Exploring the everyday lives of disabled people

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2021

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[1] Policy Lab is an established innovation function for policy-making, operating as a service for commissioners in government departments. The team has 7 years' experience of testing, learning and demonstrating how policy innovation works, partnering with policymakers right across the UK Civil Service and internationally, through policy projects, training and knowledge-building activities. Policy Lab is multidisciplinary, drawing on expertise from social research, ethnography, design, data and futures, alongside policy expertise.
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Executive summary

The objective of this research was to gain deep insight into the lived experiences of disabled people, rather than to provide a representative picture.

Lived experience refers to knowledge acquired through direct, first hand and personal experience. This is essential with regard to disabled people as the variety of impairments makes assumptions about them problematic.

The aims of the research were to:

- inform cross-cutting policy development and policy announcements
- enable policies developed for disabled people reflecting their lived experiences
- help inform the government how to better integrate departmental policies and services

This research was conducted prior to the COVID-19 pandemic and a follow up to this project looks at the effects of COVID-19 on disabled people’s everyday lives.

Chapter summaries and main findings

Chapter 1 focuses on the barriers that participants faced in terms of feeling valued and having a sense of self-worth. Maintaining independence was fundamental to participants, yet they experienced boredom, inflexible working systems, and a host of other barriers. It was difficult for the participants to find meaning and purpose in their lives, specifically those who had been declared ‘unfit’ for work, were isolated, or were excluded from opportunities to socialise, have hobbies, or enter public spaces. Traditional work environments excluded some participants who had specific physical needs, for example they found full-time employment inflexible. Prevailing ideas about what is recognised as valuable work is also shown in our report to limit participants’ expectations of themselves, and their career ambitions.

Chapter 2 looks at participants’ ‘disabled’ identities and covers issues such as labelling, stigma, risks associated with social exclusion and hostility as well as perceptions of self-worth. Participants faced additional societal barriers which they felt excluded them from having a ‘meaningful’ life, at least as far as personal and societal expectations were concerned. This resulted in feelings of shame about not living up to normative ideals of what constituted a good life. Moreover, support services often reinforced feelings of inadequacy by focusing on what participants were not able to do, lowering their own internal expectations further.

Chapter 3 examines participants’ experiences of receiving and living with a diagnosis. The research found that any difficulties associated with diagnosis and personal identity were compounded by factors such as the length of time taken to receive a diagnosis, the age at which participants were diagnosed, as well as the attitudes of family and friends following diagnosis. Receiving treatment for health conditions can resolve certain problems for people, but it can also create new ones. Almost half of our participants had received treatment which had gone wrong or triggered further medical complications. Participants also described spending much of their lives waiting, for example for medical appointments, medical transport and regular visits from professionals.

Chapter 4 focuses on participants’ experience when using the benefits system, including their fears of cuts and changes to support, and difficulties surrounding assessment and reassessment. Applying for state support can be a confusing and difficult process which many of our participants began at moments of increased vulnerability. They did not all feel they received the support or clarity needed.

Chapter 5 explores the ability of participants to access and manage formal support. Monitoring and tracking paperwork, chasing up processes, and holding social and medical experts to account were key requirements in being able to access and maintain support, and participants did not feel their time was valued. Formal support models undervalued the importance of social time for the participants. Reduction in participants’ social support further isolated them and they were unable to leave home. Participants who used

Direct Payment (DP) to pay and manage their support felt there was no training for them as employers, or recognition of the skills needed to work in this way.

Chapter 6 concentrates on participants’ family relationships and friendships. Many experienced loneliness as a result of barriers to social inclusion and the fact that they were physically isolated in their homes. Loneliness was also exacerbated by empty time, such as not having activities to keep them occupied, and could intensify the isolation. For some, loneliness was pervasive and stemmed from the sense of stigma attached to being disabled.

Chapter 7 covers a range of issues relating to participants’ living spaces. There was a lack of suitable housing available to meet people’s needs. This had negative repercussions in terms of mental health, as people were often forced to live somewhere inaccessible and unsuitable. Accessing appropriate housing adaptations, and the ability to live in a suitable location, were also key factors for wellbeing.

Chapter 8 explores issues affecting the participants when going outdoors. The availability of transport, the accessibility of public spaces, and the attitudes of the general public all presented significant challenges. Non-disabled people often reinforced the physical barriers preventing entry or access to places, because of a lack of knowledge about needs, a reluctance to make necessary adaptations, and even attitudes and actions of hostility and aggression.

Research methods

We recruited 12 participants, some via a research recruitment agency, and others via local charities. We selected participants who did not have regular voluntary, professional or academic experience in promoting disability rights. The aim was to reach people who might not usually make their voices heard in public. We deliberately chose participants to include a range of life experiences.

The participants reflected a broad mix of ages, impairments, social and ethnic backgrounds, living situations and locations:

- their ages ranged from 26 to 70 years
- 3 were from ethnic minority groups
- 7 were women and 5 were men
- 2 lived with their children and one lived with their parents
- 2 were married and lived with their spouses (included in the table of participants in brackets)
- 4 lived in some form of supported housing
- 5 had invisible conditions and 7 had visible ones

Table of participants

Pseudonym	**Approximate age**	**Area of residence**
Alan	Mid 60s	North West
Armaan	Late 30s	South East
Avinash	Late 20s	South East
Diane	Late 30s	South East
Efstathia	Late 50s	South East
Jessica (and Simon)	Early 30s	North East
Joyce (and Clive)	Mid 50s	East
Kathryn	Early 70s	South East
Latanya	Mid 20s	South East
Roxanne	Mid 40s	South West
Shawn	Mid 60s	South East
Tony	Late 20s	South West

In June and July 2019, we used timeline interviewing and diaries to gather initial insights into lived experience. We kept the focus of the interviews broad, to explore the issues that mattered most to disabled people. Once we had carried out this first-look fieldwork, from June to September 2019, we analysed our findings into recurrent themes which were used to centre the film ethnography on:

- identity
- health
- relationships and society
- the environment

We spent around 70 hours with 12 people (ranging from 3 to 8 hours each) in locations across the UK. We listened to participants, including when they were at home, out at the shops, at their place of work, or in other places they visited regularly. Finally, we went through a process of grounded thematic analysis. Examples used in this report come from the body of evidence and were chosen because they best represented the themes identified from the analysis.

Cross cutting themes

In addition to the key topics, we identified a number of cross cutting themes:

Waiting and time

Participants spent a lot of time waiting. This included waiting for diagnosis and appointments, for treatments to become available, for accessible medical transport to be available, and the recovery time after treatment. They were also expected to wait for responses after interacting with the state system for various benefits. Participants felt this devalued and wasted their time.

Impact of public perceptions

Personal and organisational prejudice was strongly felt by participants and affected their confidence and sense of self-worth.

Isolation and loneliness

Participants experienced loneliness and social isolation. Small acts of negligence in care were experienced as dehumanising and exacerbated feelings of loneliness.

Independence and dependency

Dependency on other people and formal support limited opportunity to work, retain meaning and purpose, and a sense of privacy, choice, control and spontaneity in every area of their lives.

Lack of support

Participants experienced a sense of anxiety and fear around losing existing support, and built a distrust in the intentions of local authorities and assessment processes. Participants strongly disliked being asked to demonstrate what they could not do when being assessed for their needs.

Chapter 1: Barriers to feeling valued

Key findings

- The current delivery of formal and informal care can lead to increased dependency, wasting the skills and capabilities of disabled people and eroding their sense of self-worth.
- There is a lack of social provision for disabled people who are of working age, in terms of accessing support and social opportunities.
- There is often little employer awareness of non-traditional, flexible and inclusive ways of working.
- The traditional non-flexible work environment can undervalue and exclude disabled people's skills and contributions.

Introduction

Participants said that feeling valued was key to their sense of identity. They discussed a range of attitudinal and physical barriers that hindered or prevented their positive feelings of self-worth.

Findings

Maintaining independence

Whilst support from the government, family and friends is vital for many disabled people, it can also induce dependency and erode a person’s sense of self-worth. Jessica and Simon, for example, were keen to carry out their household chores themselves, but care workers often did the jobs for them, as they could do so at speed. For Jessica, doing work around the house was important, even if it took her longer, because she wanted to maintain her independence. Jessica and Simon, who are married, explained: “We understand when social services say: ‘It would be a lot quicker to get someone in to do it.’ We get that. But we don’t want it done for us, we want to take part."

Similarly, Joyce said that her friends, family and carers would regularly jump to her aid to help with everyday tasks, but that this eroded her sense of capability. Joyce found the process frustrating, since she fiercely held onto the moments of independence she still had. She said: “It’s hard to accept I can’t live a full life, as you can’t capture that freedom. And sometimes it’s such a trip-up, as I see myself as perfectly able, and something happens that shows that I’m really not." Shawn was also keen to do as much as he could. Even though he had health conditions that caused him a great deal of discomfort, he enjoyed gardening and would try to go to the shops when he felt well enough.

Alan took great pride in the work he had carried out on his house, modifying and extending it. He and his wife had lived there for over 35 years, but he was no longer able to do this type of work. Alan had always enjoyed doing things for other people, and liked that people used to depend on him for help. It was a great source of distress to him that roles had reversed, and he had come to a point where he needed to ask others for help.

Participants discussed the fact that it was not just dependency on others that could cause distress. Jessica, for example, relied on state support, and felt she was significantly constrained by the conditions attached to receiving that help. This included feeling that she could not use her university degree to gain work, which was upsetting for Jessica as she had become bored and felt underutilised.

Boredom

Inaccessibility of public spaces meant that participants often experienced long periods of time with little to do. Alan reflected: “This is how bored you get. You can be surprised by how the day can go past."

Participants communicated that whilst there are local services and activities on offer, they tend to target young people or older people, leaving other people with very few appropriate and stimulating options. Jessica and Simon asked: “What is there for us to do?” They described how they were invited to lunchtime clubs for the over 65s, but that they felt they would be better placed to run those groups rather than participate in the activities. They said they fell into an “age-gap black hole” that was not being catered for. Jessica and Simon said they were effectively stuck at home, with no outlet for their skills and no people their own age to connect with, other than their carers.

However, Joyce and her husband Clive had a contrasting experience. They regularly visited a palliative care centre near where they lived. At the centre, they were able to have tea, take part in activities and have massages and other natural treatments. Despite their initial reservations, Joyce and Clive enjoyed their time there, as it was “not just for old people, and a lovely environment”.

Participants said they often found activities and hobbies to keep themselves busy. For example, Jessica was learning sign language, Tony was a part-time radio DJ, and Efstathia wrote short stories. However, some participants felt that they were artificially filling their time rather than meaningfully contributing to society, as they wanted to do.

Work

Some working environments can be physically exclusionary. However, participants spoke about the difference that adjustments could make in terms of their ability to contribute. Diane worked in a flexible and adapted environment. She worked for a disability charity, enjoyed her job, and had gradually taken on more responsibility within her role, performing inclusion and advocacy work for disabled people. In contrast, Alan had not been able to maintain his work due to a lack of adjustments to allow him to continue in employment and Shawn reported similar experiences. This was clearly a source of distress for both of them. Tony shared some attitudinal barriers he had encountered in applying for work: “I went for a job interview a couple of years back and the interviewer was asking the carer the questions, not me."

Normative notions of work also appeared to affect people’s expectations and ambitions for themselves. Jessica explained that she would be unable to spend a 35 hour week in an office, but that she wanted desperately to be doing some kind of work. She felt that her talents were being wasted. Similarly, Armaan had always believed that he would not be able to work in an office, and so 16 years previously had decided to become a maths tutor. His career choice had been led by his impairment rather than his desires and preferences. He would have liked to have taken a different career pathway, and felt unfulfilled in his role as a tutor.

The future

While some participants were optimistic about their future, others found it a source of concern. They felt they were not able to plan ahead for independent lives like their non-disabled peers. For Alan, making sure that his wife would be taken care of after his death was important, given that he felt he would pass away before her, due to reduced life expectancy following a transplant in 2006. They have been together all their adult lives, and he wanted to make sure that she is financially secure.

Armaan wanted to live independently, to have a family, and to look after his ageing parents, but for him this was “inconceivable”. He said: “It’s something that’s on my mind all the time." He felt that his hopes and dreams were outside the realm of possibility.

Conclusion

For participants, maintaining their independence, boredom, inflexible working systems, and fears for their future were key challenges they faced in terms of feeling valued and having a sense of self-worth. Participants who had specific impairment needs found the inflexible full time work environments inaccessible, lowering their career ambitions.

Policy makers are invited to reflect on the following questions:

- How can we develop public services and policies which protect a person's sense of independence while offering support where needed so that they can have opportunities to partake in activities, work and relationships which are considered socially valuable?
- How can we ensure that disabled people are able to spend their time engaged in meaningful activity, so that society does not waste their skills and talents?
- What can we offer working-age disabled people, who are not included in social

provision targeted at young people or the elderly?

- How can we provide the right level of support to both disabled people and employers to make workplaces more inclusive?

Chapter 2: Identity

Key findings

- Labels, services, systems and treatment can focus on problems, challenges and the negative aspects of being disabled. This means that an outlook focussing on aspirations and making things happen can feel at odds with the way public services treat disabled people.
- Invisible impairments become something that people feel they need to conceal or manage privately. This can reinforce self-stigma surrounding disability identity.
- Disabled people can be vulnerable to physical or verbal abuse, which can be hard to recognise or investigate. If the person has difficulties communicating with others this can decrease the likelihood of identifying these issues.

Introduction

Participants discussed how they felt about and experienced their identity as a ‘disabled’ person.

They agreed that relating to this identity could lead to complex situations that were difficult to navigate.

Findings

Labels

Participants described ‘disability’ as a negative label. Avinash noted that disability started with the prefix ‘dis’ and therefore immediately implied something was lacking.

Some participants struggled to reconcile knowing their own value with the ‘disabled’ label given to them by society. They described how it could be challenging to feel positive in the face of such a negatively framed description. Diane found ‘disability’ reductive and preferred to label herself by naming her specific condition, or better yet, using her name, Diane.

In Jessica’s view, labels like ‘disabled’ did not serve the disabled person living with the condition. She said clearly: “Labels aren’t for me.” Rather, Jessica saw labels as something used by the non-disabled world to make sense of disabled people. She further commented that it was rare for disabled people to ask each other what their disability was.

While several participants disliked the term ‘disability’, others saw it as helpful in establishing recognition from others. Armaan’s parents did not recognise him as ‘disabled’, mainly owing to the invisibility of his impairment and lack of a diagnosis, despite the significant impact his condition has had on his daily life. He also felt that his acquaintances and friends did not understand the physical pain he experienced. For Armaan, not being given this acknowledgment in close relationships made him doubt himself and his experiences.

This issue specifically affected participants with non-visible conditions, who wanted to be recognised as ‘disabled’ in order to be better understood by others. Kathryn was frustrated that her mental health issues were hidden and thus not recognised or acknowledged. She believed that if her impairment was visible, she would have felt safer socially and been better accommodated for.

Stigma

Despite having to be formally recognised as ‘disabled’ to receive appropriate support and reasonable adjustments, participants with invisible impairments said they were sometimes reluctant to disclose their impairments or health conditions. This uncertainty and conflicting decision was often a result of negative experiences, associations and stereotypes about disabled people.

Participants discussed the ways in which they kept their impairments and health conditions hidden. Avinash feared people would not understand him and would treat him differently. Much of his fear stemmed from his family’s reaction to his diagnosis, creating a worry that everyone would react in a similar way. As a result, Avinash deliberately concealed his impairment from his friends and relied solely on his girlfriend for support. Shawn said he felt embarrassed when he showed signs of his health condition in public, and he often disguised his need to catch his breath by stopping to look in shop windows. Diane also concealed her impairment from others, especially when dating, for fear she would be seen as unattractive.

Kathryn felt that she had been misunderstood for years by health professionals and family members, given that there were no physical signs of the mental health issues that she lived with. Kathryn talked about society’s negative view of her condition: “I don’t want to say I’ve got a mental illness. I feel people look down on that kind of thing. It’s, again, an attitude of ‘pull yourself together’. It is a mental illness, I guess. I don’t really like to label it, but it is what it is."

Social exclusion and hostility

Fear of disclosing a disability may, in part, stem from the way in which people with visible impairments are treated. Participants with visible physical impairments had experienced apathy, exclusion, and even hostility.

Participants reported that they were often misunderstood or treated differently, or seen as an inconvenience. This led to a feeling of being unwelcome in social spaces. Tony had regularly experienced apathy from bus drivers who did not bother to put out the wheelchair ramp for him so he could board the bus. As a result, Tony felt like a burden to fellow passengers.

Latanya felt conspicuous in public and noticed that people appeared to dislike her distinctive way of walking because of her visual impairment. Therefore, Latanya did not like using her white cane and tended to minimise her physical use of space. Diane described the mental toll of having had people, particularly children, stare at her.

Several participants had experienced outward hostility from members of the public, who often showed a lack of understanding and disability awareness, such as receiving abuse for taking up space on the pavements while using mobility aids. Roxanna described her tendency to stay indoors at night, for fear of drunken abuse from others targeting her based on her impairments.

Perceptions of self-worth

Despite obstacles that were beyond their control, participants felt judged for “failing” to carry out socially valued roles, which in turn caused feelings of embarrassment and shame. Armaan recalled feeling ashamed when his friends asked why he still lived with his parents, despite the fact that he had been unable to find a job that could accommodate his needs, and this prevented him from receiving a stable enough income to live independently. Joyce talked about the prejudice she had experienced from the general public: “They say: ‘Ahhh, you’re just a benefits claimant. You’re not worth anything, you do nothing all day’, and it makes you feel unworthy. In the end you can start believing it." Similarly, Shawn noted: “I feel embarrassed sometimes being disabled. I think people look at you differently when you’re disabled." He stated that he even felt self-conscious when going to the shops.

Jessica, Joyce, Shawn and Simon all faced additional challenges which prevented them from taking part in paid employment. Different barriers meant that Armaan was not able to care for his parents, and Alan could not look after his partner. They all saw these roles as being socially valued. Despite their additional difficulties, some participants blamed themselves for failing to fulfill these expected roles and responsibilities. They stated that they felt that others judged them for not meeting these societal standards as well. As a result, some felt a sense of personal inadequacy.

Jessica explained that assessments, services and care provision reinforced these senses of inadequacy by focusing on what disabled people could not do. Diane described how patronising it could be when people celebrated her carrying out everyday tasks, like going to work or being “out and about”. She felt that their low expectations of her, like not being able to work or be “useful”, were detrimental to her.

Gaining qualifications and caring for others were 2 vital elements for participants in building and retaining participants’ sense of progress and achievement. Efstathia shared that keeping her past achievements visible, for example by having her graduation certificate on show, improved her wellbeing, particularly when she was feeling depressed and “useless”. Similarly, Jessica expressed her sense of pride about her academic achievements.

Avinash gained a sense of purpose and joy from caring for his 2 dogs, describing one of them as “like my daughter”. He also said that attending to his car, which he had modified significantly, provided great satisfaction. He had decided to start an Instagram page for his car and wanted to enter it into shows and magazines.

Kathryn derived a sense of self-worth from caring for her disabled granddaughter once a week. Similarly, Joyce valued being a wife and mother, roles that she was able to maintain even when her condition stripped her of other capabilities.

Gender and sexuality

Participants felt that overt social attitudes and expectations about disabled people meant their biological sex, their gender and sexuality went unacknowledged. They felt that social attitudes towards disability affected their gender identity and denied them the ability of being perceived as a sexual person. Joyce was concerned that her partner would no longer find her attractive because of her deteriorating physical health, and Jessica felt that society no longer saw her as a woman. She gave the example of toilets being assigned to men, to women and to ‘disabled’ people, effectively asexualising disabled people.

Conclusion

Recurring issues such as labelling, stigma, social exclusion, hostility, and negative perceptions of self-worth as well as perceptions of sexuality were some of the reasons given by participants as to why they did not generally feel comfortable expressing their ‘disability’ identity in the world.

Some questions to reflect upon are:

- How can we help the general population better understand disabled people’s lived experiences?
- How can we improve people’s communication, empathy and awareness towards disabled people?
- How can we improve awareness, understanding and recognition of invisible impairments among people and the wider society?

Chapter 3: Health and diagnosis

Key findings

- The process of receiving a diagnosis can be turbulent and easily mishandled, with long-term effects on how a person views their impairment and disability.
- Being an expert in one’s own health condition can be exhausting for disabled people, especially in the case of rare conditions.
- Disabled people without a diagnosis struggle to get the formal and informal care, support and recognition they need. This means diagnoses can unlock treatment.
- The most effective treatments for managing a condition, or pain, can fall outside National Health Service (NHS) provision, and are therefore only accessed by people with sufficient knowledge, money or support to seek out alternatives.

Introduction

Participants talked about the impact their conditions had on their lives. They shared how they were affected when they received a diagnosis, and the impact this diagnosis had on their medical treatments.

Findings

Receiving a diagnosis

Receiving a diagnosis can be a source of comfort. Some participants craved the legitimacy that a diagnosis provided. Without a diagnosis, Armaan felt invalidated and disingenuous about calling himself disabled. However, the process of getting to a diagnosis can also be traumatic for disabled people. Latanya was diagnosed with idiopathic intracranial hypertension (IIH) in 2013, just after she started university. Latanya described her journey to diagnosis as traumatic, due to the dismissive attitudes of medical professionals. This resulted in irreversible sight damage.

Participants’ reactions to their diagnoses were at times influenced by the responses of people around them. Diane explained that her parents had been told abruptly about her condition (a rare form of dwarfism) before she was born and had received little support in coming to terms with it. When Diane was a child her parents had rejected the reality of her hearing difficulties, and she felt that she had always struggled to accept this aspect of her condition herself due to her parents’ negative responses to it. As Diane learnt more about her childhood experiences, she began to understand how all of these were linked to her symptoms.

Impact of a diagnosis

A diagnosis can be a gateway to treatment or wider support. Without it, disabled people are often ineligible for formal care, and can go without informal support and recognition. Without an accurate diagnosis for his debilitating symptoms, Armaan believed he was ineligible for state benefits. He said service providers viewed people as disabled or not disabled, with no space for anyone in between.

Some participants felt it was worth accepting a diagnosis, even one they did not believe to be fully accurate, in order to access support. Jessica said she had only accepted her diagnosis of a learning impairment because it enabled her to receive much needed support.

Everyday health

Coping with severe pain can be extremely debilitating. Many of our participants experienced daily pain, affecting their ability to concentrate, maintain relationships, stay in employment and stay positive. Despite having a close circle of friends, Armaan's pain meant that he could become reclusive. He explained he would not put himself in a situation where he might feel uncomfortable or cause others to change their plans. Participants described how it could be hard to plan ahead. For Latanya: "Day to day is never the same. I just try and do what the body allows."

Efstathia was constantly exhausted by pain, and managing her pain was a daily task. Sometimes the pain was so bad she felt "crippled" by it and could only wait for it to pass. She explained: “When the pain is that severe, and there’s no painkillers that can cope with it, it affects you psychologically as well. My memory goes when I’m in extreme pain. I’m more likely to despair and become depressed."

The variance in pain levels was not the only issue people faced. Kathryn noted that her days varied, with good days and not so good days, and she could not prepare for this in advance. Her vertigo and agoraphobia meant that she had difficulty with everyday tasks like shopping in supermarkets, driving on busy roads, and dealing with unexpected events and new places. Kathryn’s health conditions made it harder for her to look after other aspects of her wellbeing. She had been invited to the hospital for an MRI scan for her knee, for example, but did not know how she would get there without a lift from her children, who she thought may have been too busy to take her.

Avinash struggled to cope with the impact of his impairments, including an anger management issue that significantly affected his daily life. He said he was trying to get himself back to “square one”, having fallen behind with home administration tasks over the years, including insurance, late payment fees, and dealing with various charges. Avinash believed he did not have the capacity to manage these things alone, so they had been put to one side.

Finding out about impairments and health conditions

Participants used different means to learn more about their health conditions and how to manage them. When Avinash was very young, he was diagnosed with attention deficit hyperactivity disorder (ADHD) and Asperger syndrome. Nobody had explained to Avinash what his diagnosis really meant. He had spent most of his life accepting his conditions, but not fully understanding their impact or how he could manage them. He had felt little interest in learning more until a much later trip to his GP had changed his mindset.

Some participants connected online with other people who had similar conditions in order to learn and share experiences and coping strategies.

Participants often felt that they knew more about their conditions than health professionals. Some participants with rare conditions said they regularly had to explain their condition to non-specialist medical professionals. Latanya had been required to educate herself on her condition, and regularly suggested treatment and medication options when dealing with doctors. Diane was also used to explaining her condition to professionals. She therefore appreciated the specialist hospital in her county because she did not need to explain her condition to the professionals treating her.

Treatment

Treatments can be vital in managing physical and mental health conditions. They range from traditional medical symptom treatments to holistic options, and can be offered on a frequent or infrequent basis. However, medical treatment can have negative side effects for disabled people, creating further problems and having a considerable impact on their body and future health.

Medication administered to Alan during an operation had resulted in severe memory loss, which had significantly impacted upon his quality of life. Efstathia had endured 5 operations on her back – an early operation had been performed incorrectly and metal had been left in the wrong place in her body. As a result, she had developed a number of other comorbid conditions, such as Addison’s (the result of ongoing steroid use), fibromyalgia and polymyalgia. Tony had little faith in medical professionals after numerous operations that had been carried out inadequately.

Latanya said that she had repeatedly had her concerns dismissed by medical professionals, during which time her condition deteriorated and caused irreversible sight damage. As a result, she had a permanent shunt in her head, and experienced nearly permanent migraines, extreme light sensitivity, very poor vision, and exhaustion. Latanya expressed how she felt: “I’m still coping with a lot of stuff. A lot of things could have been prevented. My vision wouldn’t be as bad, and possibly my symptoms wouldn’t have been so bad either. But it’s because… I get they’re medical professionals, but what happened there was more ego. I was not medically fine. What’s done is done."

Despite Kathryn’s agoraphobia, she had been referred to a therapist based in the town centre. She described the visit as “a nightmare”. After one session, she never returned because of the inaccessibility of the therapy setting due to the location. Kathryn felt she had mostly accepted her state of health and did not want to explore new treatments.

Participants had accessed a wide range of medical treatments, from free bespoke medical care to holistic support from new private centres receiving state support. Bespoke medical support was described as key to participants’ treatment plans, alongside alternative therapy for pain management. Joyce had a specialist myalgic encephalomyelitis (ME) nurse who saw her every 6 months and coordinated her medical treatment. Joyce called her treatment team “Team Joyce” and strongly praised the service she had received. Diane spoke highly of her specialist treatment service based in her county, in contrast to her experiences of general practice.

Several participants had sought out alternative treatments as the NHS did not provide what they needed. Armaan’s pain was managed most effectively through massages. He paid for the massages himself for relief. Tony had just started receiving sound bath treatments, which were effective for calming his mind and body.

Many participants reported spending long periods of time waiting, at varying stages of the medical process. They waited for diagnosis and appointments, waited for treatments to become available, and then waited to recover after treatment.

Conclusion

For participants, the age at which they had received their diagnosis and the length of time taken to be diagnosed were as important as the attitudes of family and friends about their condition. Participants discussed long waiting times, for example for medical appointments, medical transport and regular visits from professionals. For some, any negative effects of receiving a diagnosis, in terms of personal experiences and understanding of self, were mitigated by the treatments or services that had been unlocked through diagnosis.

It is vital to consider the following questions:

- How can we provide more support for disabled people who are in the process of receiving a diagnosis?
- How can we improve the experience of receiving a diagnosis, for disabled people and their families?
- How can we create a system in which disabled people with rare conditions feel supported?
- How can we move to a system in which support, care and recognition can be unlocked without diagnosis?
- How can we replicate the “Team Joyce” experience for more people?
- How can we encourage the NHS to provide alternative forms of treatment for disabled people?

Chapter 4: Accessing and managing benefits

Key findings

- There is confusion around eligibility to formal support.
- There is the need for more support to help disabled people apply for benefits and extra assistance.
- Assessments for Employment and Support Allowance (ESA), Personal Independence Payment (PIP) and Universal Credit (UC) can be experienced as confusing and lacking medical expertise. Some participants felt excluded by a system designed to help them and found the process invasive, arbitrary and subject to mishandling.
- There is little consistency across disabled people's different experiences when accessing benefits. Disabled people may experience multiple assessment processes, mutually exclusive benefits and considerable

bureaucracy.
- Reliance on the system, and the risk of formal support being withdrawn, can put some disabled people in receipt of benefits under significant mental strain.
- Participants felt that the system does not adequately encourage and incentivise paid work – if a household member goes to work, disabled people can lose eligibility to benefits.

Introduction

Participants discussed the barriers to accessing their state benefits. They shared their experiences of being assessed for different benefits, and ways they had found to help them manage the process of applying for and maintaining benefits.

Findings

Confusion surrounding eligibility for support

Eligibility and application processes for state support were reported to be confusing and unclear, with more support needed to help participants to navigate the system. Participants were unsure about what benefits they could claim to support their needs from either local or national government. Participants like Armaan, who did not have a clear diagnosis, were even more confused about their eligibility and ways to obtain support.

Participants described their confusion about starting the process of making a claim. Shawn explained how you need “your faculties” even to begin. There was the responsibility of assembling all the relevant paperwork. On turning 18, Avinash lost all of the support he had been provided to assist with his impairments and had no idea about his eligibility for support beyond that point. Avinash disclosed that the situation caused to retreat into his shell and that as a result his world became very small. This demonstrated the impact the transition from youth to adult services can have upon disabled young person and their lives.

Confusion can increase when someone applies for multiple benefits. Participants found parallel application processes tiresome and unclear. There is also a major issue of accessibility for people who do not have a computer at home, or access to one, and who find online services difficult. Some charitable organisations provide help to fill out forms, but waiting times can be long and issues can go unaddressed in the interim period.

Experiences of assessments

As there is a great deal at stake (for example, losing housing, benefits and social support) assessments can be distressing experiences for disabled people. This stress can be exacerbated if they have had negative experiences of assessments in the past, in terms of both process and outcome. Participants relayed that this was compounded when assessment centres did not allocate sufficient time to deal with claims. Some participants also noted that their assessors did not seem to be medical professionals, and did not appear to have the expertise required to properly judge their situation or to evaluate the impact their impairments had on their daily lives. Shawn was highly critical of the assessment process: “9 times out of 10 the people doing it are not doctors. They are usually paramedics, nurses, physiotherapists. The last one I had was a paramedic. They just talk to you. I had no physical examination or anything, so how can they really comment on how it affects me? She’s seeing me for about an hour, an hour of my life, and after that she knows how everything affects me."

A number of participants noted that the assessments were “all talk” and that there was no physical assessment of the body, nor was there observation of the person going about their daily life. Jessica explained that she could never remember everything in one sitting. She knew that she would misrepresent herself in assessments, so she would prefer to be watched over a period of time in her home so that her needs could be properly evaluated.

Latanya found the questions invasive and felt the Universal Credit (UC) assessment process started from a position of scepticism about her needs. The questions made Latanya feel that she was lying.

Living as a couple, Jessica or Simon could only have their capability for work assessed one at a time, which presented extra barriers when attending appointments, as well as increased costs. Jessica described this experience: “We have social services who just get in the way and create havoc. They want to look at us as individuals when we work as a team. And we don’t really know how we work as individuals as we’ve been married for 8 years."

Importantly, most of the participants strongly disliked being asked to demonstrate what they could not do in assessments. They felt that the system encouraged them to think negatively about their condition. Some participants felt they had been deliberately asked to do things beyond their ability.

Participants spent a great deal of their time waiting for responses after interacting with the state system. They felt this devalued their time. Jessica commented: “Most of our lives are sat waiting." Participants often had to wait many months for decisions affecting support. Shawn described waiting for his Personal Independence Payment (PIP) assessment outcome and the mental load this placed on him mostly because there had been no communication to reassure Shawn as he waited.

Reapplying for support

Reassessments can feel like an unnecessary source of anxiety for disabled people with long-term conditions. Participants noted what they say as an unnecessary frequency of assessments, even for impairments and medical conditions diagnosed as chronic. Shawn experienced regular anxiety about reapplications, which he felt were unnecessary because he had a chronic illness, which was unlikely to fluctuate. The process also exacerbated his anxiety which was the result of a previous assessment where his car had been taken away, leaving him unable to go out independently.

Reapplying for PIP was particularly difficult for Tony. He had a visual impairment and relied on housemates to read his letters. Tony disliked the “burden” of having to rely on others for regular reapplications and found the process highly stressful, as well as dealing with the loss of privacy throughout the process.

For 10 months Efstathia had been appealing for her PIP to be recalculated. She had been assessed 3 times whilst in hospital. She expressed her frustration: “I’m always getting letters through saying I need to reapply for my PIP. It does my head in. It’s infuriating how you get a certain amount of money each month and then it changes and then it stops and then it changes."

Cuts following assessments

Cuts to benefits and personal care plans can have significant detrimental effects on people’s health and lives. As a result, participants shared that the possibility of new or additional assessments caused great anxiety and stress.

Efstathia had her social care hours cut from 30 to 20 hours a week. She was in the process of appealing the decision with the help of a charity lawyer, but was finding the process difficult. She was totally “housebound”, and had not been out for months, as her caregiver did not have time to accompany her outside. She was left alone at least once a week for an extended period of time without any company at all. Efstathia stated that she felt “locked down” even before the COVID-19 pandemic. She felt that her local authority had made the decision to cut her hours as a result of limitations to their budget, rather than based on a true assessment of her needs. She commented: “My needs are irrelevant. They think that just so long as you’re getting your meals and your personal care, that’s enough, but a person needs more than that."

Disabled people communicated that they viewed future assessments, and the reduction in benefits and support that can accompany them, as a continuous threat. Participants felt that their support was precarious and could easily be removed at any time. Shawn described the devastation he had experienced after a PIP interview, when he had lost his motability support and his car was taken away. Shawn was distraught as he saw his car as a critical lifeline.

Managing benefits

Certain benefits are mutually exclusive. Joyce and Clive were not able to receive Carer’s Allowance (CA) and Income Support (IS) at the same time. Clive’s £64 CA was deducted from his IS, making his claim for the latter pointless. Joyce said that this “completely takes away any kind of worth”, or recognition of, his dedication to her care.

Furthermore, while Clive was still in work, Joyce was not eligible for the housing adaptations that the local council had initially promised. She felt that this was “very wrong” and created an incentive to stop working. Joyce believed that home adaptations should be ‘needs based’.

Jessica and Simon were prevented from saving, because if their savings reached a certain threshold [£6000] it would negatively affect their benefits. This meant that Jessica and Simon could never plan for bigger things in the future and felt that they lost an element of control over their money. They were drawn into never-ending dependency on the state for their financial security.

Conclusion

Participants felt confused and frustrated when using the benefits system. They experienced difficulties surrounding assessment and reassessment and had real fears of cuts and changes to support that could greatly impact their lives.

Addressing the following questions may help to overcome some of the difficulties experienced by disabled people in relation to their benefits and support:

- How can we create a transparent system and clarify what benefits and support disabled people are eligible for?
- How can we ensure that assessments are carried out expertly and empathetically, and address the needs and preferences of disabled people?
- How can we iron out clashes, inconsistencies and duplication across assessments for support?
- How can we remove the mental burden and stress of people being reassessed for their eligibility for support?
- How can we create a system of support which is flexible towards individual and household needs?
- How can we give more value to the social and emotional needs of disabled people in the benefits system?

Chapter 5: Accessing and managing support

Key findings

- Some types of care fall between the cracks of medical and social care, for example changing a bed or getting food.
- Disabled people feel they have to fight for what they are eligible for, by monitoring and tracking paperwork, chasing up processes, and holding social and medical experts to account. Individuals who are not able to do this may not receive the support they need.
- Certain activities are not given sufficient priority, like making sure people leave their house or do something sociable they enjoy.
- There is no training for disabled people who opt for Direct Payments (DP) and manage their own care, or recognition of the skills needed to work in this way.
- Boundaries can become blurred between professional care relationships and informal

relationships and friendships.
- Small acts of negligence in care can be dehumanising and exacerbate feelings of loneliness.

Introduction

Participants shared their experiences of using social care services. They talked about the assessment process for getting the support they needed, as well as different issues arising within their working relationships with carers.

Findings

Assessment for support

Social care and healthcare services often provided conflicting advice to participants, and some forms of vital care were said to be covered by neither service. Participants generally experienced tensions between the different priorities of social care and NHS care. Jessica said that she “hated social care”, and that she wanted all her care to come from the NHS. Jessica pointed out that social care staff had no medical expertise about her condition and that they provided unhelpful recommendations like suggesting that she should stay in bed to avoid risks. In contrast, Jessica praised the NHS occupational therapist for understanding her needs and encouraging her to make progress and challenge herself. She said: “I don’t want the wheelchair, I want to be walking. But social care have to catch up because NHS are helping me get back walking. But social care are saying ‘Please sit back down because that’s dangerous, you might fall’.

Several participants were unable to leave home or were at risk of becoming ‘housebound’. In certain cases, neither social care nor healthcare offered the services required for participants to go outside or visit the high street. Not being able to leave her home to shop had very real impacts on Efstathia. In addition, gaps in her ‘domestic care’, often led to her not having adequate groceries. These gaps in services provided other issues for Efstathia as well. For example, she was unable to change her bedding independently and gaps in services resulted in her bedding remaining unchanged. Likewise, Diane also struggled to change her bed regularly. These gaps emerged because this type of support technically fell outside the remit of either care system and played a vital role in restricting Diane’s ability to live independently. Diane also found that the help she needed with cooking and cleaning support was difficult to obtain and she felt that she had to fight for the services she received.

State support systems were also reported to determine what is a ‘necessity’ and what is a ‘luxury’ when it comes to providing appropriate support. Sometimes, vital human needs such as social interaction or fresh air can be deemed unessential. Efstathia felt that social interactions were seen as a luxury. As a result, she did not have enough hours with her carer to be able to go outside or to have the relationships that are a human necessity.

Carers

Participants stated that using Direct Payments (DP) enabled them to take control of their care. A key to this being successful was for disabled people to hire carers which met their needs. For example, Jessica and Simon had designed a unique way to interview the candidates, playing a card game with them to gain better insight into the candidate’s personality. They felt that this method provided insight into a potential carer’s personality and attitude. Efstathia directly employed an old family friend as her carer. This meant she felt more comfortable, as she had a pre-existing personal relationship with them. Another key benefit to DP that participants discussed was that using direct care allowed them to choose the duration and frequency of their carers’ visits. This created flexibility and the ability to tailor services to their needs.

However, employing carers directly was also described as a labour intensive process, and one that was under-supported. The necessary skills cultivated through employing carers often go unrecognised and are undervalued in the current system. Some participants felt that managing DP was akin to running a business. Jessica saw her work as being the manager of the 5 personal assistants she and her husband Simon employed to care for them. She reflected that the amount of administrative work involved in operating 5 staff was equivalent to that of a part-time job, for which she was not paid. Using the DP system involved managing pay slips, paying income tax, and a range of people skills. This was both time consuming, and required a specific skill-set. This created barriers for some participants using DP as they had no first-hand experience of being in work. As a result, they often had little knowledge about how to employ or manage someone. Jessica and Simon pointed out the irony of being deemed ineligible to apply for work, but being deemed capable of employing and managing carers.

Having care managed by the council was expressed as a way to reduce the workload for disabled people. Joyce and her husband Clive used their local authority to arrange care, so that they did not have to spend time organising it. They were happy with the carer they were sent via their local council. They appreciated the fact that it was the same carer each week, allowing them to arrange a routine that suited them.

Some participants used Carer’s Allowance (CA) to support family members who provided them with care, and liked being able to reimburse their family for their support. Other participants felt uncomfortable about monetising the care they received from family or friends.

Family was cited as an essential form of support for a number of participants. Shawn’s daughter lived close by and visited multiple times a week to provide care for him. She would often cook and prepare his meals and helped him to bathe. For Jessica, Simon was not just her husband but her official carer as well. In actual fact, as they both pointed out, their care for each other was very much mutual.

On the other hand, Roxanna was uncomfortable with her family providing support. She sometimes felt her family’s focus was on supporting her needs when they were together, rather than spending time as a family. Diane had similar concerns and tried to protect her time with her family by having them not become her carers.

Those using care outside of familial relationships expressed other challenges. For them, normative categories of professional care did not always reflect the relationships that existed between the disabled person and their carer. This often created a mismatch between expectations and reality in care relationships. Roxanna found it upsetting when staff in her shared accommodation moved on, because she had come to view them as friends. She felt abandoned by their sudden departure and she reported that she was constantly having to get to know new people and help them to understand her needs.

However, a number of participants said they preferred these over-personalised relationships when compared with the anonymity of over-professionalised care. Different participants had different views on how much the categories of professional and personal should mix. For example, Jessica and Simon made it clear that the personal assistants they employed to provide care were not their friends. They had experienced problems in the past when boundaries had become blurred, and so made clear from the start that their assistants were at work when spending time with them. Others, like Tony, admitted he did not always understand or respect the line between paid for, professional relationships and informal relationships, because in his life the two were regularly mixed together.

The quality of relationships between the disabled person and their carer was of utmost importance as being cared for can sometimes feel patronising, dehumanising, brusque, invasive and isolating. Roxanna was supported by a number of carers, who were a mixture of agency staff and staff employed by her supported housing organisation. They visited her up to 4 times a day and someone was always available outside of these hours, which was very important for Roxanna. However, she reported that the interactions with her carers felt fleeting, and she observed that staff preferred to chat amongst themselves rather than talk to her. Roxanna was given food and ate alone. Staff interacted with her to perform set tasks, but socialised amongst themselves while ignoring her.

Social isolation was not all that was shared. So was the lack of recognition of disabled people’s requests. During our visit, staff at Roxanna’s accommodation had left her washing in the machine while she was out. This upset Roxanna, as she felt that this was in part due to staff's avoidance in communicating with her. Alan’s carers also neglected his laundry. He expressed his disappointment: “When I came in, I was very angry. They’re supposed to come in and they didn’t. I wish I could do it on my own. I can’t.”

Jessica and Simon described constantly waiting for visitors, decisions, services, treatment, and carers to arrive. Professionals came and went, and Jessica explained that it was rare for her and her husband to have a day to themselves without being interrupted. They saw days like these as a luxury. Jessica and Simon described constantly waiting for the long line of professionals who all had a role to play in organising their lives and medical needs.

Privacy

Some participants experienced a significant and unwanted loss of privacy as a result of their dependency on social care services. Carers accompanied Jessica to the toilet and helped her to wash. She commented that with the invasion of privacy from carers “you lose everything”. Jessica and Simon felt constantly watched. They felt that having CCTV monitor them in their home would be preferable to their situation, as it would mean they could continue to be watched without having people physically intruding on them all the time.

Jessica and Simon’s professional carers and local authority representatives had keys to their flat, which felt like an invasion. Jessica shared one poignant example where professionals had entered their living space late at night, without permission, to fix their toilet. The couple’s days were punctuated by people coming into their home and they longed for the days when nobody came.

Latanya described how the carers in her accommodation had regularly entered her home without permission to check up on her. She had decided to reject this loss of privacy by keeping her front door locked from the inside.

Conclusion

Participants highlighted a range of difficulties in accessing and managing their care and support. Reduction in participants’ social support resulted in further isolation, confining them to their homes. Direct Payment (DP) user participants reported there was no recognition of the skills needed to work and receive support in this way.

This is a list of questions to reflect on, to create a more inclusive care system:

- How can we identify, understand and provide the care that currently falls between the cracks of departmental responsibilities?
- How can we ensure that disabled people have the formal care they need to have a fulfilling life, and are not ‘housebound’ or isolated?
- How can we improve non-medical and domestic care to be more person centred, accessible and available for disabled people?
- How can we improve the process of directly employing personal assistants for disabled people?
- How can we provide ongoing support for disabled people who are managing their own care, and recognise the skills they are developing?
- What support can we offer to families and carers of disabled people?
- How can we ensure that care is delivered empathetically and with a desired level of privacy?

Chapter 6: Relationships and support

Key findings

- Disabled people can face additional barriers to meeting their social needs – these can be individual, physical and mental health issues, such as being in constant pain or fear.
- The state support system provides formal support and opportunities to socialise, but disabled people can feel lonely when this support ends.
- Disabled people also encounter physical obstacles including inaccessible houses or buildings when socialising outside of their personal environment.
- The social and medical care systems expect family members to care for disabled people, leaving little room for other types of relationship within the family unit, and lowering expectations of disabled people themselves.
- It can be hard to keep intimate relationships distinct from caring ones.

- The social care and NHS systems struggle to recognise that disabled couples can provide care for each other, and there is often an inflexible understanding of who is a carer.

Introduction

Participants shared their feelings of loneliness and explained that formal social opportunities did not always meet their needs. They also talked about how they felt about their families providing support.

Findings

Loneliness

Physical impairments and mental health conditions can create obstacles for disabled people trying to meet their social needs. Diane and Avinash had limited energy for socialising because they both had to manage their pain almost continuously. Both had to sacrifice their social lives during the week because they needed physical rest, but this did not meet their need for social connectivity. Tony had regular contact with friends but admitted he was exhausted and needed to rest more than he did.

People can feel most lonely in the times between care or service provision, especially when living alone. Efstathia’s ex-husband attended hospital appointments with her, but the time it took for him to reach her on public transport meant they did not see each other as often as she would have liked. Efstathia described the sadness of coming home from a long episode in hospital, with no one there to care for her.

Participants also expressed that their sense of loneliness could increase in the hours between activities, when at home and when nothing was happening. Roxanna desired to be highly sociable but felt the acute pain of loneliness from living alone in her flat. She also stated that she felt that she lacked true companionship and that outside of organised activities such as wheelchair dancing and art classes she felt alone.

External physical and social obstacles can also prevent people from socialising. Participants described being unable to visit friends and family at home because their houses were not wheelchair accessible and feeling isolated because of the way disabled people were viewed and treated by individuals and society.

Joyce said that wherever she went in the world with her husband, they had to do lots of planning, such as finding out whether or not the doors were wide enough, if there was a wheelchair accessible lift, and if there were steps in and out of doorways that did not have ramps. The old buildings often presented limitations. Joyce wished that the whole world were more accessible and that it was standard design on all buildings. Being able to move around as independently as possible and be part of the world was a major factor in maintaining her wellbeing. Joyce explained when she was happy and active, she experienced less pain and that her mental health was a major factor in how she survived her condition.

Similarly, for Armaan, events that were fairly straightforward for most people like going to dinner, having a night out with friends, or going away for a weekend often needed a considerable amount of organisation, where everything needed to be planned out and thought through on his part.

When it came to social obstacles, many participants described how their impairments led to a lack of dedication from others to maintaining a relationship. Latanya noted that her university friends had dropped away as her condition had deteriorated. She felt they did not understand the implications of her illness: “People tell me that it makes them uncomfortable when I’m not feeling well so it’s hard for them to be around me. I found that very strange." She further reflected: “I couldn’t be who I was before, and they fell back." After that, Latanya had relied on a friend from school for much of her emotional support. She explained that her family were also not comfortable with her medical condition.

Likewise, there were times when Diane felt very lonely. She felt that no one could understand the challenges she faced, not just with her health but also in establishing her identity. Diane talked about the acute loneliness of her teenage years, until she had connected with other people with the same condition, online and via conferences.

Online communities

Disabled people with the skills and equipment to access online communities, including communities of interest, reported that this provided them with companionship. Online Facebook groups were a source of comfort for several participants, and particularly so when health conditions or interests were very specific or rare. Diane’s form of dwarfism was incredibly rare. She had learnt more about herself and how to manage her treatment by talking with people online.

Kathryn regularly spent time connecting with fellow Cliff Richard fans on Facebook, bonding and building friendships, despite not leaving the house much. Jessica used online communities to discuss issues arising for people when employing personal assistants. She had never worked in an office so found this incredibly useful.

Care and support from family and friends

The social and medical care systems can expect family members and friends to provide care for disabled people. When this does not happen, people can find themselves without the support they need. A number of participants observed that medical staff had expected their parents to accompany them to appointments, even when they were many years beyond their childhood. Diane described being asked where her parents were, even though she was an adult. Jessica and Simon noted that their parents were expected to be involved too. However, they felt strongly that they wanted their parents to visit them only as their parents and not as their carers.

Wanting to be viewed as independent responsible adults at appointments did not mean that disabled people did not rely on their family members for care. For participants like Shawn, family was an essential form of support. His daughter lived close by and was his full-time carer. She visited multiple times a week, would often cook and prepare his meals, and helped him wash. As Shawn’s daughter said: “I do everything for him." As a result, she could not have another job. Similarly, Kathryn had experienced years of being unable to leave her home. She had relied on her young children to do her food shopping, and relied on the kindness of neighbours to take her children to school. Kathryn valued and depended on this support. Without similar support, Armaan said that he struggled to cope with household tasks when his parents went abroad for half of the year.

Putting people into normative categories, with boundaries defining different kinds of relationships, does not always reflect reality for disabled people. However, participants were mindful of keeping intimate relationships distinct from caring ones.

Roxanna felt that her family’s focus was more on supporting her care needs than simply spending time together as a family. Diane had similar concerns and made it clear to her family members that she did not want them to be her carers. She preferred to protect the family time she spent with them: “But they’re my family and friends. When they come round, they come round to see me, not do my housework."

Joyce and Clive commented that many relationships between married partners “cannot stand the stress” of coping with impairments or illness. In addition, Joyce wanted her teenage sons to be free to “roam the world and live full lives", rather than feeling a sense of obligation to provide care for her.

Caring responsibilities

Disabled people can have their own caring responsibilities, and this can be a source of concern when thinking about their futures. Armaan feared for a future in which he would fall short of being able to care for his ageing parents, or look after any children.

Formal care systems were also described as struggling to recognise disabled people as carers. Kathryn looked after her disabled grandchild, and Jessica and Simon looked after each other. This kind of care is often not recognised by others, and Carer's Allowance is only awarded to one person in a relationship, even when both people are disabled. Simon had been asked whether he wanted to place Jessica in a care home, just after they were married. Jessica and Simon were clear that their care was very much mutual, and they functioned as a team. The categorisation within social care systems is not equipped to recognise this.

Conclusion

Participants reflected on their personal relationships and how they were able to meet their social needs. Some participants experienced extreme levels of loneliness and isolation resulting from barriers to social inclusion.

According to the ONS, data from the Community Life Survey, conducted by the Department for Digital, Culture, Media and Sport showed that the proportion of people who felt lonely “often or always” was higher for disabled people than for non-disabled people across all age groups (ONS, 2019b).

Here is a set of questions to inform policy and practice addressing some of the social barriers disabled people face:

- How can we understand the specific challenges arising for disabled people, preventing them from building or maintaining social relationships?

- How can we reduce experiences of loneliness for disabled people?
- How can we create inclusive opportunities for the social participation of disabled people?
- How can we better understand what kinds of support would be useful for disabled people’s families, carers and their wider networks?
- How can we improve support for families, carers of disabled people and disabled people themselves?

Chapter 7: Home

Key findings

- There is a lack of appropriate social housing for working age disabled people, as opposed to social housing specifically designed for young people or the elderly.
- Disabled people can experience long bouts of being isolated in their inaccessible home environments.
- Equipment and records relating to disability treatment and services can take up a large amount of physical space in a person's home.

Introduction

Participants discussed their living arrangements. They shared with us the details of the adaptations they needed to make their homes accessible.

Findings

Housing

Disabled people can be placed in inaccessible and unsuitable accommodation owing to a lack of appropriate housing. Diane knew she was lucky that she had been allocated adapted housing by her local authority more quickly than expected, and that it met her needs. However, this had not been the case for many other participants.

Roxanna had been placed in a nursing home, despite only being in her late twenties, because there was no appropriate housing for her age group. She had not been satisfied with the situation as the nursing home did not permit her to be as independent as she felt she could be. As a couple, Jessica and Simon had been given a council-owned specially adapted bungalow, on floodplains, which had flooded the previous year. The adaptations that had been made did not really address their needs. They were also isolated, far from local amenities.

Partly due to housing barriers, several participants had experienced long periods of isolation, which had impacted adversely on their wellbeing and mental health. Efstathia continued to be ‘trapped at home’, with no carers to help her make the trip outside. This was a direct result of a reduction in support from her local council. Efstathia struggled to stay positive. She felt that she was stuck in a small space, and hoped that COVID-19 would create more empathy for people in her situation. As a result of her experience, it was very important to Efstathia that her living space was homely and accessible.

Supported housing

Supported housing can vary greatly in terms of quality of care and sense of community. Tony’s supported accommodation was a lifeline to him, because he had acquired a new set of flatmates who he had started to call ‘family’. Tony had a good relationship with staff and enjoyed the balance of independence and the support they provided.

Meanwhile, although Latanya was able to live independently, she was not keen on her home environment and thought it had been mis-sold to her. Her housing was part of a pilot programme identified by her social worker. Latanya shared that her accommodation was not comfortable and felt the carers lacked empathy. She also did not like that they were able to enter her flat whenever they wanted to. To gain control over who could enter and when, Latanya had started to lock her door at all times. On the whole, at her residence Latanya did not feel like there was a sense of community, and she was not able to make any close friends. Similarly, Roxanna did not know any of her neighbours and felt that there was little sense of community in her sheltered housing unit.

Home adaptations

Home adaptations can have significant physical and emotional benefits, but many participants had to negotiate with their local council to secure what they needed to live independently. Diane needed to have her thermostat placed lower on the wall and to have the height of her kitchen counters adapted to meet her needs. Some of the adaptations she needed had taken a long time to be implemented.

Joyce and Clive found that their local council would not provide any adaptations so long as a member of the household was in work. The council had visited and as Joyce stated: “wrote a huge list of what we needed." When Joyce mentioned Clive was in work, they had said: “Well you can’t have that, can’t have that, can’t have that. Oh dear, you’d better manage." Joyce and Clive had to pay what they could to make the changes they needed, until Clive left his job.

Adaptations were expressed as improving lives. Expanding Joyce’s door frame had meant that she was able to go outside in her wheelchair. She expressed how it had felt: “To actually go out of the door, without anyone helping me, was incredible." Shawn had a range of medical conditions, which significantly impacted his mobility. As a result, he had received adaptations to his house from the local authority, including a stairlift and a downstairs accessible bathroom, comprising a wet room and specialist toilet. The accessible features in the bathroom, allowed him to clean himself properly and gave him back some dignity.

Some participants had made their own adaptations to live comfortably. Diane’s Dad had stepped in to make numerous changes to help her to make her house so that she could be more independent, for example by lowering cupboards and rails. Latanya had made sure that her entire flat felt as comfortable and as soft as possible, so that she could fall down anywhere in her home without hurting herself. Joyce and Clive had restyled their door handles so that Joyce would not get trapped inside any of the rooms.

Smart home technology was also conveyed as helping disabled people to live well in their homes. Shawn found voice-controlled lights useful. His daughters set frequent reminders on his smart device so that he was able to take his tablets on time. Kathryn enjoyed asking her smart speaker to play Cliff Richard songs in her living room. He was her favourite singer.

Life at home

Many participants felt inundated with paperwork from the Department for Work and Pensions (DWP) and NHS. Since it was clear that people needed to hold onto documents from the central and local government to monitor their support disabled people reported devoting whole sections of their home to storing administrative documents. Efstathia's bedroom and living room were full of piles of papers from the local council and DWP. Jessica and Simon kept boxes of all their paperwork, dated in paper trays, stacked in their bedroom.

Specialist equipment for different health conditions and impairments can also take up extra space in the home, like Joyce's stairlift and hoist, Shawn's electric toilet, and Jessica's wheelchairs. Some participants had specific equipment for going outdoors, like more powerful wheelchairs or rollers, which they also had to store inside their home for regular use. While this equipment could provide extra independence, it could also lessen living space.

Location of home

Home location was a key factor in determining whether participants felt connected to their local area. Tony's housing location was crucial to him.

The bus routes outside his front door provided a vital link between his home and local amenities. Conversely, Joyce noted that the rural location of her home meant that she could become isolated as the local paths lacked wheelchair access. This had huge consequences for her wellbeing. She observed: “It’s so important to see things and still be part of the world."

Conclusion

Participants’ living experiences were significantly affected by the quality of their housing, the suitability and availability of home adaptations, and their home location.

Figures from the ONS showed that the percentage of disabled people aged between 16 and 64 owning their own home has decreased from 43.6% in the year ending March 2014 to 42.4% in the year ending March 2019. A similar drop was seen in social rented housing (26.6% to 24.7%), however private rented housing increased over the same period (13.9% to 14.9%) as had the number of disabled people living with parents (12.7% to 14.4%) (ONS, 2019a).

This is a list of questions for consideration to make housing more accessible and comfortable for disabled people:

- How can we create more housing, both social and private, that matches disabled people’s needs?
- How can we support disabled people who are isolated?
- How can we ensure disabled people receive the housing adaptations necessary for them to live as independently as possible?
- How can we reward working households, rather than remove eligibility for household adaptations?
- How can we reduce the amount of physical paperwork needed for disabled people to monitor and manage their support and services?
- How can we ensure disabled people's housing is in locations that allows them to be socially participatory?

Chapter 8: Outdoors

Key findings

- Poor quality pavements can hinder disabled people with mobility impairments, affecting their ability to move around outside or use their local high street.
- Arranging suitable transport can be time consuming, which means disabled people cannot be spontaneous and free to choose and participate in activities.
- Medical transport services can exclude people with non-physical impairments. Services can also be poor quality, for example leaving unwell patients waiting at home or in hospital for many hours, or failing to give advance warning when nearby or delayed.
- State services can undervalue the human need to leave the house and spend time outdoors, and they also underestimate the time it can take to go out with a carer.
- Disabled people can find public spaces hostile, owing to public attitudes, a lack of toilets, and a lack of safe and free places to rest.

Introduction

Participants shared their experiences of stepping outdoors. They identified a range of barriers to doing so, despite it being widely accepted that time outside is a basic human need.

Findings

Pavements

Accessible pavements are key to enabling people with mobility impairments to move around freely. In our research, pavements were particularly important in rural areas, where people did not live on main roads. Inaccessible rural paths could prohibit disabled people from being able to move around their local area.

For some participants, uneven pavements in their town centre caused major issues for their wheelchairs, particularly manually powered wheelchairs. For Tony, moving his wheelchair around the town required a great deal of effort and physical strength, because of poor quality pavements. For people who use walkers, support canes, mobility canes or who have ambulatory issues, uneven pavement can also pose significant barriers. Additionally, for Tony, weather affected his ability to navigate effectively as the rain made surfaces in the streets slippery. A further complication was that the rain masked the sounds he needed to hear to identify what part of the street he was in.

Transport

Having a car can play a key role in maintaining a sense of independence. 6 of our participants felt very strongly that their cars provided a continued sense of freedom, personal choice and safety, even while other aspects of their lives were changing.

Joyce’s car was wheelchair accessible and enabled her to visit her local high street as well as travelling to different parts of the country. Shawn’s car was of the utmost importance to him. It enabled him to do a bit of shopping and connected him to the outside world. When Shawn’s car had been removed following a Personal Independence Payment assessment, he recalled: “I had nothing."

Diane and Armaan depended on their cars to continue working. Public transport was not accessible to either of them so their cars were key to their continued employment.

Public and accessible transport options can be useful, but can also involve intense preparation and long waiting times. Jessica and Simon liked to travel independently on public transport when they could. They explained that they needed to book accessible transport ahead of time, meaning they had little freedom and spontaneity to travel as they would have liked. Jessica reflected: “The world is different. You have to book if you want to use a bus, you have to book if you want to get a train. That’s a luxury."

Medical transport

Relying on medical transport can be highly inconvenient, and the option is often unavailable for disabled people with non-physical impairments. Kathryn’s agoraphobia, vertigo and panic meant that she was unable to drive. Since she was also ineligible for medical transport, she was unable to reach a hospital appointment.

Efstathia relied on medical transport for hospital appointments. The researchers went with her to hospital and experienced first hand the long waiting time, the lack of communication about when the bus would arrive, and the risk that Efstathia would miss her medical appointment. Efstathia described many such instances of waiting several hours, and of missing appointments, because of the transport system.

After Efstathia’s appointments, there was often another long wait for transport to take her home. Additionally, Efstathia was not permitted to take someone with her, so her carer had to travel the long journey to Efstathia’s accommodation, and then make their own way to the hospital. Returning in the same manner resulted in a long working day for the carer.

Preparing for outside

Some participants needed to do a lot of preparation to go outside. Armaan described his routine for leaving home. He made sure that he had everything he needed, and carried out a series of exercises to minimise his pain. Many participants had additional equipment for going outside, including outdoor wheelchairs, wheelchairs for going in cars, and rollators to lean on. Setting up equipment took a lot of additional time in the lives of participants.

Other participants needed a person to support them to go out. Without appropriate support, disabled people can become stuck indoors. Efstathia had not left her home since her social care hours had been cut by her local council. Her carer did not have time to accompany Efstathia to the high street as well as making sure she had food and a clean home. As a result, Efstathia had become entirely isolated.

Public spaces

Public spaces can fail to meet disabled people’s needs. As such, disabled people can have concerns about using them. Shawn tried to go to the shops when he was able, but did not have anywhere to rest when he visited the local high street. He described trying to cover up his rest breaks by pretending to look in shop windows.

Shawn also needed to use the toilet regularly, and had to ask cafes and restaurants for permission to use their facilities. He presented his disability card in order to justify his request, and normally he was allowed access. However, this did cause him some embarrassment.

Kathryn’s agoraphobia meant that she had difficulty accessing public spaces. Kathryn felt that no one in her local supermarkets would understand her needs. She was concerned that she would be trapped outdoors and have a panic attack. Kathryn commented: “The biggest problem with it is the fear of the attack, rather than the attack itself. That makes the agoraphobia worse because I don’t want to go out."

The general public

The general public can lack understanding of disabled people's needs and can even demonstrate hostility towards them. Latanya had experienced hostility for taking up space on the pavements, so she felt conspicuous and insecure in public. She had a white cane but did not like using it. Latanya was tall and felt that she took up too much space using the cane. However, without the cane, people were rude to Latanya if she accidentally walked into them or moved slowly. Kathryn summarised her general experience of the public: “One of the worst things is people being patronising."

Wheelchair-user participants revealed that public spaces and businesses often did not understand what it meant for them to be ‘wheelchair accessible. Diane frequently asked if restaurants were wheelchair accessible, only to be given the wrong advice. Diane explained: “It feels like it’s obvious to me what it means to be wheelchair accessible, but obviously some people don’t even know what it means."

Avinash was concerned about going outside and getting into trouble owing to his anger management issues. He rarely left his home and made sure someone was with him when he did. His family’s reactions to his impairments had created a fear that everyone would react in the same way. Avinash said: “It’s not that I like staying at home. Certain things stop me from going out.

I’ve got a few issues that mean it’s safer if I stay at home."

Tony frequently travelled to London, either with a support worker or on his own, staying in the same hotel where he knew the staff. Tony was also a regular public transport user, which gave him independence. He greatly benefited from the availability of the public transport system in his city, however, he was often let down by bus drivers who remained in their cabs rather than putting out the wheelchair ramp for him to get on the bus. Tony described how it was exhausting to explain his needs to others and that sometimes he could not face another day of struggle. He often used alcohol to help him feel able to lower his inhibitions about his conditions and open up to others.

Importance of being outside

Being able to step outside can be critical to wellbeing, specifically for disabled people whose opportunities to venture out is often limited due to different social barriers, such as lack of access and appropriate transport, and the negative attitudes of the general public. Both Jessica and Shawn described the importance of having a garden they could access. For Shawn keeping active and being out and about improved his health and well-being. Kathryn also enjoyed gardening as it gave her a safe space outdoors which she was comfortable in.

Holidays can provide joy and improve people’s quality of life. Joyce described the joy of a holiday with her husband to Scotland. She was grateful for all of the adaptations that tourist sites had made so that she could experience them. For Kathryn, however, going on holiday could involve lots of trials due to the lack of understanding of invisible impairments by the wider public. She felt that having some kind of identification lanyard could work toward raising awareness of mental health issues.

Conclusion

Participants faced difficulties when going outdoors. Inaccessible pavements and public transport, as well as the attitudes of the general public, presented various challenges.

This is a list of questions that we feel will help to direct policy and practice to accommodate disabled people with a range of impairments when using transport and public spaces:

- How can we ensure that all pavements are inclusive of those with impairments that impact their mobility?
- How can we improve medical transport so that all disabled people can access medical and other important appointments?
- How can we enhance public spaces so that they meet disabled people’s social, emotional and physical needs?
- How can we ensure that everyone feels safe and supported to leave their home, when they wish to do so?

Conclusion

This report evidenced the findings of our research project, which put a spotlight on the everyday lived experiences of a broad range of disabled people. The project was carried out at a time when data about disabled people was of variable quality and when there was very uneven coverage.

This report presented the views, insights and lived experiences of disabled people. Its goal is to aid government departments to identify the policy changes that are urgently needed, and to help them develop and monitor specific policies that may break down these identified barriers. This is expanded upon in the National Strategy for Disabled People (NSfDP). The data consistently indicates that disabled people face enormous challenges and barriers to living a socially valued life of inclusion compared with non-disabled people.

Participants said that they believed in opportunities for change, given the radical reformulation of every aspect of life brought about by COIVD-19, and subsequent empathy and understanding about the experiences of disabled people. What is needed is a clear and positive vision on disability which is fully owned across government departments and bodies.

At the end of each chapter we highlighted specific questions relevant to the given topic, to inform practical changes to policy that could strengthen the ability of disabled people to participate fully in mainstream society.

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