal tirade about....I shouldn't even be on the planet, "You should be dead, people like you," and things like that. (Male, 50-65, mobility impairment & mental health condition)*

For another participant, a serious crime had been committed against her which had affected her quality of life and meant she felt unsafe in her home:

> *Another reason why I want to get out of there, a few years back a taxi driver sexually abused me. Then he just wouldn't leave me alone, and in my flat as well, so that's another reason why I want to get out my flat. And he [went to prison]. (Female, 50-65, learning disability)*

Although participants spoke about their perceptions and experiences of crime and safety, few suggested specific improvements they wanted to see. One participant at the mental-health focus group however, did feel that increased services might improve her perception of safety in the city:

> *I mean, I'd like to see the occasional Support Officer cycling around at night, just as a deterrent, do you know what I mean? Or a subsidised taxi service for women at night, you know, because I wouldn't get a taxi, I'd think 'I can't afford it' (Female, mental health condition)*

A7.3.2. Police service

Participants recounted various experiences in which they were involved with the police. The most common experience was where a participant had reported a crime. In these situations, satisfaction with the service provided by the police was mixed. The participant above who had experienced verbal abuse from a van driver reported the incident to the police and was satisfied with their response, as he felt it had been dealt with:

> *The Police...I got an answer phone message saying that they knew who it was and it was so unlike him, as it always is. They had a speaking to or whatever. If that was enough, that was ok, I didn't need to contact them....but if I wanted to take it further...I could do. And I thought no. Cause you know, he's been made aware of it. (Male, 50-65, mobility impairment & mental health condition)*

Another participant who experienced problems with youths attempting to break into his property, reported the incident to the police and felt that the involvement of a Police Community Support Officer had been effective in preventing further incidents:

> *We had to get the Housing Officer and the Police Community Support Officer because there's two little boys upstairs and there's children up the road. And I can hear my front door handle going up and down, up and down...I went to the front door. The next thing I know I've got this little arm coming through and when they put the new front door on, I got a lock on the outside like that, on the inside you've just got a turny knob. So they could quite easily put their hand in and turn the lock and open the door. So that really shocked me. So I managed to get a new barrel and now I've got a lock on the inside. I mean we've had a few issues with a few kids on the estate. But ever since the police have been I haven't had a problem at all...It's done the trick. (Male, 50-65, mobility impairment & long term health condition)*

Some participants had less positive feedback about the police response to reports of crime. One of the participants mentioned above who had witnessed drug dealing and assaults around St Peter's Church, reported making numerous reports to the police but felt the response was insufficient, feeling that the area had been " written off":

> *We're constantly phoning the police. The police have been up onto our roof and have sat there and monitored it. And we've had committee meetings, residents meetings, but it's still going on. In terms of the police support, unless someone's actually being assaulted, they're not actually that good. We did actually see someone ripping the copper off the roof of the building opposite.... we told them where they were but they didn't bother turning up. So faith in the police services in that particular area is not particularly high. In Hove if there was a problem, the police seemed a lot more interested. It's like they've just written off this area as trouble. They keep saying oh, there's a PC outside wondering round. The next time you see her just ask her and that's all you get. But she only does nine till five. And then it's usually after five o'clock that the trouble starts off. It's seven nights a week. Right through two, three, four, five in the morning. It kicks off. (Male, 50-65, mobility impairment & long-term health condition)*

Another participant had reported drug-using to the police call centre for nonemergency reports, and felt that poor local knowledge had made it more difficult to report the crime:

> *I look out on to the High Street. I'm several floors up, it's real eye in the sky stuff, but I was taking my dog for a walk, just round the block, and I saw two people on the wall behind the co-op and they had syringes and all the paraphernalia to start taking drugs. Obviously, I didn't say anything I just went on back in and rang the 0845 number which actually, I've since found out that I should have rung 999. But, I rang the 0845 number and I was out on the balcony, I could actually see them you know, and they said "well are they still doing it?" I said yeah, "well we haven't got anyone near". I said look I can see them and I can see the Police Station and I'm in the middle of both of them. You could send a copper, could walk round in two minutes. Oh! And about twenty minutes later a couple of coppers did come round but she had no idea where it was, you know, absolutely no idea at all. (Male,50-65, mobility impairment, long-term health condition & mental health condition)*

For several participants, their main experience with the police had been when they were personally involved in crime as victims or witnesses. One participant had a particularly negative experience over 10 years ago when he was the victim of a violent assault. For this participant, the lack of follow-up and investigation by police was a key failing and led him to claim compensation from the courts:

> *I was walking home through Brighton town centre while I was down here on holiday for a couple of weeks. On the last day of me holiday I was walking home and a couple of lads decided to jump on me and beat seven bundles of [censored] out of me. That's basically what happened. I'd say the police let me down greatly. I only vaguely recall them coming to the hospital, because I was on morphine for the first couple of weeks I was in there. Only vaguely, I don't even know if they did, but they certainly didn't get in touch with me at all after I came out or when I was better, so I felt quite let down there. Especially since this incident happened right in the centre of town. If I'd have parked on a yellow line down there, I'd have got a ticket quick enough. And I've always felt the same since, I've always felt let down by them. Yeah, they haven't come back to me, they haven't said, do you know, did you see anybody, do you know who it was, or anything like that. Nothing, nothing at all. I did receive a bit of compensation because I sued the police. For failure to do what they should be doing. That took ten years. I took them all the way through to the very end, I took it to Temple Court in London in the end, I wasn't going to let them get away with it. (Male, 50-65, mobility impairment & mental health condition)*

For other participants, their experience with the police was more positive. One individual who had been the victim of a sexual assault found the police to be particularly supportive:

> *Something very traumatic happened to me a couple of years ago...this is another reason why we had to move and go into temporary accommodation. And the police were involved, and they were really great, the police. I had to do a video to see if the CPS will send it to court rather than me having to attend in court. The police said I was very, very brave. And then I just broke down afterwards. Anyway, I found the police were so supportive. (Female, 25-50, visual impairment & mental health condition)*

Another participant with a physical impairment had a positive experience of the police when required to attend an ID parade as a witness:

> *The police are really good round here…Peter and Lisa. I was caught up in a gun crime a few months ago and the police gave me an escort to the police station to do an I.D parade and brought me back again with my husband and they were absolutely bloody amazing…I can't praise them enough. (Female, 25-50, mobility impairment, long-term health condition & mental health condition)*

For two participants with mental health conditions, their involvement with the police had been more complex and overall a negative experience. One participant approached the police when feeling suicidal and seeking help, to be turned away:

> *One thing I will say, last year I had my worst day ever and I felt very suicidal, I'd been drinking and I was very reckless and I was a fool, I threw myself out in front of a car, the car swerved and missed and I was glad it did. But then I walked to the police station, I said 'Help, I need help, right now," and they told me to go to the hospital and I was like "you don't get what I'm saying, I need help right now," and nothing. I was bawling my eyes out, I was totally distraught, I'd lost everything, everything had fallen apart and I'm being told "Sorry, wrong office. Up there on the left are for people like*

> *you," it's just like gahh. So I don't think the police officer really was very compassionate or caring at all, that was in the reception of the police station itself and yeah, that wasn't very nice. (Male,25-50, mental health condition)*

Another participant had been held in a cell for 18 hours and felt subject to a poor standard of care when she was sectioned after a period of mental health crisis:

> *Well the Police were alright, but it wasn't their fault I was there for 18 hours. It was a bank holiday I think, and they couldn't get a doctor and a social worker together they said, but on the other hand I wasn't treated very well. I mean, a nurse did come round in the morning and give me my medication, so that was alright. .. I kept asking if I could have a wash and clean my teeth because I'd been drinking. I mean sometimes that's part of being bi polar. You get reckless, and you know my mouth was horrible. And they kept saying we'll bring you a toothbrush, because they keep toothbrushes and toothpaste so, and soap. "Oh yeah, we'll get a female officer to come along with a toothbrush and some soap so that you can clean up." Never happened. Also food, they knocked on the door and opened the little window and said um, "Are you hungry?". And I said well, I wouldn't mind a sandwich. "We're not asking if you want a sandwich, are you hungry?", "Yes.", "Right, cottage pie." No question of what my dietary needs were (Female,50-65, mental health condition)*

Participants at the deaf and hearing impaired focus group also reported negative experiences where they had been involved with police. For this group, it was felt that the police often did not have sign language interpreters available which prevented effective communication with deaf people. For one participant this happened repeatedly over several weeks and left him unnerved and confused:

> *Last Monday morning he had the Police arrive at his house, he was shocked, he didn't know why... he saw the Policeman there talking, had to ask his daughter what they're saying... then again Tuesday evening late, 11 o'clock at night they knocked on his door and disturbed the family, they were in bed asleep and now he's saying you could easily buy a uniform and pretend to be a Policeman, how will we know, there's no proof that they're the Police knocking at the door. So that disturbed the family late at night, no interpreter again. (Male, hearing impairment)*

A7.3.3. Antisocial Behaviour Team

Most participants' experiences of services relating to crime and safety focused on services provided by the police. One participant, however accessed services provided by the Council antisocial behaviour team, and spoke positively about her experience

> *Harassment I had at my previous flat, I had rats put in my bin…I had used needles thrown over into my garden so I had to leave there and the anti-social behaviour team were fantastic in helping with that. They moved the people...they did they evicted them which I was so happy with...although I'd moved by then and then again I took the first place available because my daughter was only eleven and I didn't want her witnessing that sort of behaviour. (Female, 25-50, mobility impairment, long-term health condition & mental health condition)*

A7.3.4. Fire Service

Only two participants reported any involvement with the fire service in the city. For one participant, this was through the Council tenants' movement. This participant felt that involvement of residents in fire drills provided him with an important opportunity to raise awareness of issues faced by disabled council tenants.

> *Another good thing that's happening is, later this month, date to be absolutely confirmed, is one of the tower blocks on Albion Hill, they're going to have a fire drill. There's gonna be five appliances down there and they're going to do a practice run up to about the fifth or sixth story and talk to residents. Because in the tower blocks we've got a stay put policy because of the construction of the tower blocks you're safer staying where you are... so I should go down there and I should then talk to the fire service about wheelchairs and what have you (Male,50-65, mobility impairment, long-term health condition & mental health condition)*

Another participant had a positive experience of the fire service when they carried out a safety check of her property following an electrical short:

> ***And what about your experiences of the Fire service?***
> *Well they, they were good. They came out straight away and I mean I was left without electricity overnight but that couldn't be helped. I mean they didn't know I've got a mental health problem. They just treated me the same as everybody else but then, they were very prompt and did what they had to do. (Female,50-65, mental health condition)*

A8 Appendix 8: Finance & Benefits

A8.1. What are Finance and Benefits Services?

For the purposes of this research, data relating to finances and benefits is defined as comments made by participants regarding the use of the benefit system and how they manage money. Finances and benefits were identified as an important priority by many participants in regards to service provision and its impact on their lives.

A key point of interest in the section of the report is the barriers that participants identified to accessing and applying for benefits and how they manage financially in the current economic climate. In the context of further upcoming benefit reviews and changes, the research team was also interested in how participants felt about their financial future.

A8.2. Approaching the topic

As many benefits services are determined at a national level, finances and benefits were not a topic focused on in this research. However, as interviews were semi-structured, flexibility was given to participants to discuss issues of service provision which they felt were important, even where these were not included in the research design. This approach was an important tool to ensure research reflected disabled people's own priorities and experiences.

As such, not all participants were questioned about finances and benefits, nor chose to talk about this issue. Most participants chose to talk about benefits where they had negative experiences or concerns.

A8.3. Detailed analysis

Participants in the research claimed a range of benefits including Disability Living Allowance, Incapacity Benefit/Employment and Support Allowance, Council Tax Benefit and Housing Benefit. The main issues raised by participants related to negative experiences of the application process, the importance of advice and support with the benefits process, and difficulties they faced with managing money. Many participants also spoke about concerns with upcoming Employment and Support Allowance reviews and proposed changes to Disability Living Allowance.

A8.3.1. Benefits Application/Appeal process

Several key themes emerge from the data relating to experiences participants had of applying for benefits.

A8.3.1.1. Form-filling

Several participants noted the complexity of application forms for Disability Living Allowance. As will be seen later in this section, many participants had as a result accessed informal or formal support with completing the form. One participant felt that the complexity of the application had delayed his claim and stressed the need for support:

> *DLA now that is a totally different story…took me over four years to get that. It took the involvement of social services, the hospital, hospital social services, my GP, respiratory nurses… I should have had it you know ages ago. It took a hell of a long time to get it and even then it's because you didn't fill the form out properly you know…you look at the form and it's…a nightmare. You need someone who knows how to fill that form out.*
> ***And did you have help with that?***
> *Oh yes in the end they gave me a number of a place to ring up and they come out and helped you fill your form in. (Male,50-65, mobility impairment & long-term health condition).*

For one participant, the complexity of the form was such that even with support from Brighton Housing Trust, when turned down she did not appeal due to other problems she was experiencing at the time:

> *I find that most of the benefit service treat you like a criminal, and you should probably start on a dissertation before you embark on the Disability Living Allowance form, because it's, like, forever. It's, like 48 pages. It's on and on and on, yeah. It just takes forever, and then they say no, and you go, right, wait a minute and they go you're not getting it. But it's just, like, I'm not filling in that form again. And they make the form so difficult that you'll just go, oh, I'm not going to bother. They make it so difficult that you think, what's the point?... I had to do it twice, because the first time they knocked me back, and then a whole lot of stuff happened and I didn't get round to appealing because there was lots of things happening and, I mean, we're talking, like, monumental, life-changing stuff going on (Female,25-50, mobility impairment & long-term health condition)*

For most participants, application forms also required supporting medical evidence. For one participant this created a barrier to applying for benefit as she felt that medical records accessed from her GP did not provide detailed information about her hospital admissions to support her benefit claim:

> *I got my last DLA form back with comments and it had on it 'No medical evidence to prove this', you see now I'm paranoid that I've got to get medical evidence to prove*

> *everything. But it seems that the medical profession doesn't keep accurate records, at least not for people with mental illness. (Female,50-65, mental health condition)*

A8.3.1.2. Face-to-face Assessments

Several participants had negative experiences of face-to-face assessments for both Incapacity Benefit/ESA and Disability Living Allowance. Participants attending face-to-face assessments for Incapacity/ESA benefits felt the assessors unfairly characterized their level of ability. One participant, a man in his late 50s with chronic obstructive pulmonary disease and chronic pain, which he characterised as a severe fluctuating condition, felt penalized for walking in to the assessment:

> *This ESA is a total joke…really is a laugh…I've actually got a copy of the report and their doctor I saw said there was nothing wrong with me and I was fit to return to work in two to three weeks. Well I've actually got the report so you know…that's how bad it was. When I went to the appeal I was only given I think it was six points coz I can walk from the car to their doorway you know; I was fit enough to work. It's stupid. It really is. (Male,50-65, mobility impairment & long-term health condition).*

Another participant, who had a mobility impairment and multiple health conditions and experienced chronic pain, fatigue and stomach problems, felt that the DLA assessors at his tribunal were hostile and misrepresented his ability to cook for himself. This participant subsequently attended a second tribunal where he was awarded indefinite DLA:

> *It was a total farce from beginning to the end. So many things went wrong and my money was reduced and it was just one of the worst things I've ever had to go through in my life, it was just horrendous. .. They are obviously trying to reduce the money people get. They asked me what I had had for lunch the previous day. And I couldn't remember and when it came to it, oh, I had I warmed up some boiled rice mixed in meat and veg… but the hand written notes said we are reducing your benefit because you were able to cook a meal from scratch and I hadn't you know..., I mean there were four of them and they each took it in turn to have a pop. (Male,50-65, mobility impairment, mental health condition & long-term health condition)*

One participant with chronic fatigue syndrome felt that the assessor for Incapacity Benefit misrepresented his ability and ignored his answers to questions throughout the process:

> *I'm on long term incapacity…I had quite a few problems with it in that the first doctor which was a guy done my diagnosis on Chronic Fatigue Syndrome… every question I'd written on the questionnaire, crossed out and writ the opposite on and then I had to wait for a second diagnosis six to eight months later where it was confirmed (Male, 25-50, mobility impairment, long-term health condition & mental health condition)*

One participant with a health condition characterised predominantly by pain and fatigue, felt the assessments for Incapacity Benefit, and also Disability Living Allowance, were physically harmful:

> *The first Incapacity Benefits assessment was the most horrendous experience I've ever had in my life, because the tests they do on you for me were very, very painful, and I had no idea that that was going to happen. It's horrendous the way that they treat you, utterly horrendous… they bend your fingers back to see how much it hurts, that's literally what happened. So then when I had my Disability Living Allowance assessment at home I said to the woman 'Look, I've had the Incapacity Benefit assessment, I'm not doing tests like that, that are painful', and she said 'Don't worry, they're different tests', and of course they weren't. So I was sitting on the settee and she came towards me, and she was just about to do these tests that are really painful, pushing your wrists back and bending your fingers back, and I said 'I'm not doing that because that's painful'.*
> ***Did that affect the assessment at all?***
> *Well no, it didn't actually. No, because I got what I was entitled to. (Female,50-65, mobility impairment & long-term health condition)*

A8.3.1.3. Making appeals

Many participants had been rejected for Disability Living Allowance and/or Incapacity Benefit on their first application, but had successfully appealed this decision. Participants generally felt that the appeal process was slow, particularly where they were required to attend a tribunal. One participant, who had recently claimed a higher allowance of DLA, felt that applications were turned down automatically on the first attempt, regardless of merit:

> *I'm on the higher rate of mobility, although that's only been changed in the last three or four weeks, two or three weeks.*
> ***How did you find the application for DLA?***
> *Absolutely horrid. Stressful, slow, humiliating. I can go on forever there, really. I mean in the beginning I had to go to a tribunal. I just applied for it and they just sent back "no", which I wasn't going to accept, obviously... it was just a straightforward no, because of the current economic climate, isn't it? It's no to everybody and then you have to appeal... The tribunal took twelve months (Male, 50-65, mobility impairment & mental health condition)*

Another participant felt that the process of benefits applications and appeals did not respect the fact that he had worked and contributed to the tax system for many years:

> *I applied for it then because I felt I needed some sort of support with getting around because the problem with my leg. I had to appeal, but on the appeal they gave me the higher rate of mobility. Only mobility, I felt that was fair…I can manage indoors.*
> ***And in terms of appeal how long was the turn around?***
> *The whole thing was five or six months. …I just felt a little bit on my own actually, you know. You spend your life working and paying your taxes and stuff and then when you need extra help…you seem to be elbowed all the time the old sharp elbow you know. (Male, 50-65, mobility impairment & mental health condition)*

One participant, a woman with ME in her 20s, had extensive experience of benefits tribunals for both DLA and Incapacity Benefit which had resulted in successful claims, and experienced multiple delays and cancellations of appointments when applying for DLA:

> *I think I've been to…six [benefits tribunals]. I've got twelve A4 lever arch files of all the evidence that's had to be collected. It went to the Ombudsman, I had to get the MPs involved, DLA I was turned down for, went to tribunal and I was awarded that. The Incapacity Benefit I was turned down for, went to tribunal I was awarded that. They lost all of my notes, all of my casework for nearly eighteen months, I wasn't receiving any benefits for over a year... I was receiving, it was up to like five letters a day from different departments and no-one seemed to talk to each other and I was getting letters saying one thing from one part of the DWP and another letter saying something completely different from another one and I was sending all these items off recorded delivery and they were saying, 'we never received those'. And they kept putting the tribunal off and calling us back, and they demanded that representatives from the DWP turn up and they never did, and so they put the tribunal off again, and the same thing happened a second time...if it hadn't been so stressful it would have been almost funny...it was energy writing to all of those people and making the phone calls, that I didn't have at that time. But it was either that or give up and I'm quite sure that, that's what they wanted, it would be much easier had I just gone away, (Female,25-50, mobility impairment, & long-term health condition)*

Participants appealing against benefits claims experienced a range of different approaches to the handling of appeals. In some cases, participants' applications for DLA were rejected, but overturned on appeal, with participants not required to go to a tribunal to challenge the benefits application:

> *The recent case where they asked me to fill in the other [DLA] forms, they spoke to me and said, "No, they're not going to change the decision," which it was obvious they hadn't even looked at it, and there'd be one or two points that made it obvious there, so I just wrote back to them and said, "I don't agree with that decision", and then they wrote back to me again, this time I didn't have to go to appeal and they changed their decision. (Male, 50-65, mobility impairment & mental health condition)*

In other cases, participants appealing against DLA and Incapacity Benefit had been asked to attend a tribunal but these had been cancelled at the last minute and their appeals upheld. This seemingly caused stress and concern for participants who had unnecessarily prepared for an appeal:

> *I applied for the Disability Living Allowance … they actually rejected me the first time which I decided to appeal against and I was ready for the appeal, had all my notes, had the doctors behind me and then at the last minute they changed their mind and awarded me. But yeah, had to go through a lot of stress to think about that. (Female, 18-25, mobility impairment & long-term health condition)*

> *Years ago when I first went on long term sick…I was due to go up to Dyke Road or where ever it is that it is to be seen. And I was just really getting ready to go catch a bus up there, and phone call from them saying Mr [name removed] your appointment this morning? I said yeah. Said look we don't think you need to come in. We've just had a look at your medical records and we'll give you a ring in a couple of years. (Male,50-65, mobility impairment, long-term health condition & mental health condition)*

In some cases benefits appeals were heard over the telephone. One participant, a woman in her late 30s with MS, reported that she was required to answer detailed questions over the phone as part of her appeal against DLA, but was ultimately successful in her appeal:

> ***In terms of getting DLA in the first place, how was that?***
> *Yeah, that was hard work…I didn't know anything about it and a woman at keep fit sort of told me about it. 'Cause I'm earning I presumed I'm not eligible for anything and they said it wasn't means tested. So, did all the paperwork, did all the forms…It came back as low care and low mobility so I then challenged it and that was the tough bit. I was really grilled on the phone by this woman for about half an hour and she absolutely grilled me and at the end of it she was lovely and she was like oh my god, you did so well. She said I'm sorry I have to do all that and then it came back with a higher level of mobility which then gives you access to a whole load of stuff. So yeah it was a long process but obviously it was worth it in the end. (Female, 25-50, mobility impairment & long-term health condition)*

Another participant, who had a mental health condition and ME, was also asked detailed questions about benefits over the phone, in this case income support. For this participant, however, the phone call was problematic due to the participant's difficulty to understand the assessor and the questions being asked:

> *I had a call yesterday from Income Support, it's the first time they've ever called me, and they called me to check everything, like no circumstances had changed, so they asked me crazy questions like have I got any children in the house, sold the house in the last six months, have I suddenly developed any ISA's or any PEPs, I could barely understand the man because his English was appalling, so he asked me if I had worked for any employer but he couldn't pronounce the word so he said 'have you ever worked for an emperor', and I thought, I don't think this man's really calling me from Income Support, have I worked for an emperor? And I said that to him, an emperor, and he said 'yes, have you ever worked for an emperor', and like I'm not silly, I mean I'm not, you know, and I'm not brilliant, and I have confusion in my head, but yeah, I was really struggling, and none of the questions made sense, like he asked me if I got work and tax credit and I said of course I don't get work and tax credit because I don't have a job, and he asked me if I got attendance allowance, you know attendance allowance is for people over 65 (Female,25-50, mobility impairment & mental health condition)*

A8.3.2. Support with accessing benefits

Several participants had accessed informal or formal support to access benefits. This included provision of information on benefits eligibility and entitlements as well as support with the application process, from form filling to representation/advocacy at tribunals.

A8.3.2.1. Provision of information

One participant with MS had not been provided with information on benefits and entitlements which meant he had not accessed considerable financial support, until speaking to someone else with the condition:

> *I mean there's certain benefits like the DLA for example; I went probably five years without claiming when I could've claimed so when you add it up that's a lot of money – that's three or four grand a year, over the years that's fifteen grand or something, just because I didn't know about DLA, no one told me back then "Oh there's a benefit here that you can get and it's worth a lot of money to you," that kind of stuff and I only learnt that because one of my client's wife had MS and she was on it. (Male,25-50, mobility impairment & long-term health condition)*

Another participant, a 28-year-old woman with ME, also found there was a lack of information from formal sources regarding entitlements even where she was in contact with the local JobCentre. In this case, she had only accessed the support following advice and information from St Luke's Advice Service:

> *To begin with there were huge issues with benefits...[someone I knew] worked for St Luke's Advice Service, which was an absolute godsend at that time because she had all the resources and she was the one that started looking into it because the job centre and the council and health authority were useless. And it was actually through her working there and her doing the research for me that I was actually able to move forward and access different things.*
> ***So what support were you not getting say from the council, job centre?***
> *I wasn't getting any... I don't know whether it was the fact that I was diagnosed as a child and had then moved into being an adult, whether it was the fact that I was away at school or university and moving round at that stage, but no one had ever said, 'this is what's available, we can help you with this, we'd recommend you do this.' And I was applying for Job Seekers Allowance even though it was very clear that I couldn't work full time, and with the job centre staff it's very much a case of see you every two weeks, sign you on and then that's it until the time came up where I could no longer receive Job Seekers Allowance and it was only kind of at that stage through [name] looking through work, that actually it became very, very apparent that I shouldn't have been on Job Seekers Allowance and there were other things that I was eligible for which no one had ever said about. (Female,25-50, mobility impairment, & long-term health condition)*

In contrast, one participant with a long-term health condition had a more positive experience with advice on benefit entitlements being provided by her GP:

> *I applied for the Disability Living Allowance because I was going through quite a hard time with my health. At the beginning of the year when it went a bit sort of mad. But I mean that was the admissions into hospital but it was before then I was starting to feel like things were just getting harder and I remember going to my GP and saying this and she sort of advised maybe I could apply. So I thought "ok I'll apply" (Female, 18-25, mobility impairment & long-term health condition)*

As noted in the Health section of this report, one positive experience accessing benefits information was also noted by a participant who had been admitted to the Digestive Diseases department at the Royal Sussex County Hospital, where he had been provided with a detailed information pack on entitlements to various support services.

A8.3.2.2. Applications/appeals

Most participants who had applied for Disability Living Allowance received support with their application, which was generally considered to be invaluable given the complex nature of the forms.

One participant had a positive experience of receiving advice from the Benefit Enquiry Line, and was aware that further support was available:

> *I was getting the care part of DLA for quite a while now because I can't cook for myself or anything and then when my knee went, the second one recently, I am needing to have night time care…the great thing is I know if you can't fill it in yourself the actual people who send them out are fabulous. They are really, really nice and they give you advice so if you can't do it they say we will make an appointment and we will do it for you. So they have that option. (Female, 25-50, mobility impairment)*

Several participants received support from organisations in the community and voluntary sector to complete benefits applications. One organisation providing support was the Fed Centre for Independent Living (formerly The Federation of Disabled People):

> ***How have you found sorting out all the benefits and everything here?***
> *I had a bit of trouble with them, [my brother] tries to kind of help me as much as he can understand the forms, but the Social forms and that are a complete nightmare. When I became more disabled [my brother] was trying to get the higher rate of benefits for me, we ended up having to go out to the Federation of Disabled People. A woman helped us, if it hadn't been for her and him we'd have been stuck. We managed to muddle through eventually and get it all sorted out and get my benefits. (Male, 25-50, mobility impairment & long-term health condition)*
>
> *I had one very good person at the Disability Advice Centre which is based in Hove which I didn't know about until I moved to Brighton and they were very helpful, helping me fill forms in and suchlike… although I had quite a high job I don't really have a clue about distances – about how far I can walk – having good days and bad days – I didn't understand that and they helped me put it into perspective in completing these forms (Male, 50-65, mobility impairment)*

Another organisation mentioned was Age UK which had supported one participant in his early 60s:

> *Someone got in touch with me about three months ago about my incapacity and DLA, like they are everybody, and they said I weren't getting enough and I should apply for more, the higher mobility rate. So they sent me the forms. Which I couldn't make head nor tail of, so I went to Age UK and they filled them in. Took them all afternoon to fill them in, from one o'clock to six o'clock to fill those in… I couldn't understand them*

> *anyway, and I'm not stupid, so how some people get on, I really don't know, but obviously they're designed in that fashion to make it difficult for people, which is silly,*
> ***Age UK, okay, and were they helpful?***
> *Yeah, brilliant, no problem at all, until you got to about the sort of time where the lady was supposed to be going home and then she started to panic a bit, so the last bit of the forms were filled in very quickly. (Male, 50-65, mobility impairment & mental health condition)*

For one participant with MS, support with his Disability Living Allowance application was provided by volunteers from the local MS Society:

> *There's volunteers with the MS Society and they're helping people with the incapacity ESA stuff. So she came round to my house and we had two sessions to fill it out. (Male, 50-65, mobility impairment & long term health condition)*

One participant had received support with their application from a welfare officer at the hospital. This participant felt this support was invaluable in giving her the confidence to challenge her initial unsuccessful application for DLA:

> *My consultant said that there was a welfare officer, who could help with finding out if I was able to get [DLA]. So it was the welfare officer at the hospital who actually helped… He was very, very good, actually – very understanding. Just sort of gave me information on actually it's never really easy for the best of people. But I think when you get rejected from these things you just feel like, you know, really kind of "oh, stupid me" sort of thing and actually it was him who said "well no, not necessarily. It's just the politics behind it and if you remove that and appeal you should be ok," which is what I did with his help; otherwise I actually don't think I would've done that if it wasn't for him, probably would've just left it there. (Female, 18-25, mobility impairment & long term health condition)*

Several participants had accessed support from the Citizens Advice Bureau to complete benefits applications. One participant with a mental health condition spoke favourably of the quality of advice but felt that the CAB did not always take into account her access needs particularly during busy periods when she needed to queue:

> *MIND used to have a benefits service, used to have a woman called [name] and she was amazing, she was brilliant, and like I remember she helped me with things for like years and then they closed that service and they never replaced her… [name] used to break all my appointments up in bits and also it would be at the Mental Health Centre so you were more comfortable, more familiar and they had seats…then I started going to the CAB, but the CAB is always really busy and you can never get to the CAB and also even if they're really good … I don't think the CAB really think 'oh yeah this person might have anxiety because this...', the waiting room's like this big, or 'this person might have a physical disability' because you have to queue outside the door for hours. (Female,25-50, mobility impairment & mental health condition)*

Another participant felt that support from the CAB was of little practical benefit at his benefits tribunal several years previously:

> *I've been assessed and re-assessed and I've seen three DWP doctors, I've been to two tribunals and I've been, so I was awarded indefinite DLA last year... when I went to the tribunals, I'll tell you that was someone from the CAB and she was absolutely appalling, she didn't even turn up with any notes… it was 18 months the process I mean CAB didn't have any more funding for it. You know, coz they have, legal aid isn't it? But, yes she came to tribunal and just sat there sighing and I thought oh this is making things worse, don't sit there sighing, contribute and they were being really ridiculous. And I asked her when I went in would you mind saying something if I stall and well she didn't. (Male,50-65, mobility impairment, mental health condition & long-term health condition)*

Participants also made use of informal sources of support, such as friends and family who had experience with benefits applications:

> ***How did you come across DLA?***
> *[Someone I knew] actually used to work for the job centre plus and going round seeing older people, filling in forms for them making sure they get the right benefits. She helped me with the forms and stuff. (Male, 50-65, mobility impairment & mental health condition)*
>
> *DLA? The form was fairly big but I got quite a lot of help from a friend who had worked with the CAB for a long time so she was very experienced…in doing all that sort of thing. She told me what to say I don't think I would have managed to do it without her… It would be really hard to do if you had no experience of filling in a form like that and had no help. (Female, 25-50, mobility impairment, long-term health condition & mental health condition)*

Finally, one participant chose to complete the forms by herself although was aware of sources of support she could have used if necessary:

> ***Did you have anyone supporting you making the claim?***
> *No but I know that I could have, there was somebody at the MS centre that helps people with claims and stuff but I just did it myself in the end. Actually having said that my physio did a sort of supporting statement for it so she helped me with it and they were great. But the actual paperwork bits I just did on my own. (Female, 25-50, mobility impairment & long-term health condition)*

For several of the participants who had undergone face-to-face assessments and tribunals, it was felt that support was needed not only with filling in forms but also to support them in this process. Participants felt that advocacy was needed to give them confidence and to stand up to assessors:

> *You really really need an advocate. Which should be a floating advocate, would be like perfect for people like me. Who could just come and see me through say my ESA thing when it comes or if they are going to do any DLA (Male,50-65, mobility impairment, mental health condition & long-term health condition)*
>
> *I'm very lucky because there's an Advocacy Centre in Hollingdean, and I'd just managed to get an advocate, because they do do that, for that local area they do home visits. So I was really lucky, because she was there I was strong enough to say 'I'm not doing that, that's really, really painful' … for me at the time that was so, so*

> *important, that I had someone there that gave me the courage to stand up to this woman and to say also 'This is not acceptable, this is not an acceptable way to be treated', you know? But I wished I'd had someone there the first time, because I was on my own the first time when I had that experience. (Female,50-65, mobility impairment & long-term health condition)*

One participant felt that without the legal support she had access to from St Luke's Advice service she would have been in significant financial trouble:

> *St Luke's Advice have got a lawyer that represents you at tribunal, and that was a huge help to actually have someone there, and that could perhaps stand up to the DWP better than I could. And that was…it was a forceful person that would push through no matter what, that was actually needed. Because I couldn't do it. It was essential, I'm quite sure if I didn't have St Luke's Advice that I would have given up…way before then and I think I would have been in huge amounts of trouble at that stage. Because there…different branches of the DWP, different people telling you different things and there was no joined up advice between any of it. (Female,25-50, mobility impairment, & long-term health condition)*

A8.3.3. Managing money/costs

Some of the participants in the research expressed that they had sufficient money coming in to manage their expenditure. One participant accessed various benefits and also received rent from student lodgers:

> *I get ESA which is ok. I get DLA. My wife gets carer's allowance. So in a sense we're covered I would say financially we're alright. (Male, 25-50, mental health condition*

Other participants accessed both benefits and other sources of income which they found supported them sufficiently. One participant was able to comfortably support his family as he was claiming a sickness insurance policy from his previous place of employment:

> *Where I was working before I had this fantastic policy that if I was off sick or couldn't work they paid me 75 percent of my salary at the time till I'm 65, which is unbelievable because I was on a good salary … The financial thing is a massive thing for me, it's probably the biggest thing for me, forget my mobility or physical situation, if I didn't have that insurance policy that pays all my bills and mortgage then it would be an unbelievably stressful situation, my wife, two young children– it's a long way to go, paying the mortgage. So you see if I didn't have that money coming in then we'd just be living off benefits, the quality of life – the family quality of life would be far far lower. (Male,25-50, mobility impairment & long-term health condition)*

Another participant was supported by benefits and an early retirement pension for his previous employment, but felt there was only just enough to support him and his partner and had needed to move to a shared ownership flat to make his expenditure sustainable :

> *I get a pension from work. I get DLA as well and the old Incapacity Benefit. So at the moment I've got enough money coming in that I'm not what you call poverty strickened. But with the two of us trying to live off it it's actually not much more than probably you get on income support because we're not on income support. A lot of the assistances that we would look to get oh no, you don't qualify. Not interested. (Male, 50-65, mobility impairment & long-term health condition)*

For most participants, Disability Living Allowance helped them to manage extra costs relating to their disability. As noted in previous sections of the report, DLA money was used by participants to pay for support around the home as well as wheelchairs and cars through the motability scheme. In addition, it acted as a passport to additional savings and concessionary schemes:

> *Things are more expensive if you can't always be on the lookout for the cheapest deal, if you can't walk there apart from everything else. It's handy to say you get a higher rate mobility which means you get a disabled rail card and bus pass and all the rest of it which is very helpful and as I don't earn that much money it's quite helpful for that reason as well… I could use it to pay people to help take my daughter to school – those kinds of things so I've always used it for disability things I would never go and spend it on holidays or stuff like that. (Female, 25-50, mobility impairment, long-term health condition & mental health condition)*

As a non-means tested benefit, even those participants who did not qualify for benefits such as income support were able to offset disability related costs through DLA.

> *Because I didn't have lots of holidays and I had saved my savings regime just went over that threshold of claiming a lot more benefits. I pay my full rent to my private landlord, my full council tax etc. but because the disability allowance was on a means tested allowance I was free to receive that to help me with all the extra help I needed being in the house fulltime, with bills etc. getting other people to help do odd jobs etc. around the house. (Male, 50-65, mobility impairment)*

Some participants identified as having financial difficulties, which limited the activities they could participate in. For one participant, recent cuts to housing benefit meant that she was forced to use her disability allowance to pay her rent and could no longer afford support in the home:

> *Recently all the housing benefit has been deducted and even though I work the reduction that now I get in housing allowance means that I use most of my disability allowance to pay my rent. (Female, mobility impairment & mental health condition)*

Some other participants felt that their financial situation was more limiting. One participant felt she only had enough just to survive, while another felt that difficulties budgeting for disability related expenditure meant that she didn't have enough money:

> *We don't have enough money to live on. We get Disability Living Allowance minus one hundred pounds a week and income support that they are taking out for a loan we had because I've just had to have a hospital bed installed…We had to get rid of furniture and get another wardrobe to make room in the bedroom for two single beds, and that all came to over eight hundred pounds which we got a loan off the DSS*

> *because they said it wasn't a high enough priority for a grant, so were paying that back at thirty pounds a fortnight. I find the fortnightly payments very awkward to manage because we've gone from weekly payments to fortnightly. I phoned them up and said you know I'd rather be paid weekly because I'm not good at budgeting and they said its not a good enough reason to be given money once a week instead of once a fortnight. So we get paid fortnightly and we have one week a month where we have no food and we can't afford electricity and we can't afford to go out anywhere for a coffee or anything like that. I mean we just keep twenty pounds in for bread and milk for the week and that's it because we are really bad at budgeting. (Female, 25-50, mobility impairment, long-term health condition & mental health condition)*

A8.3.4. Concerns about the future

For many participants, the importance of Disability Living Allowance to their financial situation became clear when participants spoke about their concerns with reforms to DLA proposed by the government:

> *I'm very worried actually because my... obviously they've turned off Disability Living Allowance as well...I'm extremely worried. (Female, 25-50, visual impairment & mental health condition)*
>
> *There's been a lot of stuff talked about in the papers about money being withdrawn for disabled people and all that but as yet it hasn't happened.*
> ***Are you worried that that will affect you or what do you think?***
> *Yes, I am actually. And my benefit, because they want to bring in this new benefit… I'd really struggle without my DLA and that, well… And all my bits and bobs, that does help me out and about, like the bus pass and my Railcard, does give me quite a bit of independence. But without them things, well I'd be stuck in these four walls. (Male, 25-50, mobility impairment & long-term health condition)*
>
> *At the back of my mind it's a concern now about being called in for reassessment, you know this [wheelchair] is paid for by my DLA and it's a three year contract and if the DLA went I don't know what I'd do. (Male,50-65, mobility impairment, long-term health condition & mental health condition)*

For some participants these concerns were more immediate. One participant with a mental health condition who faced an upcoming benefit review, was so concerned with potential cuts that she threatened self-harm:

> *My DLA comes up for review. Now if they start jeffing about with that then I'm really going to be in trouble financially, so that is a big worry to me at the moment… if I don't get my DLA and everything I shall go to my MP and chop my ear off in front of him, I've told my children. (Female,50-65, mental health condition)*

Many participants were also concerned about recent changes to Employment and Support Allowance. Participants who were on Incapacity Benefit expressed anxiety about transitioning onto Employment and Support Allowance due to concerns about the assessment process, based on what they heard from other disabled people or the media. Several participants worried that they might be assessed as fit for work despite considering themselves unable to work:

> *I think the system of re-assessment is appalling – it asks what you can do but it's not real world related. I mean it's saying things like can you pick a pen up. Ok yes I can pick a pen up – I can't write with it – I can pick a pen up any time you like – you know – can you pick a pound coin up – well if I sweep it off the edge of the table, yes. They've cut it down to such a narrow banding that people are being set up to fail. They really are and it's ridiculous and I'm worried about it – I am seriously worried about it – they'll probably say to me Oh, you're fit for work. So ok you find me an employer who will take me on for 2 hours a day before I have to lie down. (Female, 25-50, mobility impairment)*
>
> *I know that I'm going to transition onto the Employment Support Allowance. And…again that's very worrying as well. I think the likelihood is that I will pass the test very, very easily, most of the time I can bend down or I can raise my arm or do things a couple of times. But it's how that actually translates into day to day working, and that it doesn't take into account tiredness levels or… I don't do well with low grade noise, with background noise, whether it's being on a bus or something like that, or any of those things that you'd perhaps get in an office environment. Plus the fact that you're not seen by anyone with medical training …I think it's, what ten percent or something that actually are not fit to work, that they say are not fit to work. And then the prospect of then going to tribunal again, again it's very, very stressful. (Female,25-50, mobility impairment, & long-term health condition)*
>
> *I read a piece in The Observer the other week that some guy had a degenerative lung disease for the medical and they cast him as fit for work, he was dead within one month or something! So basically I'm either going to have to have an ME fibromyalgia bipolar expert or, you know…I'm going to leave the country. I just keep thinking where can I live where I could support myself on like maybe four or five hours a week, you know, I can probably manage four or five weeks without dying, not the same time, yeah, I don't know, Russia! I don't know! I'll have to go and live with my mum won't I. (Female,25-50, mobility impairment & mental health condition)*

One participant expressed concern that he would be unable to provide supporting medical evidence to challenge any future benefits decisions as he did not currently receive treatment, despite still having a host of long-term health conditions and experiencing chronic pain and fatigue:

> *I'm still on Incapacity Benefit so I'm going to have to go through all that again and I'm just mortified because I don't have, I'm not in a clinic, so I've no up to date consultant letters, there's no point in writing to them though coz its so long ago, they wouldn't know who I am. One of them has left anyway there I know from my, the ME clinic. (Male,50-65, mobility impairment, mental health condition & long-term health condition)*

Concerns about future changes to benefits were not held purely by benefits claimants themselves. In addition, participants who were currently working were very concerned about the availability of support should they lose their employment or become unable to work:

> *I'm working full time so that's great. If I was to fall unwell and I found that I lost my job, I would be panicking big time because I don't really know what support is in place there …if I was to be made unemployed because of my illness or not and I'm bipolar and I can't find a new job, I don't know what kind of support there will be for me … the government is changing the boundaries, for the right reasons on many respects, I think they're right to be tightening it because there's a lot of people taking advantage, but my concern is where they're so focused on tightening up they're actually tightening up on the wrong people and they're not going to ensure that the help is there for the people that really do need it, or those people that do need it are going to have to jump through loads of hoops before they get the help and by that point they're so much in debt that they're kicked out of their house or something has gone seriously wrong anyway. (Male,25-50, mental health condition)*

For one participant, multiple factors including barriers to finding employment as a disabled person and cuts to benefit and access equipment at work, meant he felt there would be a lack of support if he lost employment. This led to the participant accepting a demotion which he did not feel comfortable with:

> *There seem to be cuts in access equipment, and at the same time as cutting benefits. So it seems to be that it's now more difficult to be able to do our jobs, for those people who have got a job, and actually more difficult for people who haven't got a job to actually live…I have to say it creates a huge amount of trepidation for me. I nearly lost my job two years ago and I probably, with losing a seniorship, probably, if I hadn't been vision impaired, I would have gone 'Oh stuff this, I'll go and find a new job somewhere else, I've been here for nine years', but I have a mortgage and I kind of felt like I, shall we say, cheapened myself a little bit and said I was just going to stay here and I'll deal with the lower wage, just because I've got a job. So it is quite frightening to think that the opportunities maybe missed for people to work because of cutbacks. (Male, 25-50, visual impairment & mental health condition)*

A8.3.5. Attitudes toward Benefits Claimants

A final theme to emerge when participants were discussing issues related to finance and benefits were the way that these issues had been portrayed in national media. For some participants, it was felt that due to reports about benefits claimants and benefit fraud in the media, disabled people were now "under attack":

> *It's pushing disabled people back 30 years – suddenly you're disabled, you're a scrounger, you're worthless… And it seems everything seems to be at the moment angled at putting disabled people … I think the way disabled people are seen and viewed at the moment is appalling really and we were actually making strides. We were actually getting there. The whole system that's come in now is pointless. It's going to cause a lot of very, very unhappy and miserable people – it's already causing deaths – it already has and it's going to keep happening until somebody takes notice…disabled people, the sick, they're just getting thumped and thumped…and people have started to believe it…I think they assume that people are just going to keep believing that we're all scrounging scum that don't deserve anything. I think they also forget that we used to have lives, we used to be productive, we used to do jobs*

> *and many of us would love to do it again. I'd love to go back to the jobs I used to do – I adored them but I'm just not capable of it. (Female, 25-50, mobility impairment)*
>
> *I do feel that there's a huge amount of anti-disabled sort of stuff going on at the moment in society, and that reflects itself in the way that people behave in the street. I also feel that the government is fostering that kind of resentment towards people who are on benefits but particularly disabled people. (Female,50-65, mobility impairment & long-term health condition)*

For some participants, it was felt that attitudes of other people towards disabled people and benefits claimants had had a direct negative impact on their lives:

> *Someone reported me for fraud. I'd done everything above board I weren't committing fraud and the fraud officer cancelled everything so I had to get help there to get it all back. I got it all back but I complained about them…I don't know why…it can be a bloomin' nightmare. (Male,50-65, mobility impairment & long-term health condition).*
>
> *It's suited the Government to let the media run loose going at anyone on benefits, anyone claiming disability is scroungers, liars. I mean, my dad got his car bashed in just through parking in the disabled bay because there's just this hate and resentment. We've gone back like 20 years in my personal opinion, or if not further (Female, mobility impairment & mental health condition)*

A9 Appendix 9: Learning Disability Research

A9.1. Introduction

Forty-one participants with a learning disability were involved in the Countability research in one-to-one interviews or two Big Meetings. However, while some useful data was gathered, this was fairly limited in scope and detail, which could be attributed to particular barriers faced by participants with a learning disability. Often questions put to participants with a learning disability received short answers with little detail, and some participants appeared reluctant to discuss problems they had experienced, particularly in relation to their home environment and interactions with staff.

On speaking with staff who assisted with facilitation of these groups, it was felt that obtaining more detailed and informative data often required lengthier interactions with participants over several visits, in order to build up trust and confidence of participants to speak about problems. As such interaction was beyond the scope of this project, it was felt that instead greater use could be made of data already collected by Brighton and Hove Speak Out to identify experiences of people with learning disabilities.

This section therefore presents data gathered by Brighton and Hove Speak Out from people with learning disabilities using their services over the course of 2010-11. Approximately 100 people took part in Speak Out’s self-advocacy groups during this period. This data is organised according to the themes of the Countability research, but is presented separately as it has not been collected using the same methods used in the rest of this research. However, it can still play a useful role in highlighting some of the issues faced by people with learning disabilities in regard to public services. Acknowledgements go to Ingrid Ashberry of Brighton and Hove Speak Out for compiling this information.

A9.2. Characteristics of Speak Out participants

Brighton and Hove Speak Out provide advocacy to individuals and support self-advocacy groups for adults with learning disabilities who live in Brighton & Hove. Speak Out supports users to:

- Have their say and be heard
- Be in control of their lives
- Know about and claim their rights
- Campaign for changes in services and attitudes
- Help services get better

Speak Out facilitates a number of meetings of people with learning disabilities:

- Big Meeting. A meeting of learning disabled people every 2 months, run by Speak Out. Learning disabled reps at the meeting come from Speak Out self advocacy groups (3 groups) and 9 other city wide groups including day services and residential care services.
- Self advocacy groups. 3 ongoing groups supported by Speak Out
- Link Group. Speak Out-supported group of people with mild learning disabilities who represent the views of people with learning disabilities at the Learning Disability Partnership Board and other meetings. The Link Group also reports what the Partnership Board says back to the Big Meeting
- Learning Disability Partnership Board and it's sub groups. Meeting of council management, commissioners and voluntary sector organisations looking at improving the lives of people with learning disabilities.
- Additional short term projects such as Cooking Together, a joint project with Brighton and Hove Food Partnership developing cooking skills of people with learning disabilities and their support staff.

As noted earlier in the report, two Big Meetings were held specifically to address themes explored by the Countability research. In addition, many meetings of self advocacy groups and previous big meetings touched on these themes and will be explored in this chapter.

Speak Out supports a wide range of people with learning disabilities from different backgrounds. In terms of living and care arrangements, people who use Speak Out fall into several groups:

1. People with mild learning disabilities living independently in their own flat or a shared house with no or little support from services. The support they receive may be from the community support team or home care services.
2. People living in clusters of flats with access to varying degrees of support on site
3. People living in private registered learning disability care homes
4. People living in a group home with 24 hour support on site
5. People living with parents or a shared lives situation

A9.3. Issues that have come up in Speak Out's advocacy work

The following section looks at issues raised by people with learning disabilities at the various meetings facilitated by Speak Out staff. Quotes have been included where appropriate but the summary is written by Speak Out staff based on feedback from participants.

A9.3.1. Community participation

A9.3.1.1. Getting out and about

People with mild learning disabilities living independently without support tend to be very isolated. They lack connections with other people.

> *I liked coming here to meet different people because I haven't got any friends. I liked cooking with everybody around the table. I usually do it on my own*. (Participant on the Cooking together project September 2011).

They may also not get out much or have the confidence to access services themselves. Those who are eligible for support will be allocated a limited number of hours which will have to be prioritised. Support around housing, money and health will be priorities.
In Speak Out's What To Do project we supported individuals to access Brighton and Hove services. We asked them what their interests were. Places that came up were going to the library, joining a chess club, and needing support to go to the swimming pool. People had not got enough support or confidence to do the things they wanted to do.

There are some people living in large blocks in independent flats who are not confident to go out without support but have only a few hours of support. There may be a communal restaurant where people can eat together or a communal activity such as boules. People in this group generally don't attend day centres, but may have some part time work.

People with learning disabilities living in care homes tend to have a full weekday programme which includes a combination of attending projects at Day Centres, college courses, volunteer work, and other learning disability projects run by local voluntary organisations e.g Care Co-ops community farm, the Rockets run by Brighton University or Carousel art projects.

In the smaller group homes and supported living scenarios residents seem to have more person-centred lives, and more flexibility to do things they want to do. They may be accessing day centres, college, community facilities, work and be supported to go out in the evenings and weekends more.

People who live in the larger homes which are registered private residential care homes seem to have much less person-centred lives. They are dependent on managers, staff and carers for evening and weekend activity. Usually people attend day centres, possibly a range of day centres to access different projects, some college courses, part time work or volunteering or are involved in disability organisations such as Carousel or Speak Out. A few people travel independently on buses during the day but most are dependent on group travel in a minibus. Many people say they don't get out much at evenings and weekends, some that they are not supported to go out by staff.

Don't like it. When you ask to go out. They say no. (Resident of registered care home).

A9.3.1.2. Clubs, groups and societies

A few people are involved in a church community. The Salvation Army offers a welcoming lunch club. People do volunteer in a range of charity shops, the Brighthelm café, 2020 café and a few mainstream cafes.

Generally people with learning disabilities do not seem to be involved in mainstream sports, hobbies and clubs. People with mild learning disabilities often lack the confidence to join them and need some support to integrate.

Online groups are inaccessible to the majority.

When asked at a recent meeting if people did any neighbourhood activities no one could identify any. As stated before people generally attend learning disability clubs and organisations.

A9.3.1.3. Community events and venues in Brighton and Hove

Few people with learning disabilities access the range of experiences available to residents in Brighton and Hove. People may occasionally go out for a meal, or go to cafes or go shopping but don't seem to access the wealth of cultural and artistic places and events or the diversity of clubs and groups.

Even mainstream activities such as going to the cinema and using leisure centres is very limited. Only few people used cinemas, only one person within the advocacy groups had been to the Duke of Yorks. Very few people have been to the Theatre Royal and if they have it is for the Christmas pantomime despite the Theatre's work on access. Many people do not access the Brighton Centre because of lack of information and high ticket prices.

Where people access a mainstream venue it is usually through a collaboration between a disability arts project and the venue e.g the Rocket Artists with learning disabilities at the Phoenix Gallery or Carousel's Blue Camel Club at the Corn Exchange. The Blue Camel Club is a hugely popular event with people with learning disabilities. It is widely and accessibly advertised through learning disability networks and word of mouth. For many people the Blue Camel club 3/4 times a year and the weekly club nights held by disability organisation Spiral are their social life. Integrating into mainstream activities does not happen for the majority of people with learning disabilities we support.

In terms of big cultural events like Brighton Festival only a very few people seem aware of this and this is usually because they have art work being exhibited through their day centre. A few people go to see the big visually obvious shows like the Circus in Preston Park, Holiday on Ice at the Brighton Centre, or the Ladyboys of Bangkok. Often people return to see the same show year after year. Advertising for these shows tends to be more visible. Many people who wanted to access Holiday on Ice found the ticket prices prohibitive. Very little work seems to go into promoting and outreaching other events to people with learning disabilities.

Limited money, lack of transport and limited staff support to go out to places at weekends and evenings has a big effect on peoples' lives. Accessing the information about places and events is an issue. A lot of people with learning disabilities won't be able to access the internet or locate or read information. People who are living independently don't feel safe travelling on the buses or walking the streets at night.

Familiarity and confidence to go into a venue is important. One self-advocacy group at Speak Out has made links with Theatre Royal, Brighton Centre, and Duke of Yorks to get familiar with the venue and service. Actually going to the venue afterwards requires accessing the information, the money, transport and staff support. It is rare that people in the groups visit again.

A9.3.2. Health

A big meeting was held with 41 participants with varying levels of need and support, to discuss the following experiences of health services:

- What makes people happy and affects their mental health
- Health Action Plans and other accessible health tools
- Seeing Doctors and other health professionals

The following major themes emerged among people with learning disabilities:

A9.3.2.1. What made people happy and affected their mental health

- People wanted relationships and friendships. People needed support to see friends and partners outside regular planned activities such as day services. Whilst many people wanted this, some care homes do not offer this support to people at all. Residents often accept this as they do not feel they can challenge their homes or have the right to ask to see their friends. It is something they would like to do but accept that they cannot
- People wanted to feel useful and important**.** 4 people talked explicitly about needing a role in society and needing to feel useful and help others.
- 2 people at the meeting had suffered bereavements in the past week. Neither of them took any time off their normal activities. It brings up the question whether people are supported well with bereavements.
- People lacked support around issues to do with sexuality. Some people

experienced staff imposing their own moral views of relationships on people with learning disabilities.

- Some people felt anxious or upset when they saw care home staff arguing.

A9.3.2.2. Health Action Plans and other accessible health tools

- People did not own their own plans. The majority of people at the Big Meeting did not think they had a Health Action Plan. This does not mean that they do not have one or their health needs are not catered for. However, as the Health Action Plan is meant to be an accessible tool for people to use in order that they understand their own health needs better, it is not a good sign that they had no knowledge of them, let alone have their own copy to keep (as intended by the scheme).
- People liked hospital passports. They were colourful and accessible. One person at the meeting had one. No one else thought they did. If they did have one it was not familiar to them and they didn't know where it was kept.
- People who do not get support from social services did not get a Health Action Plan from doctors even though they said they would find it useful
- People liked accessible pictures. People liked the picture tool which is on the Brightpart website for health professionals, but had never seen them being used by Doctors, Nurses etc.

A9.3.2.3. Seeing Doctors and other health professionals

- Some people were happy. They got the support they needed, liked the health staff and understood what was going on
- Some people did not like accessing health services. It is unclear why this was. Some people obviously feared what might happen.
- People with milder learning disabilities didn't get the support they needed to access healthcare

A9.3.2.4. Staying healthy

- People needed more information. People talked about understanding some issues relating to healthy diet and exercise. However they needed more help to understand more subtle messages. Examples included
    - Someone being told she could not eat salad because of the ecoli bug prevalent in beansprouts in Germany at the time.
    - Alternative healthy foods
    - Understanding slow release food (GI)
- People needed more support/information to carry out healthy lifestyle choices (eating and exercise). People talked about wanting to try out different exercise options (gym, swimming, cycling) but either lacked the confidence, money or understanding about how to access these. It is unclear whether people

understanding healthy lifestyle choices equated to people making healthy lifestyle choices.

- People’s experience of health checks seemed to be limited mainly to blood tests, chiropody and eyes/dentist. It was not clear how many people accessed other forms of health screening

A9.3.3. Social care

A9.3.3.1. Support to get out evenings and weekends to have a fuller life

As stated earlier there are two groups of people with learning disabilties who have limited lives, those with mild learning disabilities living independently and those living in some residential care homes. Isolation is an issue for the first group. For those in the second group weekends and evenings follow a predictable pattern with attendance at one or two learning disability clubs in the evenings, and a group outing at the weekend. Staff facilitating 1:1 outings doesn’t seem to happen. People in this situation often talk about wanting to go out and meet their partner who they might only see at the day centre.

A9.3.3.2. People with mild learning disabilities

For people with mild learning disabilities there is the issue of not being eligible for support from social services. We work with a number of people with mild learning disabilities who feel frustrated that they do not get the level of support that they would like. This can be a particular problem when it comes to finding suitable accommodation.

A9.3.3.3. People living in residential care homes.

The following themes emerge from feedback given by people living in residential care homes at various Speak Out meetings.

Support needs of people in residential care homes

Staff do not support people well enough around the following issues:

- Promoting independence and making own decisions

> *Staff had a meeting about it and we have to go to bed at 10 o’clock. Not very nice. They treating us like a baby and we don’t want that. When we say something they don’t like it. Oh you have to go to bed (they say) Just like that.*

- Better support around death and bereavement

  > *Should be more involved in funerals, chose the songs, go in the car, have somewhere to visit.*

  2 people attended one of our Big Meetings. One person's boyfriend had died, the other's friend had died. The person whose boyfriend had died did not take any time off from her day service and attended the following day. She was not involved in his funeral as she was on a pre booked holiday the week that the funeral was arranged.

- Support to get out and see friends

  Staff support is needed for people to go out to different places, meet friends, go out with partners

- Support to access resources like the library.

  Speak Out Groups have visited and joined the library. Subsequently, there have been issues as residential homes say they cannot support people to return borrowed items. People with learning disabilities feel they cannot use library facilities.

- Support to look at the magazines for people with learning disabilities who can't read.

  When asked if staff helped someone who can't read to look at Share magazine and Network News, the person replied: "Never, because they are too busy."

- Positive interaction

  People say they want staff to be friendly, kind, polite and to have a laugh with them.

  > *I like someone who's fun and makes me laugh. N (keyworker) laughs with staff but doesn't laugh with me. It makes me upset*
  >
  > *They're (staff) polite and cheerful and giggle a lot and make jokes as they're working. I told them a joke…they laughed*

  People want staff that listen to them.

  > *We talk about all sorts of things. He's chatty. He listens to what I say…in case I'm not well. Talk to him about problems. Trust him*

  People don't want to be surrounded by negativity

> *I saw the staff getting angry with each other. She (staff) was doing something with her hands angrily and shouting. I wanted to say..next time you want to argue can you close the door. It's very upsetting. Residents don't want to hear this. I don't want to get in trouble with staff so I want them to close the door*

Level of choice and control in residential care homes

There is a very mixed picture within Brighton and Hove. Some people get a good quality service and have the choice to do things that they want to do with people they want. We see people being supported to take part in their communities and establish friendships. We know people who are supported to be members of gyms, go to health spas, get work, meet their boyfriends/girlfriends, go on the holiday of their choice etc.

In our experience, there are a number of larger residential homes and some family placements that are very limited in the choices that they offer to people. We work with a number of people from these homes who lead very contained and unexciting lives. The kind of things that people tell us from these homes is that they:

- do not get out in the evenings,
- are not supported to meet up with friends or invite friends home,
- are not allowed to enter the kitchen to cook or make drinks,
- only go out with their homes in minibuses at the weekend to the same places and with other residents from their homes,
- do not get to choose the clothes they wear or buy
- cannot choose to do activities by themselves (for example going to a football match)
- find it difficult to stay out later than 9pm due to staff shift patterns
- Have little control over what they eat
- Cannot choose what time they go to bed

A9.3.4. Housing

A9.3.4.1. Experiences of different housing arrangements

A big meeting was held in September 2011 with 26 people with learning disabilities where people said what they thought about their living arrangements.

Registered Care Homes (8 people)

People had different experiences. People commented positively about their homes where they were involved in cooking and domestic duties, and where staff and neighbours were friendly.

> *I like making new friends in my house.*
>
> *I get on with the staff and all my friends. I want to stay there.*
>
> *We do our own washing.*
>
> *Know the neighbours. Always say good morning.*

People expressed negative feedback where they had a lack of choice and control and where there were arguments in the house and noise from neighbours.

> *Sometimes I can't make my own bed properly*
>
> *I can't do the hoovering.*
>
> *People shout outside the house sometimes if they have been drinking too much.*
>
> *Sometimes they take my snacks away. I don't know why.*

People living in own flats or shared houses with community support (9 people)

Most people were positive about living independently and enjoy being part of their communities.

> *Carelink helps in an emergency if unwell or need ambulance. She wears pendant and can press button if needs help. Feels safe. She does shopping and is independent.*
>
> *I'm happy there. I've got new music centre, new sofa, happy to get new things. Make cups coffee, do lots of cooking in the kitchen.'*

People expressed negative feedback where they felt choices were limited. One person felt they did not have the choice who they live with. Another person felt residents did not get the choices they should have.

Housing like Patching Lodge, New Larchwood with lots of flats and a big living room for meeting up (5 people)

People generally enjoyed the independence they got with their own flats. However, Speak Out frequently talks to people who have problems with their neighbours which can be anything from mild irritation for the person to causing great distress and this is an ongoing issue. This seems to be exacerbated by the fact that general staff in these complexes do not have time (and it's probably not their job) to mediate between the different parties.

It seems that people with learning disabilities did not understand the boundaries of the staff roles in these complexes.

> *Staff say we've got to stay in our flats, can't visit each other in flats. 'We have to be independent. We can only see them in lounge or laundry room.*
>
> *We are independent but have lots of staff to help when needed.*
>
> *Can be difficult when you can't choose neighbours in flats. One person makes us upset and angry. Our keyworker is helping sort out.*

A9.3.4.2. Making complaints

One theme which emerged from people's feedback about living in residential care homes was the lack of information people had about making complaints. The Link Group recently did some work with different homes, where several advocates with learning disabilities visited homes and asked questions to residents about making complaints. Key findings were that many residents did not know how to make a complaint, and often were afraid of getting in trouble if they complained. However a few residents felt that improvements had been made when they had complained.

A9.3.4.3. Moving to different housing

People at the Big Meeting also spoke about their experiences of moving home.

Summary
6 people talked about moving to a different home.
2 people thought they were not allowed to move.
1 person had never been asked about it
1 person's planned move was taking a very long time
2 people have had or are getting good support to move

One person was moving from a residential home after being there 9 years. She was still waiting to know what was happening because her social worker was in Portsmouth and keeps changing. *'Taking a long time. Would like to move and live with just 2 people so much quieter'*. She wanted to stay in the same area near the day centre and her doctors which was important as she had known the doctor for a long time.

Another person who moved from one part of the residential home to the other was pleased, *'Much quieter, better*.'

In one residential home 2 people felt the staff wouldn't want them to move out. *Asked S. She won't let me move. She wants your money. I am too old to move now.*

Speak Out has also provided one-to-one advocacy to people moving home where a number of themes emerged:

> Speak Out has given 1:1 advocacy to 4 independent people in the last 12 months around housing issues, all of whom felt that their housing was having a detrimental effect on their health. 2 people were in council properties and 2 in housing associations. None of these people felt they could move without significant support which they do not get from social services.
>
> All felt that the process for moving home is too complicated. 3 people found the accessible Housing Options guide too long (31 pages) and it also does not cover the complicated banding for allocating social housing .
>
> One client was given conflicting information by the council housing staff about her eligibility to go on the Mutual Exchange register and her housing association. This had a very negative impact on her, resulting in confusion and a general mistrust of services.
>
> One person was put in Band C priority (housing having a minor adverse effect on health) and was told by the housing officer that she would be unlikely to be able to move within 12 months despite having a supporting letter from her GP. She was advised to try Mutual Exchange but did not feel able to pass on her personal details and phone number due to her high anxiety levels. She felt unable to let strangers enter her home without any support so could not join the Exchange.
>
> Another couple had a more positive experience when they downsized. This was managed after significant levels of support were put in place by their keyworkers.
>
> Communication is an ongoing issue. Some clients feel intimidated by assertive housing staff. One lady felt afraid to tell housing that she had decided to stay in her accommodation. She said she was forced to visit properties as they said she must see them. She kept visiting properties and turning them down but felt afraid to tell staff that she didn’t want to move for fear of their response.
>
> The level of suitable housing stock is obviously a key issue but people we have supported simply have not been able to cope with or understand the system and have felt the banding system is unfair in relation to their specific needs.

A9.3.5. Transport and the environment

A9.3.5.1. Buses

Most Speak Out users who travel independently on buses or are part of a travel buddy scheme have brought up issues around specific buses or bus drivers. The bus company have been receptive to feedback and have raised the issues to the drivers and in their training.

Most people with learning disabilities find it useful to have the orange bus pass holder that lets the driver know the person has a learning disability and needs extra support. Not all bus drivers seem to be aware of the orange bus pass holder. Issues which have come up are:

- Bus drivers not being willing to put the ramp down for someone
- Bus drivers moving off before someone sits down
- Bus drivers not giving people enough time to get up and off the bus
- Bus drivers not responding to the bell possibly due to the person not being able to press it hard enough
- It was felt to be more difficult to complain now as you don't get a ticket unless you ask for one.
- If bus route changes it is difficult for people to know what is happening and what to do.

People also say there are good, friendly bus drivers who do wait for them and give good support.

A9.3.5.2. Taxis

People with learning disabilities have said regarding going out in the evening that taxis are too expensive.

Feeling safe in the taxi and with the taxi driver is important. A couple of incidents regarding abuse by taxi drivers have been reported.

A9.3.5.3. Trains

Very few people with learning disabilities use trains. Southern Rail have produced some accessible information. Other companies have not and the stations themselves need to look at the support they offer.

A9.3.5.4. Cycling

A survey a few years ago by Grace Eyre around cycling revealed that a lot of people would like to learn how to ride a bike. A few people said they used to when they were little but hadn't for years. As far as we know there is no particular organisation offering lessons or access to bikes to people with learning disabilities currently.

A9.3.5.5. The Built Environment

Buildings being wheelchair accessible has been raised by people with learning disabilities who use wheelchairs and their peers who don't. Some work took place by one self- advocate to challenge access at Hove Station and Emmaus.

One person only gets taken out to the Marina because it's easy, it's wheelchair accessible. One group brought up the issue of signage and information being clear whether there was a lift in the building.

Not knowing where to go or not being able to follow signage is a big barrier to physical access. Signage is not necessarily visible to someone with learning disabilities and they cannot necessarily read it. Where it works well is big familiar signs of fire exits, toilets, wheelchair user. Otherwise people don't recognize the meaning of the picture. If this is the case the service needs to provide support to individuals to find their way round. Where people are taken around a supermarket or library and shown where the things they want are, this works best.

One of the advocacy groups recently discussed physical access and brought up issues around:

- Pavements sticking up and being dangerous around day centres
- Not enough public toilets and not being sure where they are
- Making sure places are wheelchair accessible and there is good signage about this.

A9.3.6. Employment and volunteering

At the Big Meeting in February people talked about the work they did or wanted to do, and some of the issues around finding and retaining employment.

A9.3.6.1. The importance of employment and volunteering

Jobs were important to some people, while others were happy not to work. Some people felt 'work would make them feel happier, and others felt that having a job made them feel less excluded by society:

> *Being out of work makes you feel like you are on the scrap heap.*
>
> *Not having a job makes you feel like you don't fit in. It makes you feel horrible.*

Nobody wanted to work every day. Most people wanted to work or volunteer, 1 or 2 days per week. People's ideas of work days were typically about 4 hours in a day.

A9.3.6.2. People wanted more choice of employment opportunities

> *They don't think we can do anything but basic jobs.*
>
> *Job Centre jobs are all typist or catering jobs that people don't want.*

Some people had had jobs in the past but not now. Some people had jobs now. Most of the jobs were in laying tables, in second hand shops or helping in the kitchen. One person worked in a hairdresser. Several people felt that people with learning disabilities only had a few choices of jobs.

People wanted more choice in jobs e.g several people wanted to work with animals, children, gardening, retail work, DIY shop, actress, film maker, advocacy worker, hairdressing, typing letters.

People found it hard to choose what job they wanted. They wanted to know more about different kinds of jobs and try them out to see what they wanted to do.

A9.3.6.3. Fears and anxiety about getting a job

Several people were worried about no jobs being available, while others were concerned about not having the skills employers needed. People were also concerned that they did not have the money for travel, shoes and smart clothes they needed to get a job.

Some people were worried about working with a disability, and one was concerned that the wrong type of work could make her ill.

Many people were very worried about their benefits being cut if they were in paid work. Some people found being paid and how it affects your benefits confusing:

> *They want you to get a job so they can stop your benefits, council tax, water rebates, everything.*

A9.3.6.4. Availability of support around work

Most people felt that some support was needed in volunteering and paid work, from key workers or other work colleagues. Some people felt they would need a lot of support from an assistant to do the job.

One person felt they didn't have enough support when jobs had finished to understand why and look at what she wanted to do next

A9.3.6.5. Finding Jobs

One person who is paid to work at the reception at a Day Centre said the process of getting her job was good, she did volunteering first, was trained and then given a paid job.

People at the meeting with mild learning disabilities felt very strongly that the government were not doing enough to help people with learning disabilities get into work:

> *Job centres don't help people with learning disabilities– all they do is point you to a telephone.*
>
> *Go to a job centre no-one wants to know.*

Several people who use job centres felt they were awful and felt "like a prison", and that "they don't give you any support".

A9.3.7. Crime and safety

A9.3.7.1. Not being treated equally or with respect by the general public

There are a few people with learning disabilities who have told us about incidents involving the general public pushing past them in the street and on buses and being impatient with them and occasionally rude or calling them names.

> *Adults saying four eyes. All look at me. The ones upstairs give me a scare. Makes me feel uncomfortable. Sit there and feels like I don't want to do it anymore. When I am minding my own business. When I see them they swear at me. I aint done nothing to them. Just don't want to be on the buses no more.* (Member of an advocacy group August 2011).

Someone had a bad experience in Pavilion Gardens with a café customer who called her a horrible name. This often means people don't want to go back to those places. If people have additional mental health issues such as anxiety it can make them very heightened to unhelpful responses from people they interact with.

A9.3.7.2. Feeling safe

There are a few places that people have mentioned they don't like going to and don't feel safe where there are people hanging around and smoking and drinking e.g the Old Steine and the Level. Some people feel nervous of the dogs that people have on the Level.

People don't feel safe at nights when it is dark and generally people don't go out unless someone takes them. Even people who travel independently on the buses during the day feel nervous about being on the buses at night.

A9.3.7.3. Experiences of crime

Being a victim of crime is not an issue that comes up a lot at Speak Out. Recent exceptions have been a report that someone has been watched at a cash point and been followed back to their house. Being called names is an issue for a few people. There are a few people with mild learning disabilites who have received advocacy support who are very vulnerable and this attracts people into their lives who are known to the police.

A9.3.7.4. Reporting problems

People's awareness of the community safety team is limited. A few people with learning disabilities we support seem to be nervous of the police and worry that they have done something wrong if the police are around.

In the Big Meeting October 2011 we looked at the different forms of abuse, how to report and what happens when you report these. People were particularly concerned about having a phoneline that is manned 24/7 so they could always speak to someone and not just listen to an answerphone message with another phone number in the evening.

A9.3.8. Finances and benefits

At a Big Meeting and subsequent workshop people talked about how they managed with money.

A9.3.8.1. Managing their own money

Most people have their own bank accounts. Some people get good support to use them but others do not. One person said that he would like to go to the bank to get his own money out. Some people do not have bank accounts and would like to learn more about money.

Many people in residential care homes talked about their money being locked away in the safe. Most people felt ok about this but a couple were unhappy.

One person said she was not allowed to keep her bank book nor were any of the other residents in her home. She did not think this was fair as she felt capable of looking after her bank book.

Lots of people talked about not being able to carry money around with them. People talked about being frustrated because if they see something they like they cannot buy it as they never have enough money on them. People only carry a little bit of money to day centres. The money is used to buy drinks. As people do not carry money to the centres, they can only go out of the centre if it is planned. They do not have money to go out otherwise.

People talked about having to ask their staff for money if they wanted to buy things. They said they are normally given the money when they ask.

A9.3.8.2. Financial Services

Some staff at high street banks can be very good. A couple of people talked about how they always see the same person at the bank so they get good support. People felt other bank staff are not helpful. They need training on how to help people with learning disabilities when they visit banks.

A9.3.8.3. Living costs

One person (residential home) said she did not have enough money to live on. She said she has to pay her home £7 to take her out. Staff often take her out when they are off duty so she does not have to pay.

A9.3.8.4. People with mild learning disabilities

People are very fearful at the moment about changes to the benefits system which might mean they come off DLA and onto Job Seekers Allowance as they do not feel well enough to take on permanent work.

A9.3.9. General Service issues

A number of issues have been raised in various Speak Out meetings regarding service provision in general terms, which cut across multiple service areas.

A9.3.9.1. Inadequate support from staff in mainstream services

Some people with mild learning disabilities have raised the issue that they are not always recognised as having learning disabilities on the buses or in shops and therefore the staff do not recognize the need for accessibility and appropriate support. Therefore they can rush them or not explain properly or not be sensitive to their support needs.

A9.3.9.2. Not understanding information or how to access services

Many people with learning disabilities do not read and write and therefore can't access information easily. Most information from services takes a written form, very little locally takes an easy read format with easily recognisable pictures. A lot of the information produced people find hard to recognize what it is about unless there are very immediately recognizable photos or pictures. Even in an easy read format people need support to make sense of the pictures. Often people interpret them in a different way to that intended by the writer.

For people with mild learning disabilities who do not have support from day services and residential services it is very difficult for them to deal with letters and forms from services. Forms are often very complicated and people need support to fill these in. Council processes e.g for housing are complicated.

A9.3.9.3. Finding it hard to complain or challenge services.

People with learning disabilities find it hard to complain about learning disabilities services, council services and mainstream Brighton and Hove services. Complaint processes generally rely on being able to communicate confidently and clearly verbally over the phone or through letter, email or to fill out a form. All of these things are difficult for people with learning disabilities. Advocacy workers at Speak Out, and some support workers will support someone to make a complaint sometimes e.g to the bus company, but complaining will not happen for the majority of times people are unhappy with a service. For the services people are reliant on for support it becomes even more challenging as they don't want to say they are not happy for fear of offending or threatening the relationship and support they do have.

The Link Group at Speak Out did some work in a number of residential homes to support people to speak up about the service and know their rights. This work was then continued by Southdown Housing who supported residents to set up residents' meetings and bring up issues with staff. There is a follow on project to create a video for people with learning disabilities about what to expect from staff. However for a lot of residents who have lived in a place for a long time relationships get blurred and they can feel bad or guilty about saying anything wrong about a member of staff. People can also be made to feel pressure for wanting to move on .eg someone received advocacy support because she felt the residential home was not supporting her decision to move on.

A9.3.9.4. Having a say in local services.

Through Speak Out’s learning disability awareness training a few connections have been made between council departments and advocacy groups. One group did some consultation around the Level development which involved going to the site and looking at options for activities on the site pictorially. They also gave feedback on their perception of the Level and usage which highlights their concerns around community safety. Often the consultations and surveys sent out by the council are too complicated or more recently are online which is difficult for the majority of people with learning disabilities to access. The majority of people with learning disabilities do not have computers or only access them during a basic skills session.

One of the advocacy groups recently met with disability champion Councillor Stephanie Powell which provided an important opportunity for people to raise issues around problems with services in the city.

A9.3.9.5. People with mild learning disabilities

People with mild learning disabilities often find it difficult to negotiate their way through general services which are inaccessible on a number of levels. Staff in general services often do not understand that people need extra support in order to understand procedures. This is made more difficult as forms and information are often inaccessible.

A9.4. Conclusion

The most significant issues emerging for people with learning disabilities who have been involved in Speak Out's advocacy work are largely those which affect the level of choice and control in people's lives. Key barriers are a lack of support for people to participate in community activities. Although opportunities exist in the form of day centres or occasional social events such as the Blue Camel club, there was little support for many people to engage in friendships and relationships or to visit community venues. In some cases there was also limited support for maintaining a healthy lifestyle. People also felt a strong need to be valued, often through employment or volunteering, but felt there was not enough support and choice to do this.

These barriers were particularly evident for people with mild learning disabilities who received very limited levels of support from learning disability services. However many people in large residential care homes also lacked this kind of support, and had very little choice and control in their lives, particularly in regards to how their homes were run. Conversely, there are some people with learning disabilities, typically those in smaller homes and supported living, who are very well supported in their lives and provide examples of best practice in delivering Person-centred support.

Another major barrier for people with a learning disability throughout different services is a lack of accessible information which prevents many people from understanding how services are provided. Where people lack support to engage with services, this can become particularly confusing and lead to poor outcomes for people with learning disability in many areas of their lives.

Appendices: Learning Disability Research

A10 Appendix 10: Interview Guide

Interview Guide

Thank you for agreeing to participate in the Count Ability research project.

You hopefully received an information sheet about the research and a guide to the kind of questions we will be asking you during the interview. Did you get an opportunity to read these?

If not, go through the information sheet now.

We would now like to begin the interview. Please be aware there are no right or wrong answers, we just want to hear from you about your experiences living in the city and the kind of barriers, challenges and opportunities you face in your daily life. We want to learn from you and are very grateful that you have chosen to share your experiences with us!

Rather than ask you about all public services in the city we want to understand what is important in your life and find out if there is anything that makes it more difficult as well as things that make it easier. To start with we will ask you some general questions about your life, for example about any jobs, volunteering or hobbies you may have, or about where you live and any kind of support you receive. We will then ask you some more questions about specific services that you may use.

The interview will last approximately one hour and you can take a break or ask to stop the interview at any time.

GENERAL QUESTIONS

There are many different terms to use when talking about disability. Thinking about yourself, do you have a preference for the words that are used: do you prefer *disability, impairment or health condition?*

Could you tell me a bit about your disability and how it affects your everyday life?

Please describe a typical week in your life, in terms of what you spend your time doing.

- In addition to any work (paid or voluntary), we also want to know about things you do or events you attend in your community
- we also want to know about your hobbies and interests
- we are also interested in the people who are important in your life, for example friends, families, or partners

Please tell us a little about your experiences of living in Brighton and Hove?

- We would like to know what you like/dislike about the area you live in
- We would also like to know what is easy/hard about living in Brighton and Hove?
- Is there anything you currently have that helps you to do what you want -- this might be a piece of equipment, or someone who helps you in or out of the home
- Is there anything that prevents you doing the things you want to do?

As someone with a disability/impairment/health condition , do you face any particular barriers/challenges/problems in your everyday life?

Prompt:

- In relation to getting out and about
- In relation to housing
- In relation to participating in the community, e.g. accessing community groups and events, accessing leisure and social facilities, meeting friends, etc
- In relation to accessing health & social care

Where you have experienced a barrier/challenge/problem we would like to know how it affected you and how you responded to it

- we also want to know how the problem might be avoided or removed
- we also want to know whether you were able to get round the problem, or if there is something that would have helped you to get round it
- we also want to know about problems you may have experienced in the past

<u>ADDITIONAL QUESTIONS:</u>

Once we begin to understand a little better about you and your situation, we will then ask some more specific questions about services that may be relevant to you. We will not necessarily ask all of these questions but will ask you what is important to you. Here are some of the questions we may ask :

Crime and community safety

- How safe do you feel in your neighbourhood?

    - Have you ever experienced crime
    - have you ever experienced bullying , intimidation or harassment
    - Have you ever contacted the police/fire service/community safety team. If you did, we want to hear about your experiences
    - How safe do you feel in the city centre?
    - What makes you feel safe or unsafe?
  - Have you ever experienced any problems relating to fires or fire evacuation procedures?
    - Are you confident about what you should do in the event of a fire in buildings that you regularly use (e.g. your home, workplace, etc)

Housing

- What do you like/dislike about your housing? We are interested in what you think about the property as well as the people in it.
  - Are you able to go where you want, and do what you want, when you want in your own home?
  - Is there anything or anyone that helps you in your own home?

Health

- How easy is it to get the health services you need?
  - What health services do you use regularly? What do you think of them?
  - Do you feel you have enough information about your impairment/disability/health condition?
  - Are you able to access all the health services you need?   Is there anything else that could improve your health?

Social Care

- Please tell us a little about any support you receive with your everyday life

  - we want to know about people who help you with personal care
  - we want to know about people who help you with domestic duties (cooking, cleaning, shopping, childcare)
  - we want to know about people who help you to access your community (leisure, etc)
  - we want to know about equipment and adaptations you use

How well is this support working for you? Is there anything that you would like to change about the support you receive?
How important is it to you? Do you want it to continue?

Transport and the environment

- How easy is it for you to get out and about in the city?
  - We want to know about any places you go to often as well as places you avoid
  - we want to know about any Problems you have accessing buildings (shops, community buildings, leisure facilities, pubs, cafes and restaurants)
  - we want to know how you travel around the city (on foot/bus/taxi/car)

Services related to community participation

- What kind of activities do you like to participate in when you have time available?

  - We want to know about any clubs, groups or organisations you are involved in
  - we want to know about any volunteering you do
  - we want to know about social activities with friends, families and partners
  - we want to know about any Sports, leisure and hobbies you do
  - we also want to know about any Online groups/activities
  - What kind of activities exist in your neighbourhood? Do you get involved in these? Is there anything that stops you getting involved?
  - Is there anything you would like to do more of?

A11 Appendix 11: Focus Group Guide

Focus Group Topic Guide

Introduction

- Welcome and thanks and general stuff about timings, refreshments, where the toilets are etc.
- Point of project
- Confidentiality/recording
- Being respectful and listening to each other – taking turns to have say
- Divergent views equally valid – no right or wrong answers
- Feedback after the group

Icebreaker

Go round the group and ask people to say their name and the best and worst things about living in Brighton and Hove.

For each issue explore:

- Impact on day-to-day life
- Potential solutions

General introduction

- What issues and barriers do people encounter on a day to day basis?
- What one change would make your life easier in regards to these services?

Transport & Getting Around

- How easy is it to use taxis and buses in the city?
- How do you find the attitude of bus & taxi drivers?

Community participation

- What benefits do you get from being part of Sussex deaf Association? How important is it to have groups like these?
- Are there any other groups which you are part of
- How did you find out about these different groups? What are the best ways for service providers to communicate to people?

- Do you feel you have enough information about community groups, clubs or organisations in the city? Are there any types of groups you would like to know about? Do you know what is going on in your neighbourhood?
- Are there any groups that you would like to be a part of but cannot? How well do groups meet your needs? E.g. signers etc
- How involved do you feel in the community? Is there anything that would help you to feel more involved?

Health

- How happy are you with the health care you receive?
- (Hospitals, GPs, polyclinic)
- have you had any negative experiences with doctors? How about with hospital staff and at accident and emergency?
- How well do the medical staff understand your needs? Do they provide the support you need e.g. with signers etc? How well does this work?
- How easy is it to access GPs when you need them?
- What experiences have people had of changing GPs? Has the quality of care been affected?
- How involved do you feel in your treatment? Do the medical professionals listen to you about your experiences/symptoms?
- Do you feel you have enough information about health services available to you on the NHS?

Social care

- How easy has it been to get advice and information on your entitlement to social care services? How about regarding other services – e.g. private or community services?
- How easy has it been to get equipment to help you in and around the home?
- How do you find the attitudes of social care staff – e.g. social workers, occupational therapists, etc?
- How important are family, friends and neighbours in helping you to stay independent? Does the need for support cause any problems for you?
- Have carers encountered any issues supporting others

(Probe on limitations to independence, problems asking for support, perceived impact on carers)

Housing

- How easy has it been to get information about different types of housing?

- How many people have homes that fully suit your needs? How easy has it been to get a home which suits your requirements? What are people waiting for?

(Probe on different methods e.g. moving - private v. Housing Association, adapting your existing home, waiting times)

- What do you think of the quality of your current housing?
- How easy is it for you to deal with problems relating to your housing?

(Probe on making complaints, getting things fixed)

Crime and community safety

- Is there anything that makes you feel unsafe in Brighton and Hove?
- Are you concerned about the level of crime in B&H?

(Probe on differences between areas and times)

Employment & Volunteering

- Are there any adjustments that enable you to work or volunteer, or could allow you to work/volunteer in the future?
- How have employers reacted to people becoming disabled at work?

Appendix 11: Focus Group Guide

A12 Appendix 12: Screening Questionnaire

INTRODUCTION

Thank you for getting in touch. My name is……………….. and I work for the Federation of Disabled People's Count Ability project.
Count Ability is a research study which is being funded by public services including the Council, NHS trusts, and emergency services. The study is being carried out to help the Federation to understand more about the experiences of disabled people and hopefully improve services.
We are using various methods to gather information including interviews and focus groups.

This research is **confidential** and **anonymous**. This means that anything people tell us will be treated confidentially, and that any comments will not be linked to peoples names. The council, NHS and other agencies will not be given the names of the people who take part in this research.

If you agree, we would like to ask some general questions about you now, as the first stage of the research. We will then tell you how you can get more involved. It will take about 10 minutes.

Would you like to proceed?

You do not have to answer any questions you do not want to, although the information will help us to make sure we hear from a wide range of people.

Appendix 12: Screening Questionnaire

Can I ask you how you heard about the research project?

Q1: Do you have a long-term illness, disability or impairment?
(Long-term means anything that has lasted for at least 12 months or is likely to affect you for at least 12 months)

☐ Yes
☐ No -- CLOSE

Q2: How would you describe your illness, disability or impairment:
Notes:

Q2a: Would you describe it as

☐ 1. Physical impairment
☐ 2. Visual impairment
☐ 3. Hearing impairment
☐ 4. Learning difficulties
☐ 5. Mental health condition
☐ 6. Progressive, cyclical and fluctuating conditions (Cancer, MS, HIV, Parkinsons, muscular dystrophy)
☐ 7. Other

Q3: Does your illness, disability or impairment substantially limit your normal day-to-day activities in any way?
(Normal day-to-day activities include everyday things like eating, washing, walking and going shopping)
(substantially limits means nontrivial and difficulties which affects time taken to carry out an activity or the way the activity is carried out)

☐ Yes
☐ No -- CLOSE

[DON'T ASK] Gender

☐ Male
☐ Female

Q5: Which of the following age ranges applies to you? [Read options]

☐ Under 18 --CLOSE

☐ 18-25
☐ 25-50
☐ 50-65
☐ 65+ --CLOSE

Q6: Are you currently working, either part-time or full-time?

☐ Yes – GO TO Q7A
☐ No – GO T Q7C

Q6a: If not working: can I ask which of the following best describes your main activities at present? [Read options]

☐ Doing unpaid/voluntary work
☐ Unemployed - unable to work due to disability or illness
☐ Unemployed - looking for work
☐ Student
☐ Retired
☐ Other

Q8a: In which area of the city do you live? [Do not read options]

☐ **Outskirts**
☐ Portslade
☐ Hangleton & Knoll
☐ Withdean
☐ Patcham
☐ Hollingdean & Stanmer (Hollingbury)
☐ Bevendean
☐ Moulsecoomb
☐ Woodingdean
☐ Rottingdean (Ovingdean)
☐
☐ **Hove**
☐ Wish
☐ Hove Park
☐ Westbourne
☐ Goldsmid
☐ Brunswick & Adelaide

☐ **Central Brighton**
☐ Regency
☐ Preston Park
☐ St Peters & North Laine,
☐
☐ **East Brighton**
☐ Whitehawk & Manor Farm
☐ Queens Park & Craven Vale
☐ Bristol Estate
☐ St James Street & Kemptown
☐ Hanover & Elm Grove (Tarner)
☐
☐
☐
☐
☐
☐

To help us make sure we cover many different areas of the city, we would like to record your postcode:

Q8b: What is your postcode?

In this research we are aiming to involve people from a wide range of backgrounds. We are particularly keen on speaking to people from different ethnic backgrounds as well as people from the LGBT community, and people from the travellers community. In addition to interviews we are therefore holding focus groups for people who identify with these groups.

Q9: Would you be interested in attending any of the following:

☐ An LGBT focus group
☐ A black and minority ethnic focus group
☐ A focus group for the traveller community

Q10: And finally, is there anything you would like to tell us about your experiences as a disabled person that we might want to investigate in this research? These may be problems you have faced recently or something that annoys you. Or it might be about a positive experience you have had with service providers or other people.

Reserved slots
Learning Disability: 5 slots, any age/location
Physical Disability: 5 slots, any age/location
Mental Health: 5 slots, any age/location
Long-Term Health Condition: 5 slots, any age/location
Deprived area: 5 slots, any disability
Youth (18-30): 5 slots, any disability

Notes for interviewer:
If the participant qualifies for one of the reserved spaces:

Thank you for answering those questions. We would now like to invite you to take part in an interview at a convenient time for you sometime in the next few weeks. Interviews will be held at Montague house in Brighton, and all travel expenses will be paid. Would you be willing to take part in an interview?

[Offer to hold the interview in the participants own home if this is more appropriate – e.g. where participants have mobility impairments]

[If the participant agrees, record their contact details in the database]

The venue is fully wheelchair accessible, but could you please tell me if you have any access requirements we need to take into account?

[E.g. signer, hearing loop, translator]

Book a date, and arrange to send confirmation in the post/email. You should mention that this will also include an information sheet about the research and the consent form. Ask if there is a particular format that you need to send any correspondence in [e.g. via e-mail, large print, etc]

If the participant does not qualify for one of the reserved spaces:

Thank you for answering those questions. If it is okay, we would like to take your contact details so that we may contact you at a later date to get more involved in the research. This might be in the form of a focus group, interview or completing a survey about your experiences in the city. Would you be willing for us to contact you at a later date?

[If the participant agrees, record their contact details in the database]

Appendix 12: Screening Questionnaire

A13 Appendix 13: Consent Form

Count Ability - barriers, challenges and opportunities experienced by disabled people aged 18-65, living in Brighton and Hove

Name, position and contact address of Researcher: Dr Jon Hastie, Federation of Disabled People, Montague House, Montague Place, Brighton, BN2 1JE

		Please initial box
2.	I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions.	☐
	I understand that my participation is voluntary and that I am free to withdraw at any time, without giving reason.	☐
3.	I agree to take part in the above study.	☐

Please tick box

		Yes	**No**
4.	I agree to the interview / focus group / consultation being audio recorded	☐	☐
☐	I agree to the use of anonymised quotes in publications	☐	☐

5. I agree that my data gathered in this study may be stored (after it has been anonymised) on a password protected computer at the Federation of Disabled People and may be used for future research. ☐ ☐

______________________________ ________________ _________________________

Name of Participant Date Signature

______________________________ ________________ _________________________

Name of Researcher Date
Signature

A14 Appendix 14: Research Information Sheet

If you no longer wish to participate in the research please contact the research team on 01273 296755 or e-mail countability@bhfederation.org.uk

*

Please read the following information about the research before you attend the interview. Please also sign the consent form attached and bring it to the interview.

Count Ability - barriers, challenges and opportunities experienced by disabled people aged 18-65, living in Brighton and Hove.

You are being invited to take part in a research project about people with an impairment, disability or health condition in Brighton & Hove. Before you decide whether or not to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully'.

What is the purpose of the study?

The aim of this research is to gather information about people's experiences of services from the council, NHS and other public services, and to find out about the different kinds of support people need in their everyday lives. The research will be used to inform how public money is spent in the future. It will also help the Federation of Disabled People to ensure it represents the best interests of people with an impairment, disability or long-term health condition in the city.

The research will run between June-October 2011. We will be conducting 50 in-depth individual interviews and 10 focus groups. There is also an online survey for anyone who wants to take part but cannot attend an interview or focus group.

Why have I been invited to participate?

We are contacting you in response to your enquiry about the research, and would like to invite you to be interviewed by one of our researchers.

Our research is open to anyone with an impairment, disability or long-term health condition aged 18-65 in the city.

Do I have to take part?
It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason.

What will happen to me if I take part?
If you agree to take part, we will arrange a time and date to interview you. This interview will last approximately one hour and will involve questions about your experiences in regards to a range of topics (such as housing, health and social care services, employment, transport and your involvement in the community). There are no right or wrong answers, we simply want to understand about the barriers, challenges and opportunities in your life and hear about your experiences. You do not have to answer any questions you do not wish to.

The interview will be audio recorded to allow us to analyse it later. The information you give us will not be linked to your name, and the council, NHS and other public services will not be given the names of people taking part in the research. It is confidential and anonymous.

As any information you share will be anonymous, there are no risks to you personally from taking part in this research. However, the final research report will be used to help public authorities make sure they spend their money in the best way, which means some services may be cut if people tell us they are not needed.

What are the possible benefits of taking part?

Funding decisions will be made whether or not this research is conducted, but this research will make sure the council and other authorities have a better understanding of what disabled people need in the city. By sharing your experiences you are helping groups and organisations to understand how to improve.

Will what I say in this study be kept confidential?
Interview recordings will be stored securely on a password-protected computer at the Federation of disabled people's headquarters. They will not be linked to people's names.

Contact information for participants will be stored in a separate file and kept securely on a password-protected computer.

What will happen to the results of the research study?
The results of the research will be published in a summary report on the Federation of Disabled People's website and will be available in hard copy on request.

The report will be used by local public authorities to help inform how they provide services in the future.

Who is organising and funding the research?

The Federation of Disabled People is being funded by the Brighton and Hove Local Strategic Partnership to deliver this research in consultation with the University of Brighton.

Dr Jon Hastie, at the Federation of Disabled People, is leading the Count Ability research project. Interviews will be carried out by both Jon Hastie and research assistants Alice Turner and Clare Karslake.

Who has reviewed the study?

The research team has received advice and guidance on conducting the research from the University of Brighton.

Contact for Further Information

You can contact a member of the Count Ability research team on 01273 296755 or at countability@bhfederation.org.uk

If you have any concerns about the way in which the study has been conducted, you should contact the Chief Officer of the Federation, Geraldine Desmoulins on 07795 312 709 or geraldine@bhfederation.org.uk

Thank you

Thank you for taking time to read the information sheet and for taking part in this research.

Appendix 14: Research Information Sheet

A15 Appendix 15: Equalities Monitoring Form

We want to make sure that this research hears from as wide a range of people as possible.

We will only use this information to identify any groups of people not included in the research. Please fill in as much of the information as you feel comfortable with.

It is anonymous and confidential. A short guide to the form and the questions is also available. Please ask for this if you haven't received it with the form.

Thank you.

Your age:	
What age are you?	………………………………….. ☐ I do not wish to disclose this

Gender	☐ Male ☐ Female ☐ I do not wish to disclose this information
Is your gender identity the same as the gender you were assigned at birth?	☐ Yes ☐ No I do not wish to disclose this information

I would describe my ethnic origin as		
White ☐ English / Welsh / Scottish / Northern Irish / British ☐ Irish ☐ Gypsy ☐ Traveller ☐ Polish ☐ Portuguese ☐ Any other White background	**Black or Black British** ☐ African ☐ Caribbean ☐ Sudanese ☐ Any other Black Background **Mixed** ☐ Asian & White	**Other Ethnic Group** ☐ Turkish ☐ Arab ☐ Japanese ☐ Any other ethnic group (please give details) ………………………………………..

Appendix 15: Equalities Monitoring Form

Asian or Asian British ☐ Bangladeshi ☐ Indian ☐ Pakistani ☐ Chinese ☐ Any other Asian background	☐ Asian & Black African ☐ Asian and Black Caribbean ☐ White & Black African ☐ White and Black Caribbean ☐ Any other mixed background	☐ I do not wish to disclose this After you have ticked a box: If there is an ethnic category that is not included here that you think should be, please tell us what it is: …………………………………….. ……………………………………..

Please select the option which best describes your sexual orientation
☐ Heterosexual ☐ Lesbian ☐ Gay ☐ Bisexual • Other (please state) …………………………………………………….. ☐ I do not wish to disclose this

Please indicate your religion or belief		
☐ I have no particular religion ☐ Buddhist ☐ Christian ☐ Hindu ☐ Jain ☐ Jewish ☐ Muslim	☐ Pagan ☐ Sikh ☐ Agnostic ☐ Atheist ☐ Other (please state) ………………………………	☐ Other philosophical belief ………………………….............. ☐ I do not wish to disclose this

Are your day-to-day activities limited because of a health problem or disability which has lasted, or is expected to last, at least 12 months?	☐ Yes ☐ No ☐ I do not wish to disclose this
Please state the type of impairment which applies to you. People may have more than one type of impairment, in which case you may indicate more than one. If none of the categories apply, please mark 'other'.	

☐ Physical Impairment ☐ Sensory Impairment ☐ Mental Health Condition ☐ Learning Disability/Difficulty	☐ Long-standing illness ☐ Other (please state) …………………………………………………

Are you a carer?	☐ Yes ☐ No ☐ I do not wish to disclose this
If yes, do you care for a…….?	☐ Parent ☐ Child ☐ Other family member ☐ Partner / spouse ☐ Friend ☐ Other ………………………………………………………..