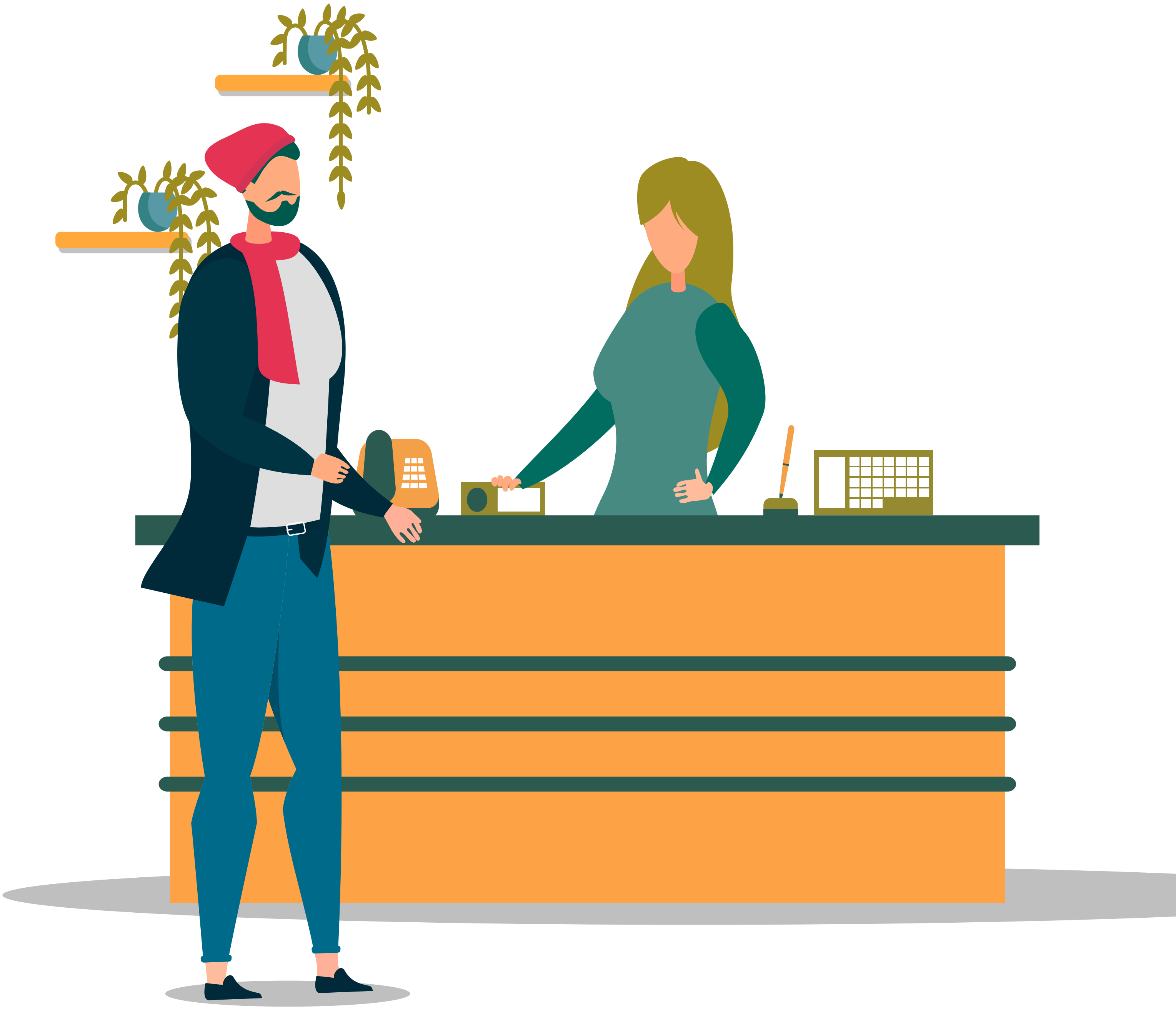
Services for Who?

The experiences of disabled people with other characteristics when accessing services

2020



drill
Disability Research on Independent Living & Learning

COMMUNITY FUND

Inclusion Scotland
Disabled People's Organisation
Our voices ■ Our choices

Contents

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Executive Summary

Discrimination due to a person's impairment together with one or more of their other identities is often described as intersectional discrimination. For example, a gay disabled person may be treated unfairly not just because they are gay and not just because they are disabled, but because of their identity as a gay disabled person.

This report sets out the findings from a research project which explored the experiences of disabled people who have other characteristics when accessing services. Many of the people we spoke to said that they had experienced intersectional discrimination.

Key Findings

Disabled people with other characteristics experience distinct forms of unfair treatment and barriers when accessing services.

- Our survey and interview findings show that some disabled people attributed the unfair treatment they experienced when accessing services to their intersectional identities. Discrimination against disabled people is therefore more complex than we may first think.
- Our research suggests that the types of treatment and barriers participants experienced appeared to be compounded by the addition of their other characteristic(s).
- Our findings show that disabled people with other characteristics were not listened to by professionals, were not given access to information about what they were entitled to and had to contend with inaccessible systems and processes. Disabled people with other characteristics also experienced bullying and invasive questioning from service providers.
- Overall our research shows that disabled people with other characteristics experienced denial of choice, control and person-centred services and this denial was very much linked to their intersectional identities.

Negative attitudes are the main reason that disabled people with other characteristics experience distinct forms of unfair treatment.

- Our research shows that many of the treatments experienced by the disabled people we spoke to were underpinned by negative attitudes and assumptions and a lack of knowledge and understanding on the part of service providers.
- The negative attitudes and harmful assumptions discussed by our participants reveal a potentially deep-seated prejudice towards disabled people with other characteristics.
- Our research suggests a lack of knowledge and understanding was connected to the types of attitudes and assumptions service providers held about disabled people with other characteristics.
- Our research also suggests, however, that a lack of knowledge and understanding seemed to sometimes be used as an excuse by service providers to avoid having to deal with some disabled people.

Service providers understand the need for person-centred services but are not always able to deliver these.

- Our research shows that service providers seem to be aware of the importance of person-centred services. While the term intersectionality was not as familiar, discussions around person-centeredness included an awareness of the need to consider the whole person, including their different characteristics, relationships and life circumstances.
- Our findings highlight that service providers work in challenging environments where they are constrained by various issues including reducing or stagnant budgets, issues with staff and recruitment and reputational risks.
- Services seem to be aware of the need to tackle issues around staff attitudes and assumptions and lack of knowledge and understanding. However, the extent to which they feel able to do this while operating within challenging environments and using existing service processes was limited.

Conclusion

Overall this research suggests that disabled people with other characteristics do experience distinct forms of unfair treatment when accessing services because of their intersectional identities. This unfair treatment is underpinned by negative attitudes, assumptions and a lack of knowledge and understanding from service providers.

Service providers do show an awareness of the importance of person-centred services, however putting this into practice seems to be challenging particularly because of constraints around staff, resources and risk aversion.

Disabled people make up one fifth of the Scottish population and each disabled person has a unique combination of characteristics and circumstances. It is therefore imperative that service providers see and treat disabled people as individuals with individual needs and preferences. To do this service providers should adopt a genuinely person-centred approach to how they deliver their services. They must also ensure that staff are trained and are given the right support and supervision to be able to develop their knowledge and continuously challenge their own beliefs and assumptions about disabled people.

Only once negative attitudes towards disabled people are effectively challenged and eliminated will services be able to be genuinely inclusive of all disabled people.

> **Disabled people** make up **one fifth** of the **Scottish population**

Chapter 1

1.1 Background

There is some evidence, including from our engagement activities with seldom-heard groups, that disabled people with other characteristics experience distinct forms of discrimination when accessing services essential to independent living, which cannot be attributed to negative attitudes around disability alone (Acker-Verney, 2017). For example, disabled women often receive poor information and experience constraints on choice within reproductive and parenting services (Engender and Inclusion Scotland, 2017). Black and minority ethnic disabled people report specific healthcare barriers as a result of being disabled within a Western cultural context (Shah et al., 2001). Lesbian, gay, bisexual and transgender (LGBT) disabled people report carer prejudice/ignorance which restricts their access to LGBT resources and therefore independent living and wellbeing (School for Social Care Research, 2017).

There are widespread failures to take account of intersectional discrimination, to take an intersectional approach when developing policy or services targeted at disabled people, or to include disabled people in policy or services targeted at other equality groups. Equality groups, including Disabled People's Organisations (DPOs), do not always take account of intersectionality among their particular group. This may not reflect deliberately negative attitudes but, rather, lack of awareness – perhaps unsurprisingly, given the apparent insufficiency of work that makes the experiences of disabled people with other characteristics publicly visible. Indeed, there are difficulties with the very concept of 'intersectional discrimination' and legal scholars are increasingly debating ways of accounting for intersectional discrimination and access to justice (Fredman, 2016) (Social Platform, 2017). This legal gap was first used by Kimberlé Crenshaw to illustrate 'the problem of intersectionality' (Crenshaw, 1989).

The Equality Network in Scotland has created a useful resource to support service providers to be more inclusive of intersectional disabled LGBT people (Rankin et al., 2016). Some academic work which charts discrimination occurring in relation to disability and other characteristics does exist (Shaw et al., 2012). However, it is quite limited and is generally not widely accessible to disabled people.

> **The Equality Network in Scotland** has created a useful resource to **support service providers** to be more inclusive **of intersectional disabled LGBT people**

1.2 Our project

Our project is aimed at increasing the visibility of the experiences of intersectional disabled people and exploring the attitudes that underpin their experiences of unfair treatment when accessing services.

Our project does not seek to give a comprehensive overview of all of the experiences that disabled people with different characteristics may have. Combinations of characteristics and the specific treatment/ barriers experienced in different services are many and varied. This is a small-scale piece of research and there are some groups that are not represented in this project.

The focus of this research therefore is not on the particular categories or characteristics, but on the relationships that exist between disabled people with other characteristics and service providers, and the common themes that emerge in how these relationships play out. We have identified similar themes across different characteristic combinations which supports the contention that we should not become preoccupied with identities or categories but instead examine 'how and why differences are interpreted in privileging and penalising ways' (Dhamoon, 2011).

This project engaged disabled people with lived experience of intersectional discrimination, as well as service providers. It established the types of unfair treatment that disabled people with other characteristics experienced and explored the reasons for this treatment. It also brought disabled people together to come up with some recommendations about how services can be more inclusive of all disabled people.

This project is important because ongoing failure to include intersectional disabled people compounds their pre-existing exclusion from accessing services and renders their chances of securing independent living ever more remote. Through this research we hope to shed some light on this important issue.

1.3 Our research questions

This research set out to answer the following question: What are the experiences of disabled people with other characteristics when they access services?

To answer this question we explored the following sub-questions:

1) Do disabled people with other characteristics experience distinct forms of unfair treatment and barriers when accessing services?
2) Why are disabled people with other characteristics experiencing distinct forms of unfair treatment?
3) What are service providers' understandings of intersectionality and how do they make services inclusive for all disabled people?

We have also come up with some recommendations for addressing unfair treatment against disabled people with other characteristics.

1.4 Methodology - Co-produced research

This project used a co-production approach. Co-production means working in partnership with disabled people to design and undertake the research. This research project was led by a group of disabled people with lived experience of intersectional discrimination in partnership with Inclusion Scotland.

The co-production group were recruited at the beginning of the project and worked together to develop the research methodology. They were also involved in designing and testing the methods, analysing the data and producing the recommendations.

We chose to use a mixed methods approach as this allowed us to gather quantitative and qualitative information.

Literature review

A rapid literature review was undertaken by an academic from Stirling University.

Survey

A survey was designed by the co-production group and distributed via Inclusion Scotland's networks to gather initial information on disabled people's experiences of intersectional discrimination. The survey asked about experiences of accessing leisure services, public services and housing services. We received 96 responses to the survey.

Interviews

Thirteen interviews with disabled people were carried out in locations across Scotland. All participants except one identified as disabled people. The other participant identified as a carer of her disabled son.

Interviewees were asked about their experiences of accessing services. We did not limit the types of services people could speak about, however the majority of interviewees spoke about their experiences in public services.

The table below shows the characteristics that the participants identified with. It should be noted that while these are the characteristics which participants identified with initially, other characteristics sometimes became relevant in the course of the interview.

Participant	Characteristics
1	Woman, disabled, older, on a low income
2	Carer, on a low income
3	Woman, disabled, younger, from abroad, from an ethnic minority
4	Woman, disabled, transgender
5	Woman, disabled, younger, on a low income
6	Man, disabled, younger, religious
7	Woman, disabled, older, co-occurring conditions
8	Woman, disabled, from abroad
9	Woman, disabled, co-occurring conditions
10	On a low income, disabled, bisexual, woman, religious
11	Lesbian, disabled, mother, married
12	Man, disabled, older, religious
13	Transgender, disabled, bisexual, co-occurring conditions

Interviews were also undertaken with four service providers. We aimed these at a strategic level to get an understanding of the policies the services had in place to ensure the inclusion of all disabled people. We spoke to representatives from the NHS in Scotland, Social Security Scotland, a social worker and a care provider.

Focus group

An online focus group was held for members of the co-production group. The group was open for 2 weeks and allowed members to contribute their ideas on the recommendations that should be included in this report.

Analysis

We used a thematic analysis to analyse our interview data. A thematic analysis identifies patterns and common themes in the interview data.

Limitations of the data

It should be noted that this is a small-scale piece of research which is intended to highlight that some disabled people with other characteristics experience unfair treatment when accessing services. The research is not representative of all equalities groups and is not intended to be.

Ethical considerations

This research project was approved by the DRILL Ethics Committee. Our application to the committee addressed ethical issues such as: ensuring the anonymity of research participants; provisions allowing participants to withdraw from the research; and how we would gain informed consent from participants.

Each participant was given a Project Information Sheet and Consent Form before the interview. These forms were produced in standard and easy-read formats. Participants were given the opportunity to ask the researcher questions about the research before participating. In line with the ethics procedures, the researcher talked through the forms and gained prior consent from each participant before the interview.

To ensure confidentiality the written transcripts of the interviews and focus groups were anonymised. All personal and identifiable information was removed from the written transcripts, including participants' names, place names and organisation names.

1.5 What is intersectionality and intersectional discrimination?

Before presenting our findings it is important to understand what intersectionality is.

It is about identity – There are around 1 million disabled people in Scotland, however we are more than just disabled people. There is no one part of our identity that completely describes who we are. Every person is unique and has lots of different parts to their identity. Disabled people are also men, women, young people, elderly people, LGBT people, black people, people with religious beliefs, parents, partners etc.

Despite this obvious diversity, disabled people are often assumed to be part of the same group and consequently assumed to share the same views and experiences. This means that the label of 'disabled' is often highlighted while other characteristics are ignored (Goethals et al., 2015).

The concept of intersectionality recognises this problem and demands that individuals and their experiences are considered in light of their complex identities. Any approach which concentrates on one aspect of a person's identity risks overlooking those at the intersections of different characteristics and the unique experiences they have.

The concept of intersectionality was first introduced by black feminist scholar Kimberlé Williams Crenshaw in 1989. She argued that black women experience distinct kinds of discrimination from white women and black men. The focus on the experiences of black men in anti-racist activism and scholarship, and white women in feminist activism and scholarship, 'conflates or ignores intra-group differences' (Crenshaw, 1991). This makes those at the intersection of these identities (black women) invisible because they do not fit into the 'normal' experiences of either race or gender. Crenshaw said that this has meant that black women's experiences and needs were ignored.

Since then the concept of intersectionality has increasingly been used as a tool to understand the complex nature of people's identities and experiences. It has been expanded to all kinds of intersectional identities, including disability, and enables us to go beyond basic single-dimensional understandings of people's lives (Abrokwa, 2018).

It is about power relationships and privilege – Everyone has more than one characteristic that they are identified by and therefore is a member of different 'groups'. Our identities can be legally imposed or self-assigned (Dhamoon, 2011) and are important to how we navigate the world. These groups or identities have been described as:

- 'Dynamic', meaning they evolve and change.
- 'Historically grounded', meaning they have existed for a long time.
- 'Socially constructed', meaning that they are determined by the way we live (Goethals et al., 2015).

As a result of assigning characteristics and dividing people into different socially constructed categories, particular values have been attached to each and 'power has clustered around certain categories and is exercised against others' (Crenshaw, 1991). People can therefore be in positions of privilege or oppression/disadvantage depending on what characteristics they have (Fredman, 2016).

As we all have more than one characteristic we can simultaneously belong to groups where we experience privilege and groups where we experience oppression, for example a disabled man (Goethals et al., 2015) (Van Mens-Verhulst et al., 2008). An intersectional approach allows us to understand that people's experiences and choices change depending on the complex and evolving relationship between their characteristics and the power relationships operating within society (Acker-Verney, 2017).

It also helps us to appreciate that disabled people may experience social barriers in different ways and that this should inform how we approach tackling these barriers (Acker-Verney, 2017). The concerns of disabled people therefore can only be properly understood when put within a dynamic context of relations and interactions (Goethals et al., 2015).

It is not about competing – Importantly, an intersectional approach is not about working out who has the 'most' oppressed or privileged identities. It is also not about pitting different groups and intersections against each other (Abrokwa, 2018).

It is about ensuring the individual's experience of unfair treatment is seen even if it happens at the intersection of two or more identities, rather than rendering these experiences invisible because we are overly concerned with one specific characteristic (Abrokwa, 2018).

It is interactive rather than additive – Intersectionality is not just about adding together people's experiences of discrimination. The intersectional experience is more than the sum of experiencing racism and ableism for example (Crenshaw, 1989). It is about the different parts of a person's identity being interactive, interdependent and inseparable which gives rise to unique experiences (Goethals et al., 2015). The intersectional experience is therefore distinctive to traditional understandings of discrimination based on a single part of someone's identity.

1.6 Policy Context and Terminology

The law and terminology

This research explores the experiences of disabled people with other characteristics. We use the terms ‘discrimination’ and ‘unfair treatment’ interchangeably throughout this report to describe many of these experiences. However, it should be noted that ‘discrimination’ has a legal meaning under the Equality Act 2010.

The Equality Act protects people from unlawful discrimination. The Act contains different types of unlawful discrimination, including direct and indirect discrimination and failure to make reasonable adjustments. Discrimination under the Act has a legal definition and tests that must be met before someone can be said to have been discriminated against.

Although section 14 of the Equality Act 2010 provides for ‘combined discrimination’ to deal with situations when a person is discriminated against because of a combination of two relevant protected characteristics, this section is not yet in force.

While we use the term ‘discrimination’ in this report we do not use it in its legal sense. We use the term ‘discrimination’ to describe experiences where people feel they have been treated unfairly by service providers. However, we also acknowledge that some of the experiences of unfair treatment that people have told us about may meet the legal definition of discrimination.

The Equality Act also contains a list of protected characteristics. Protected characteristics are parts of people’s identity that it is unlawful to be treated unfairly because of. The nine protected characteristics are:

- Age
- Disability
- Gender reassignment
- Marriage or civil partnership
- Pregnancy and maternity
- Race
- Religion or belief
- Sex
- Sexual orientation

In carrying out this research we have spoken to people who identify with some of the protected characteristics in the Equality Act. We have also spoken to people who identify with other characteristics that are not listed as protected characteristics. This includes things like being on a low income (socio-economic status), being from a rural area or having more than one health condition (co-occurring conditions). We have taken a broad approach to understanding identity and encouraged project participants to talk about any characteristics, identities or circumstances that they felt were important to how they experienced services.

Policy context

The Scottish Government's 'A Fairer Scotland for Disabled People Delivery Plan' sets out the Scottish Government's approach to policy for disabled people. It contains the actions the Government plans to take to realise the following five ambitions:

1. Support services that promote independent living, meet needs and work together to enable a life of choices, opportunities and participation.
2. Decent incomes and fairer working lives.
3. Places that are accessible to everyone.
4. Protected rights.
5. Active participation.

Under ambition 5 there is a commitment which relates to intersectionality:

'Our current record level of investment in supporting the capacity of DPOs will be maintained during the lifetime of this parliament. Through this programme of work, **we will explore how disability impacts different equality groups and what this means for our policies, services and communities.'** (Action 86) (Scottish Government, 2016a).

This intersectional approach is promising and signals that the Scottish Government is aware of the importance of understanding the experiences of disabled people with other characteristics. There are no updates so far on how this action is being achieved but it will be interesting to see how the Scottish Government tackles this issue.

Some intersectional statistics

Intersectional analysis of equality data is important to get a better understanding of the lives of disabled people. However, it is challenging to undertake intersectional analysis of data due to a number of factors, including: small sample sizes, high numbers of possible intersections and some data not being routinely collected.

Scotland's Equality Evidence Strategy 2017-2021 sets out evidence gaps in equality data and the strategic approach to strengthening Scotland's equality evidence base. The Strategy states that stakeholders highlighted various evidence gaps around intersectionality. The Strategy therefore includes various intersectional evidence gaps that need to be filled in relation to specific groups or issues. It does not however include overarching solutions on how to increase the collection and analysis of intersectional data but states that:

'Intersectionality requires government and the wider public sector to think more carefully about what services are provided, how, and to whom. It is widely acknowledged that it can be challenging to evidence impacts on particular intersections of protected characteristics because of low population numbers and the sheer number of different variations… Moving forward we will continue to use statistics, social research and economic analysis to fill the evidence gaps, using both quantitative and qualitative information as appropriate.' (Scottish Government, 2017).

The Equality and Human Rights Commission (EHRC) also reported in 2018 that data sources can often only provide evidence for broad overarching categories of people who share particular characteristics, such as disabled people. These broad categories and a lack of intersectional analysis conceal the variation in people's experiences (EHRC, 2018).

The Scottish Government is attempting to provide more intersectional analysis of equality data. In a recent publication it reported some intersectional statistics for disabled people:

- In 2017, 32% of the adult population had an impairment or impairments.
- In 2017, over half of the over-75 age group had an impairment(s). The prevalence of disability increases with age.
- In 2017, 34% of women and 29% of men reported having an impairment(s). Men were less likely than women to report having an impairment(s) in most age groups.
- In 2017, 23% of people in the least deprived areas reported having an impairment(s), compared to 43% of people in the most deprived areas.
- In 2011, people in all other ethnic groups were less likely than the people in the 'white' group to report having an impairment(s). This may be explained in part by minority ethnic groups typically having younger age profiles than the population as a whole.
- In 2017, 29% of those identifying as lesbian, gay, bisexual and 'other' reported having an impairment(s), compared with 23% of those identifying as heterosexual (Scottish Government, 2019).

This limited intersectional analysis gives rise to some interesting questions around the needs and experiences of disabled lesbian, gay and bisexual people and disabled women for example. It also demonstrates that disabled people are a diverse group and that more intersectional data is needed to better understand disabled people's lives and needs.

1.7 Human rights and independent living

The right to independent living is a cornerstone of disability rights. It means all disabled people having the same freedom, choice, dignity and control as other citizens at home, at work and in the community. It does not necessarily mean living by yourself or fending for yourself. It means rights to assistance and support to participate in society and live your life in the way you choose.

The right is contained in Article 19 of the United Nations Convention on the Rights of Persons with Disabilities (UN CRPD). Article 19 requires states to take steps to make sure that disabled people can live and participate in the community on an equal basis with others. This includes giving disabled people access to the support services they need to enable independent living including personal assistance

Having access to appropriate and accessible services is therefore a key part of independent living. The effective provision of services can be the difference between someone being able to live independently or not.

The UN CRPD also takes an 'intersectional' approach to disabled people's human rights by recognising the 'difficult conditions faced by persons with disabilities who are subject to multiple or aggravated forms of discrimination on the basis of race, colour, sex, language, religion, political or other opinion, national, ethnic, indigenous or social origin, property, birth, age or other status' (UN CRPD Preamble). There are also various provisions within the Convention relating to specific groups of disabled people, for example disabled children.

The following chapters should therefore be understood in light of the principles of independent living and the holistic approach of the UN CRPD.

Chapter 2

Do disabled people with other characteristics experience distinct forms of discrimination and barriers?

Our survey found that 91% of respondents[1] felt that they were often treated unfairly in their day to day life because of their impairment/long-term health condition/status as disabled. The vast majority (89%) of these respondents said that they regularly (almost every day, at least once a week, a few times a month, a few times a year) avoided accessing a service because they were worried about how they would be treated. This suggests that a large proportion of disabled people are frequently experiencing unfair treatment when accessing services.

However, results from our survey also suggested that the unfair treatment disabled people experience is perhaps more complex and can be attributed to more than just being a disabled person. More than half (60%) of respondents to the survey who said that they had experienced unfair treatment said it was because of their intersectional identities – that is, because they are a disabled person plus at least one other characteristic. Of these, 98% said that they regularly avoided accessing a service and 74% said that they have had to change where they accessed a service because of how they have been treated.

This suggests that we need to understand more about the unfair treatment that disabled people are experiencing and recognise that these experiences cannot always be understood by reference to impairment alone.

2.1 Location of unfair treatment

In our survey 91% of respondents said they experienced unfair treatment every time, most of the time or some of the time they accessed public services. The three most commonly selected services where survey respondents felt that they were treated the most unfairly were social security, transport and the NHS.

These findings were reflected in our in-depth interviews where the majority of the unfair treatment experienced by the interviewees happened in public services. Interviewees spoke about the need for these essential services, such as the NHS, social work and social security, and the extent to which they relied on them to live their lives as independently as possible.

Some interviewees also highlighted that their impairment(s) and circumstances meant that they had increased contact with these services, compared with non-disabled people, and that this led them to be more reliant on the service and service providers:

“Especially because a lot of disabilities require you to interact with the system so frequently, whereas most people probably see their GPs a couple of times a year when they get the flu or something like that.” (Participant 3)

This chapter will try to establish what distinct forms of unfair treatment and barriers disabled people with other characteristics are experiencing, and in what services, by drawing on key themes which arose in our in-depth interviews with disabled people.

91%

of **respondents** felt that they were often **treated unfairly**

The **3**

most commonly selected services were **social security, transport** and the **NHS.**

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[1] Sample size of 96.

2.2 Distinct forms of unfair treatment

When our interview participants talked about the unfair treatment or barriers they had experienced they could be described as explicit, implicit or a combination of both.

Explicit unfair treatment was obvious in the way it was displayed or carried out. It included things like making offensive comments to someone or refusing to provide a service to someone because of their identity.

Implicit unfair treatment included things like not making a service physically accessible or not taking into account someone's views about how they wanted to access the service.

Explicit unfair treatment was most often deliberate, whereas it was more difficult to determine whether implicit unfair treatment was conscious or inadvertent. Different treatment and barriers (like not listening to someone's views or not making a service physically accessible) can be the result of conscious negative and prejudicial attitudes, or an unconscious lack of knowledge and understanding. Implicit unfair treatment was therefore more difficult to detect and it sometimes took in-depth discussion with interviewees to understand the root of these experiences.

60%

of respondents experienced **unfair treatment** because of their **intersectional identities**

Of these,

98% **regularly avoided accessing a service**

We have used the word 'implicit' here to show that it is not always obvious if unfair treatment is conscious or unintentional. Alternatively, we could have used the increasingly familiar term 'unconscious bias' which has been described as prejudice 'that we are unaware of, and which happens outside of our control' (Equality Challenge Unit, 2013). However, the extent to which people are entirely unaware of their biases is uncertain 'especially as we are being made increasingly aware of them' (Equality Challenge Unit, 2013). We think therefore that 'implicit' is a more accurate term since we do not know much about how people's unconscious and conscious prejudices interact and are manifested.

Research has suggested that most people have unconscious prejudices towards disabled people despite having low levels of conscious prejudice (Friedman, 2017). Other research has also found that disabled people experience the most implicit or unconscious bias when compared with gender and ethnicity (Evenbreak, 2014)

Whether conscious or unconscious, high levels of bias against disabled people may be due to ableism (discrimination against disabled people) being so entrenched in society, and common negative representations and stereotypes of disabled people not being seen as problematic (Friedman, 2017). It also highlights that disabled people who find themselves at the intersection of multiple identities will experience this bias in different ways.

> "Especially because a lot of disabilities require you to interact with the system so frequently, whereas most people probably see their GPs a couple of times a year when they get the flu or something like that."

2.3 What kind of treatment is happening?

In this section we identify the types of treatment and barriers that the people we spoke to experienced. Although it is very likely that specific combinations of characteristics (for example, being a disabled woman) result in specific barriers in specific services, we have tried to identify the general types of treatment and barriers that disabled people with other characteristics experienced.

1. Denial of choice, control and person-centred services

The main treatment that the disabled people we spoke to experienced was a lack of choice or control over how they used services. Choice and control are a central part of independent living and go beyond simply ‘consumer choice’ (Rabiee, 2013). It means that people genuinely have the power to direct their lives and have the same choice and control over decisions as everyone else.

Choice and control are a goal of various Scottish Government policies including in health and social care and social security.

The Health and Social Care Delivery Plan says that individuals ‘should be given more freedom, choice, dignity and control over their care’ (Scottish Government, 2016b). This is based on the premise that people should be involved in their own care and that support and services should be directed by their needs. In 2016, the Scottish Government also said that a goal of the recently devolved social security powers was to give people ‘an increased sense of control over their lives’ (Scottish Government, 2016c).

Essentially, the Scottish Government promotes a person-centred approach to the delivery of public services. Person-centred services ensure that the professional and the person using the service work together. How the service is delivered will depend to a large degree on the needs, circumstances and preferences of the person receiving the service (Health Foundation, 2016). Taking a person-centred approach ensures that a service does not just focus on a condition or symptoms, but takes a holistic approach to the person, whatever their characteristics are (Health Foundation, 2016). This is an approach which seems to correspond with the concept of intersectionality.

Despite this, there was a consistent view amongst interviewees that they either had to fit in with the service and the service provider’s expectations or go without the service. As ‘passive recipients’ (Rabiee, 2013) of services, the disabled people we spoke to were often denied choice and control as to when and how they accessed services. Although this may be an issue that many disabled people face, it seemed to be compounded where people had other characteristics.

The following subsections set out some of the specific ways in which people were denied choice and control in services because of their intersectional identities.

Being dismissed/Not listened to

Amongst participants who spoke about their experiences of unfair treatment because of their intersectional identity, a common theme was a feeling of not being listened to or having their views dismissed by those providing service(s).

One participant described the challenges she has faced in getting a diagnosis and the lack of awareness and unwillingness of medical professionals to engage with the idea that her ethnicity may play a role in the type of condition she has.

“My concerns about how my race could play into my illness has often been pretty soundly dismissed which is rather frustrating.” (Participant 3)

Other participants described how their age was a factor in the way that medical professionals responded to them. Young disabled people perceived that their opinions were not seen as valuable and that there was a tendency for some medical professionals to stop or avoid conversations that they did not consider relevant.

“I was trying to tell him [the doctor] how many seizures I took…and he basically said ‘look, I’ve got other appointments’, helps me out my chair and pushes me out the office.” (Participant 6)

It was also reported by some participants that some NHS staff they came into contact with used age as a justification for not doing certain treatments or tests based on the belief that the person was “too young to be in pain” or to have certain types of conditions. The young disabled people we spoke to sometimes had to deal with an expectation that because they were young their condition would improve.

“I think they think that it is reassuring to say oh you’re young [and] all this type of thing but it really just feels like you’ve ignored everything I’ve said.” (Participant 3)

Another participant spoke about his involvement with social services when transferring from child to adult services and the difficulty he experienced in having his voice heard. He felt that the social workers he worked with had predetermined well-intentioned views about where he should live and the role that his parents should play. However, these views conflicted with what he wanted and he struggled to have his views heard and respected. He expressed a deep sense of frustration at this experience and it has consequently impacted on how he now approaches his relationship with his new social workers.

People with co-occurring conditions talked about how one of their conditions was often ‘prioritised’ over another. One participant spoke about her inability to progress in her medical career because employers disengaged when they found out about one of her conditions. The participant described the “barrier” that colleagues/employers put up when she disclosed the condition and how they were unwilling to engage in any discussion about how this may or may not impact her ability to do the job.

Another participant noted that her physical impairment had a significant impact on her mental health and that the two were inextricably linked. When talking to medical professionals about these impacts she described how her concerns were dismissed:

“She looked at you as if, wait a minute, it’s not mental health we’re here about, but what she didn’t realise is that the two go hand in hand.” (Participant 7)

The relationship between physical and mental health conditions was also raised by other interviewees. There was a general perception that professionals did not see or were hesitant to acknowledge overlaps between conditions. Interviewees believed that having a physical condition acted as a barrier to being offered support for mental health issues and vice versa. One participant talked about doubting herself and being made to feel like she was “making-up” her physical condition because of the reaction she got from some medical professionals.

This is despite well-established data which shows that people with severe and enduring mental health conditions can die up to 20 years earlier than their peers, mostly because of physical health conditions (Scottish Government, 2018), and that people with long-term health conditions are more likely to have mental health problems than the general population (NHS Education for Scotland, 2015).

Inaccessible systems and processes and refusal to make adjustments

The systems and processes many of the participants had to interact with when accessing services also created barriers to successfully getting their needs met. Inaccessible systems and processes were very much connected with a lack of person-centred services. Often this was the result of the way the service was designed, but it could also be attributed to the unwillingness of service providers to adjust or adapt their systems to include people who may require a different approach.

Many of the services that participants spoke about had some elements of inaccessibility within their systems and processes. One participant talked about the challenges she had in accessing banking as a disabled person and the further difficulties she faced getting her gender on her account changed, despite having a Gender Recognition Certificate. This experience caused repeated stress and embarrassment both in the branch and when using her bank card in shops.

Another participant discussed her experiences of trying to get access to support from university disability services without having a medical diagnosis. She believed the difficulties she had in getting a diagnosis resulted from a combination of her characteristics – being from another country, being from an ethnic minority and being a young person. This then had consequences for accessing other services such as university support as she was unable to “cross the barrier” to be considered eligible. She expressed frustration with the university’s limited policy which seemed to be designed to restrict access to support as much as possible.

Social security and social work services were also viewed by some participants as having rigid requirements and processes which denied them choice and control. Participants discussed:

- Being required to attend assessments at times specified by the service.
- Having to meet rigid criteria to get access to services.
- Having to get permission to use a self-directed support budget.
- Having to accept services that were not suitable for their needs.

Another participant talked about the lack of choice and control she had when engaging with NHS services. She was more comfortable seeing a female doctor but felt “often that’s not a choice I can make”. She was hesitant to make this request because of the impact it could have on her treatment, for example increasing the amount of time she had to wait for an appointment. She also felt that making a request to see a female doctor made her an “inconvenience” for health professionals and secretarial staff and that this would put a “black mark” over her name as a problematic patient. She also acknowledged that doctors were working within a system which they could not necessarily bypass or over rule.

“It’s just hard to kind of assert yourself as an individual case, they want to kind of move everybody through a set of, you know, systems, I guess. And if you need to move through them in a different order or in a different way they can make it very difficult, very quickly.”
(Participant 3)

Two participants discussed how they were unable to progress in their careers because of the way employers expected them to work. A participant discussed the barriers women academics face in competing with men for opportunities. For her, this was further compounded by her impairment and the difficulties she experienced in dealing with the large workload expected of academics. Another participant spoke of the unwillingness of employers to make any adjustments to the established way of working to accommodate one of her conditions. She also recounted comments from colleagues about the expense related to making adjustments and the attractiveness of candidates without the need for adjustments.

Many of the experiences our interviewees spoke about were related to services having a restrictive understanding of what it means to be a disabled person. Participants were sometimes required by services to ‘prove’ that they were a disabled person in line with the service’s understanding of what that means. However, where people had additional characteristics which meant they needed personalised adjustments to the service, this was difficult to get.

Services preventing access to information

Participants talked about the apparent unwillingness of some service providers to share information and the imbalance in knowledge between them. This was particularly viewed by participants on a low income as an attempt to prevent them from knowing and claiming what they were entitled to. For example, one participant with a visual impairment talked about how over the years his parents had bought him aids such as a cane, only to learn later on that they were entitled to have these items free of charge.

An interviewee who had contact with the Department of Work and Pensions (DWP) also spoke about the experience of having her benefits stopped without being informed that she was entitled to apply for an alternative. She found the DWP to be evasive when she requested information about how a change in circumstances would affect her income.

“…but if you don’t know, how do you know to ask?...Because they have their job to do which is to prevent paying everybody money…and I understand that, but from our point of view you are entitled to some of these benefits, but how do you ask when you don’t know?”
(Participant 1)

Another participant described her experience of Self-Directed Support (SDS) and the confusion she felt when trying to get information from professionals:

“You were sent to the social worker…it was coming across as if they weren’t trained but I don’t know so much if that was the case, you know. I think it was more to protect the funding.” (Participant 2)

Several participants related their experiences to being in a conflict or to having to “fight” to get what they were entitled to. The feeling of mistrust is detrimental to the service provider/service user relationship. It further shifts the balance of power in favour of the service provider who controls the sharing of information and ultimately access to the service (Larsson, 2017).

2. Bullying and invasive questioning

Several participants discussed their experiences of overtly negative treatment from service providers.

One participant talked in depth about her experience with care providers who she relied on to meet many of her most basic needs. As a trans-woman she experienced deliberate mis-gendering from carers and was dressed in male clothing against her will. Experiencing prejudicial attitudes within her own home had a serious impact on her mental health and her ability to trust the care provider.

This invasion of personal life was also described by other participants who were subject to invasive questioning by some service providers. Many of the disabled people we spoke to reported feeling that their status as a disabled person together with their other characteristic(s) had opened them up to increased scrutiny from people providing services.

For example, a disabled participant from abroad discussed how she could not avoid discussions about her impairment and immigration status when interacting with services. Her surname highlighted that she may not have been born in this country and her accent was an additional indication that she held another nationality. She also used a walking aid. She experienced inappropriate and invasive questioning about her background and impairment from social work services, support organisations and transport providers.

She talked about making a “trade-off” when using taxis to get to work – she had to put up with invasive and sometimes inappropriate questioning from drivers in exchange for being able to travel to work independently. She also said that over time she had developed mechanisms to “de-escalate” conversations.

Transport was a location where other participants reported that they were exposed to inappropriate comments/invasive questioning from those providing the service and members of the public. Two participants had experiences of other passengers assuming they were not disabled because their impairment was invisible and because they were young. This caused a degree of fear about travelling on public transport in case of being met with negative reactions.

Some participants talked about feeling as though they were not believed by services, or viewed with suspicion, and that this was used as a justification for invasive questioning. One participant described a DWP assessment where she was subject to inappropriate and intrusive questions and comments about her relationships. Other participants used words such as feeling “victimised”, being treated like a “thief” and being treated with “unkindness” and “disdain” to describe their experiences with social security and social work services.

Overtly negative behaviours had a detrimental effect on the disabled people we spoke to. It impacted on their sense of self-worth and also reduced the extent to which they were able to use and benefit from the service.

3. Other barriers

The disabled people we spoke to also discussed other barriers that they experienced in accessing services. These barriers were inextricably linked to being a disabled person and their other characteristic(s). Ultimately the barriers resulted in them being effectively excluded from services such as support services, education and transport.

Some examples that interviewees gave:

- One transgender participant spoke about not being able to access LGBT support services because of inaccessible buildings and events. She felt that she could benefit from the support the services offered and expressed frustration that she was not able to take part or use her skills to support others.
- Another participant on a low income spoke about being unable to fully access her education because of the cost of books and resources. She relied on social security, was unable to work and therefore struggled to meet the costs associated with attending university.
- A participant from a rural area spoke in depth about how the lack of accessible transport in her area impacted on her independence. Buses were infrequent and most often inaccessible. She had to phone the bus company in advance of travelling to request that an accessible bus was put on the route. However this was not always guaranteed and this lack of reliability meant she was unable to leave the village very often.

2.4 Chapter conclusion

Disabled people with other characteristics seem to experience unfair treatment and barriers that are compounded by their intersecting identities. Denial of choice and control was central to the experiences of the disabled people we spoke to and was closely linked to whether or not they were able to live independently.

Negative behaviours from service providers such as bullying and invasive questioning were also treatments experienced by participants. Participants often felt that they were exposed to this type of treatment when they did not conform to the ideas and stereotypes of what a service provider expected of a disabled person.

All of these treatments and barriers had a detrimental impact on the people who experienced them and often resulted in people avoiding accessing services or having to find alternatives.

> Disabled people with other characteristics seem to experience unfair treatment and barriers that are compounded by their intersecting identities.

Chapter 3

Why are disabled people with other characteristics experiencing distinct forms of unfair treatment?

In the previous chapter we said that disabled people with other characteristics felt that they experienced distinct forms of unfair treatment/ barriers because of their different characteristics. This chapter explores the reasons why disabled people with other characteristics experience these distinct forms of unfair treatment when accessing services.

3.1 Power relationships

The power relationship between service users and service providers was a key theme that came up repeatedly in our interviews and which underpins many of the reasons that people gave to explain the treatment they had experienced.

No one is completely isolated from the influence of other people and we all rely on others to some extent in our day to day lives. However, some scholars believe that disabled people have been forced by society to depend on professionals who have the power to provide or withhold services (Helgoy et al., 2003).

The disabled people we spoke to felt that they had increased contact with certain services (compared with non-disabled people) which they relied on to meet their needs. This inevitably resulted in power relationships developing between the disabled person and the service provider. The service provider acted as a gatekeeper who had the final say on whether the disabled person was given what they needed.

Freedom from this type of forced dependency on services has been an important part of the independent living movement which has strived to place control over services with disabled people.

Despite this, our interview participants were often ‘powerless and resigned’ when accessing services, believing that they had little influence over what happened to them (Helgoy et al., 2003). The interaction of their characteristics made it even more unlikely that they would get the service/support they needed.

As discussed previously, characteristics/ identities make people less likely or more likely to be in positions of power or privilege. Therefore, the power relations that our interviewees experienced were very much affected by their intersecting identities and circumstances.

For disabled people on a low income, their interactions with institutions such as social security (DWP) and social work were characterised by feelings of dependency and powerlessness. One interviewee talked about the DWP having the power to make her life better and the stress of going through the system with limited ability to influence the outcome:

“But there is a power thing. Because you are also aware that this person has the power to make your life better or not. And making your life better isn’t just about money, the money enables you to have independence or to help to buy a downstairs toilet or a scooter or whatever it is to maintain your independence. So you’ve got somebody sitting there marking you to decide, playing God almost.” (Participant 1)

Another participant discussed her experiences of being on a low income and working with the social work department to use her son’s SDS budget. She described very frustrating and demoralising experiences of going back and forth to social workers to try to put services in place:

“It’s very much power and control you know, very much. Because my son I would say has a good enough budget, but…my son has no choice or flexibility to use that budget, everything is by professional view and everything has got to be authorised by professionals.” (Participant 2)

One transgender participant talked about the experience of her care provider opting to stop providing her care and transferring her to another provider. She described how she relied on the care provider for her most basic needs and felt that if she complained that they would find an excuse to stop providing her care. Having to accept inadequate services was necessary to ensure she was not without the care she depended on:

“Nobody really listens to you, you’re provided with it and that’s it…it’s like we’ve given you the honour of our services…be grateful because you could be without it and if you speak out don’t worry, we’ll outsource you to another agency.” (Participant 4)

The imbalance in the relationship between the service providers and the service users reportedly impacted on participants’ sense of wellbeing, with some reporting serious impacts on their mental health and wellbeing. This is not surprising given that power is said to be one of the fundamental factors of health and social inequality. The World Health Organisation has said that people need to be able to exercise control over the things that influence their health. Power, therefore, needs to be redistributed from service providers to service users so that they can do this (NHS Health Scotland, 2016).

3.2 Attitudes and assumptions

Another significant reason that participants gave for the unfair treatment they experienced was the negative and sometimes prejudicial attitudes that service providers had towards them.

Negative attitudes towards disabled people have existed throughout history. Being seen as ‘different from others’ or not fitting in with the ‘norm’ (Friedman, 2017) has resulted in attitudes ‘ranging from fear, disdain, paternalism, indifference, pity and disgust’ (Abrokwa, 2018). These attitudes have been detrimental to disabled people in many aspects of life. As a result, disabled people have been persistently excluded from society and controlled by people in authority, for example, by being placed in institutions and forced to rely on others to exercise their legal rights. Disabled people have been seen as a ‘burden’ that needs accommodations or modifications, which are provided or denied by people who hold the power to make these adjustments (Abrokwa, 2018).

Attitudes to disability/impairment have also been fundamental to the experiences of other marginalised groups throughout history including women and people from ethnic minorities. These groups have at various times been excluded from being treated as equal citizens due to their perceived physical and/or mental inferiority to the dominant groups in society, for example, men and white people. This historical use of disability as way to further exclude marginalised groups shows an entrenched negative attitude towards the concept of disability which still has an impact today (Abrokwa, 2018). It also has consequences for how disabled people with intersecting identities experience discrimination if they find themselves at the intersection of two or more oppressed categories.

Negative attitudes in service provision

‘Undeserving’ disabled people

It is well documented that negative views of disabled people still exist today and are widespread (Dixon et al., 2018; Equality and Human Rights Commission, 2017; Disability Rights UK, 2012). However, this research suggests that when disabled people have additional characteristics, the negative attitudes they encounter are compounded.

The overwhelming reason that our interviewees gave for their experiences of unfair treatment was the attitude(s) of the person or people providing the service. This reflects the finding of our survey where 82% of respondents said that the attitude of service providers was the reason for their experience(s) of unfair treatment in at least one of the services we asked about.

Interview participants on a low income and who had contact with public bodies such as the DWP or social work described how interactions were often stressful and upsetting. There was a perception that they were not believed or trusted and viewed with suspicion, and that they had to ‘prove’ themselves in some way in order to get access to the support/service they needed.

This was closely connected to the idea of disabled people ‘taking’ from the system without contributing – a view that some of our interviewees felt was held by some people providing services. One interviewee discussed the impact of going through a DWP assessment and feeling like she was thought of as someone who had not contributed:

“It strips you of any feeling of contributing and having contributed all your life to tax or whatever. And then it makes you less of a person.” (Participant 1)

Another participant believed that the DWP actively highlighted that disabled people take from the system:

“What I can say is that there is a propaganda about, I feel, the perceived correlation between disabled people and the benefits they need and deficits in the budget. So I think there is, from the DWP, definitely an agenda there selling disabled people as the people who disadvantage the financial system of the country because they need more, they contribute less.” (Participant 8)

The idea of making a contribution was significant for other participants too. In particular, one participant with a different nationality perceived that she was seen as especially undeserving of accessing services and support. She felt that service providers (including social workers and transport providers) saw her as someone who had moved to Scotland to be “looked after”, to have an “easier life” and to get things “for free”. As noted earlier in this report, service providers often asked her about her background and questioned her reasons for moving to Scotland, despite having lived in the country for over 6 years. This made her feel like an outsider who had not contributed to the country and who was therefore not deserving of support services.

“So I felt like my life was captured on a zero to ten scale where ten was really what an immigrant should be grateful for and possibly she was ticking off all those from zero to ten, she was ticking off all those items, whereas I think if I was local then maybe there wouldn’t be a ten scale, maybe my life would be looked at as an ever expanding something or not compared to what other people don’t have access to.” (Participant 8)

Another interviewee from abroad and from an ethnic minority experienced similar attitudes when accessing health services and university support services. She felt that there was an insinuation from these service providers that she should not have come to this country if she knew she had a health condition. Having a foreign accent and being from an ethnic minority set her apart in an obvious way when she accessed services, and she believed she was seen as “making a fuss” and taking from the system.

Several participants used the word "drain" to describe how they felt they were seen by service providers. There was a view that service providers were gatekeepers to resources/services with the ultimate goal of restricting access. One participant talked about having professionals visiting her home who reported back in meetings about her having a "nice house", suggesting that her family was not in need of support as they already had 'enough'. This was similar to another participant's experience of believing she did not have "control" over her image when interacting with the DWP and was automatically seen in a negative way.

Disabled people should "be grateful"

The feelings of being undeserving, of being a drain on the system and of not contributing resulted in the disabled people we spoke to feeling like they were expected to be grateful for any service(s) they received. This highlights the imbalance in the service provider and service user relationship and the issue of power considered earlier. If service users are being told they must accept what they are given and be grateful for it then there is no reason for services to be provided in a way which meets the individual disabled person's needs.

In connection with this, the addition of other characteristics meant that the disabled people we interviewed felt that they were seen as placing a greater burden on service providers. Some participants believed that service providers thought they asked for too much. Their intersecting identities and circumstances sometimes meant people needed more than one adjustment and could not neatly fit within a 'box'. This again relates to power relationships and the service provider typically holding the power to make or deny adjustments and the service user being in the powerless position of accepting whatever they are given.

The idea of 'adjustment fatigue' seemed to be present, with service providers being either unwilling or unable to deal with people who could be considered as being outwith the 'norm'. One participant succinctly described the desire of some providers for uniformity from service users:

"It's ok if you're in a wheelchair, but don't have an added extra on top of it, please. Don't have mental health problems, don't have a gender identity problem, be of a certain age. And whatever you do, even though you'll get older, and your disability may get worse, it's not allowed to."
(Participant 4)

Assumptions

Negative attitudes surrounding disability have created and reinforced stereotypes and assumptions about disabled people and their lives. Many of the attitudes that participants experienced were based on assumptions about disabled people.

From our in-depth interviews we have identified a few of the assumptions/stereotypes our participants experienced:

1. Disabled people are a homogenous group

Evident in the experiences of all of the disabled people we spoke to was the assumption that disabled people share the same traits and need the same things. Being seen in this way often prevented interviewees from being treated as an individual. They had to either deal with the service provider's beliefs/assumptions about what disabled people should be like and what they need, or go without the service/support.

Connected to this assumption is the invasion of privacy that some of our interviewees experienced (see page 21). The lack of boundaries with some service providers suggests that when disabled people have other characteristics that set them at odds with views of what a disabled person should be, service providers feel justified in asking personal questions.

2. Disabled people have limited abilities and aspirations

Various people we spoke to described how professionals (doctors, social workers, employers) had a paternalistic attitude towards them and seemed to underestimate their abilities. Although this is probably an assumption that many disabled people face, it can be compounded for people with additional characteristics.

As discussed previously, this assumption was often manifested through professionals dismissing disabled people's views and/or not respecting their choices. One interviewee talked about being a disabled young woman and dealing with tradespeople in her home who "just think you're a bit thick" (Participant 5). Other young disabled people also spoke about feeling like the combination of their age and impairment meant that their concerns were not taken seriously by health professionals.

Another participant with co-occurring conditions talked about how one of her conditions was met with the assumption that she was unable to undertake certain types of work. Although the condition did not prevent her from doing many tasks, she described numerous experiences of being told by employers that she was unsuitable, constant refusals to adapt ways of working and offers of jobs far below her skillset – "there's a job going organising the surgical rota" (Participant 9).

3. Disabled people do not need as much as non-disabled people

This assumption was particularly significant for people on a low income. They felt that there was a belief that they should be able to survive on the minimum amount of resources and support, even when they had extra costs to meet related to their impairment. Money and support was supposed to cover their most basic needs, but anything 'extra' was not considered necessary.

One participant talked about the experience of organising support for her son and trying to use his care budget to ensure he had access to a range of classes and opportunities to develop his skills. She encountered various difficulties in doing this due to having a small budget and having to get authorisation from social work to use the funds. This left her with the impression that her son was not worthy of such services and that it was acceptable for people with learning disabilities to spend their time at home or doing meaningless tasks. This also connects to assumption 2 above.

Another participant said she felt that she was not expected to socialise or to have hobbies or interests. Similarly, an interviewee recounted being told that a television was a "luxury", despite this being a vital connection with the world for many people. These assumptions and attitudes experienced by disabled people left the impression that if they were having their basic needs met then they should be grateful and not ask for more. One participant used a thoughtful analogy to describe this:

"You cannot possibly imagine that just because you water a plant, but otherwise you keep it in a dark corner without enough soil, and the temperature is really low, just because you water it, you won't get the flowers, because guess what, they also need sunshine and composting and the right temperature." (Participant 8)

3.3 Lack of knowledge/understanding

Lack of knowledge/understanding was another key reason that people consistently gave to explain the treatment and barriers they had experienced. This lack of knowledge/understanding can underpin negative and prejudicial attitudes, but it can also result in barriers such as how services are designed/structured. The way that services are designed/structured was the second reason (after attitudes) that people gave for experiencing unfair treatment in our survey (72%).

Many interviewees felt that an increased knowledge/understanding was key to having their needs met. For example, one participant talked about a well-intentioned service provider who suggested putting a commode in her living room as building a downstairs toilet was too expensive:

"He had sympathy and empathy but he didn't have a knowledge…He thought my issue was to go to the toilet but my issue was to maintain a certain independence and dignity." (Participant 1)

When people do not have the right knowledge and understanding they seem to be led by their false understandings, assumptions and paternalistic and prejudicial attitudes. However, other participants highlighted that service providers sometimes used lack of knowledge or unwillingness to learn as an excuse.

For example, one participant spoke about her care provider using lack of knowledge about transgender issues as a reason for not being able to provide her care. She perceived that this was an excuse used by the care provider to avoid having to deal with prejudicial staff attitudes and assumptions.

“And they’re not willing to learn about it so they’re outsourcing me because I was the first ever transgender person they’ve ever had.” (Participant 4)

Other participants with co-occurring conditions and rare conditions believed that health professionals sometimes covered up their lack of knowledge by dismissing concerns.

Another participant felt that employers placed the blame for her difficulties in progressing in her career on her health condition, rather than address “their own narrow mindedness” (Participant 9). The participant spoke in-depth about how misunderstandings and false beliefs about one of her conditions were pervasive amongst employers and potential employers and how she struggled to have her personal experience of the condition heard and understood.

This unwillingness to learn, to challenge false beliefs about disabled people and to listen to disabled people’s first-hand experiences suggests a bigger issue related to attitudes. It suggests that prejudicial conscious and unconscious attitudes towards disabled people may be so entrenched that there is little societal desire to address and eradicate these attitudes, assumptions and stereotypes.

3.4 Chapter conclusion

Many of the treatments that the disabled people we spoke to experienced were underpinned by negative attitudes, assumptions and a lack of knowledge and understanding. This was detrimental not only to how individuals accessed services and support, but also to how they perceived themselves and their feelings of self-worth.

The negative attitudes and harmful assumptions discussed by our participants reveal a potentially deep-seated prejudice towards disabled people with other characteristics. Not only are they dealing with the negative attitudes experienced by disabled people in general, but they also have to contend with stereotypes and negative attitudes towards other parts of their identity as well. Further research is needed to gain a better understanding of the negative attitudes that exist towards disabled people with other characteristics, and how these attitudes can be effectively challenged.

> **“And they’re not willing to learn about it so they’re outsourcing me because I was the first ever transgender person they’ve ever had.”**

Chapter 4

What are service provider's understandings of intersectionality and how do they make services inclusive for all disabled people?

We carried out interviews with representatives from four service providers to try to understand the services' approach to working with disabled people with other characteristics. We spoke to an NHS Scotland employee, a Social Security Scotland employee, a care provider representative and a social worker.

All of the people we spoke to worked in strategic roles where they had some oversight of their service or were involved in its design and delivery. Some of them also had previous experience of providing services directly. They were giving their own views on the issues, rather than the official views of the service.

4.1 Intersectionality and person-centred services

The representatives were asked about whether their service considered the concept of intersectionality (in relation to disabled service users) in service design and delivery. Although all of them indicated that intersectionality was not an explicit consideration, each representative said that providing a person-centred service was very important. Intersectionality seemed to be perceived by some representatives as an academic concept which they did not immediately connect to the work of their service. Language around person-centeredness was much more common and relatable.

"If you're actually listening to what the customer or your person wants, then you can figure out from there what, if anything, you need to do." (Care Provider)

"In terms of people with protected characteristics, we would always say this is about the person, we always talk about self-definition." (NHS employee)

The representative from Social Security Scotland spoke about ensuring that the service listens and adapts to the person's needs and avoids trying to label people.

"Staff are trained to have good conversations and to deal with people as individuals and to ask them what they need and be able to adapt their approach for things, rather than having to worry about giving someone a condition label." (Social Security Scotland employee)

The social worker viewed a person-centred approach as taking into account all of the aspects of a person's life, not just their personal characteristics:

"You have to have an ecological approach, you have to have an approach that considers the interactions, circumstances, history and stresses and strains in the person's world in order to be person-centred." (Social worker)

"Social work is about listening as a starting point." (Social worker)

The NHS representative talked about efforts to make the provision of health care more person-centred by using things like 'What matters to me' whiteboards and booklets in hospitals. This gives patients the opportunity to tell the staff caring for them about themselves, their families, their likes and dislikes.

However, there was an acknowledgement that in practice person-centred care does not always happen because of the way services are designed or because of how they are delivered. The NHS representative said:

"There is a neutrality attached to planning and how we deliver health services. It's assumed that everybody is this particular person, usually white male, and everybody else is different." (NHS employee)

This means that it is difficult for people to deliver services that are truly person-centred if they are working within a system that is not designed to be inclusive of everyone and which does not allow for much flexibility.

Social Security Scotland spoke about the importance of co-designing their service to try to avoid common design flaws. Experience panels were set up to advise on all aspects of the service and there is an emphasis on getting feedback from service users.

"Lived experience is critical."
(Social Security Scotland employee)

The representative also stated that the agency has an "open mentality" to learning and is taking an iterative approach to service design to ensure they get it right.

It will be interesting to see the result of these innovative mechanisms for involving service users in the design of the new Social Security Scotland agency. As discussed previously, there is often a power balance between service providers and service users. It is therefore critical for providers to redress this, not only by giving people with lived experience the opportunity to influence how services are designed, but also to equip them with the information they need to be able to do this. This means enabling service users to access a range of views and opinions on the matters they are being asked to comment on, rather than just acting as a rubber-stamp to the official position.

The inability of systems and processes to deal with the complexity of people's identities was also seen by some representatives as a barrier to providing person-centred services:

"Even if everybody [staff] looked at the person, identified their protected characteristics as they [the person] saw them, we still don't get that right. So the chance of getting intersectionality right is quite remote. It's quite a stretch."
(NHS employee)

The social work representative similarly noted that:

"There's a constant pressure to categorise and prioritise and deal with thresholds and types whereas most work is about understanding intersectionality."
(Social worker)

If services are therefore not designed to take account of and adjust to people with complex needs and/or intersecting identities then it is unlikely that a genuinely person-centred approach can take root within a service. Ultimately, services which are designed around labels, classifications and box-ticking prevent the service provider from seeing the person as an individual. As said by one of our interviewees:

"I think that's kind of the key to all of the problems that I've had is that if somebody had…stepped closer and saw me as a person." (Participant 3)

> "Social work is about listening as a starting point."

4.2 The importance of the staff who provide services

All of the representatives we spoke to believed that the staff providing services on the 'front line' were a crucial part of including all disabled people in services and making them genuinely person-centred. However, some representatives we spoke to said that some staff wanted to be told what to do when an issue arose about a service user's needs. Instead of a person-centred approach, staff sometimes did not want to deal with people's complex needs or identities. For some staff the procedural, systems-based approach to service provision was seen as safer and possibly less time-consuming than flexible, person-centred approaches.

However, for all services, and social work in particular, these kinds of approaches impact on the ability to have a constructive relationship with the service user and therefore the extent to which the person can benefit from the service.

Other representatives spoke about the impact of the attitudes of some staff members towards people with certain characteristics. Whether conscious or unconscious, negative attitudes and assumptions towards people with particular characteristics prevented staff members from providing person-centred services.

Representatives suggested that these issues may be underpinned by a lack of knowledge and understanding of some staff. One representative said that service users have expectations of services and know very quickly when a staff member does not have the right knowledge.

However, training was not seen as the entire solution to this. Two of the representatives expressed a dislike for training which is "about learning about people" and "looking up guidance". This type of approach was seen as further compounding the labelling, procedural and box-ticking approach which underpins many services. It was seen as negating the staff member's responsibility for adapting and adjusting to each individual. It was also said that training is not a "magic bullet" and that it is "not a guarantee of success".

Training of staff was nevertheless still seen as an important part of increasing staff knowledge and understanding. The Social Security Scotland representative talked about using stakeholders, including people with lived experience, to design and deliver staff training. This can be a way of making training more effective, as people are presented with real-life stories and challenges which may force them to confront their own attitudes and assumptions.

The social work representative suggested that supervision is a very important aspect of service provision and support for staff. The space and time to reflect on their work allows opportunities for learning and development:

"Without [professional supervision] it's difficult for people not to behave in habitual ways and to challenge themselves."
(Social worker)

Other representatives spoke about the importance of treating staff well and the impact that this has on how they do their job and provide services. This included things like offering peer support and mentoring, gathering staff feedback, ensuring staff know they are playing a valuable role, supporting staff forums and giving staff opportunities to volunteer in the local community.

4.3 Constraints on services

Representatives said that constraints on service providers, such as inadequate funding, was one of the major barriers to providing person-centred services. This can result in service providers becoming targets of discontent and 'force [them] into the role of absorbing the frustrations of unsatisfied disabled persons' (Helgoy et al., 2003).

Budget constraints and lack of funding is an issue for almost all public services. This leads to staff being overstretched and under pressure to deliver services to more people in less time. Representatives noted that where staff are under pressure because of budget shortages and large caseloads they "retreat to silo" and deal only with what they can control.

Particularly in health and social care services staff may be preoccupied with doing practical tasks. However, as one representative noted, well-being is affected by how a service is delivered, not just what is delivered. Genuinely person-centred services require extra time for service providers and users to establish relationships of trust. If budget reductions and increasing caseloads are the norm in services then it is unlikely that a person-centred service will be delivered.

Recruitment of staff was another constraint on service providers, particularly for care providers because of the low pay and undervalued nature of the job. Care staff are often working in stressful environments and undertaking complex and demanding tasks. As a result, it is difficult to attract the right people to the job.

"Recruiting care staff is a big issue across the country. Recruiting care staff that have the right values, attitudes and experience and knowledge, if you can't do that then you're setting yourself and the customer up to fail." (Care provider)

If the right staff cannot be recruited there is a possibility that the care provider will be unable to provide a person's care. There is a degree of risk avoidance here in that care providers may be able to refuse to provide anyone's care on the basis that they could not get the right staff. This could potentially be used as a reason to avoid providing care to anyone who presents with complex needs, or who staff may not want to work with because the person has particular characteristics.

The care provider we spoke to acknowledged this:

"There are many legitimate reasons for knocking it back [the care package] but because they [the services user] have a label and it could be perceived as, in some shape or form, discrimination rather than a recognition that we can't actually meet the person's needs effectively."
(Care Provider)

It is for the service provider to ensure that they have transparent processes in place to demonstrate that they have not been discriminatory in the decision over whether to provide someone's care. This is connected to addressing potentially unconscious prejudices against certain groups of people which has an impact on every aspect of service design and delivery.

Risk aversion was viewed by some representatives as a constraint on providing person-centred services. For example, where a service user wishes to do something that has been assessed by other professionals as not safe then the care provider may withdraw their services.

"Assessment of risk and person-centred approach can come into conflict."
(Care Provider)

It seems likely that when risk and person-centredness come into conflict, the care provider will tip the balance in favour of risk-aversion. The potential for reputational and financial damage to the provider should someone (staff or service user) be harmed as a consequence of being supported to take a risk, is probably too large to justify taking that risk.

While balancing risk and safety is an issue for some service providers, the social work representative noted that being person-centred is not entirely about giving the person what they want. However, it is about understanding where the person is coming from, what is possible for them and supporting them to have choice and control. As discussed in previous chapters, choice and control are extremely important and go some way towards redressing the power imbalance in service provider/service user relationships.

There was also an acknowledgement that individual services cannot provide everything that someone may need. This reinforces the need for service providers to see the whole person so as to be able to identify where they can bridge to other services which the person may be able to benefit from. However, if services are designed to make staff think in categories and labels, there is a good chance that they will miss intersectional issues and opportunities for service users to access other services.

Lack of data and mechanisms for feedback from service users was viewed as a further constraint on how service providers deliver their services. The NHS representative spoke about the difficulties in getting data on patient's characteristics because: the systems used across services are not linked, data on characteristics is not collected routinely, and it is not possible to track individual patient satisfaction.

Collecting and analysing data and feedback is crucial to enable services to identify where there are issues with certain groups and intersectional groups. Although this will not tell the whole story, it is an important part of monitoring whether a service is being inclusive of all people and flagging up potential issues.

Social Security Scotland regularly publishes statistics on the benefits it administers, including on some of the characteristics of the people accessing these. The agency representative said that they also plan to use this data to target specific areas and groups where benefit uptake is low. Intersectional analysis of data collected by the agency could potentially provide a richer understanding of who is accessing the services and identify where more research and investigation is required.

4.4 Chapter conclusion

While the language of intersectionality was not used by all of the service providers we spoke to, they all showed an awareness of the need for their services to be person-centred. There was an understanding that there are many factors that influence individual's lives and that staff must avoid trying to label and categorise people. However, there was also a recognition that a person-centred approach was impeded by how services are designed and the attitudes and assumptions of some staff members.

Other challenges around budgets, staff recruitment, risk and lack of data also contributed to difficulties in providing person-centred services. The combination of these constraints plus attitudes and assumptions held by some staff members created challenging environments in which service providers operate. However, there is still much that service providers should do to adjust the design of their services and how they deliver them. Regular staff training and staff supervision/support is key to this. Staff need to be supported and treated as valued individuals in the workplace to ensure that they then give a person-centred and dignified service to the people they work with.

Conclusion

This research project set out to explore the experiences of disabled people with other characteristics when they access services. Our research question was: **What are the experiences of disabled people with other characteristics when they access services?**

To answer this, we had three sub-questions for which we can provide the following conclusions:

1. Do disabled people with other characteristics experience distinct forms of unfair treatment and barriers when accessing services?

Our survey and interview findings show that some disabled people attributed the unfair treatment they experienced when accessing services to their intersectional identities.

Our research suggests that the types of treatment and barriers participants experienced appeared to be compounded by the addition of their other characteristic(s).

Our findings show that disabled people with other characteristics were not listened to by professionals, were not given access to information about what they were entitled to and had to contend with inaccessible systems and processes. Disabled people with other characteristics also experienced bullying and invasive questioning from service providers.

Overall our research shows that disabled people with other characteristics experienced denial of choice, control and person-centred services.

2. Why are disabled people with other characteristics experiencing distinct forms of unfair treatment?

Our research shows that many of the treatments that the disabled people we spoke to experienced were underpinned by negative attitudes, assumptions and a lack of knowledge and understanding on the part of service providers.

The negative attitudes and harmful assumptions discussed by our participants reveal a potentially deep-seated prejudice towards disabled people with other characteristics.

Our findings suggest a lack of knowledge and understanding was connected to the types of attitudes and assumptions service users held about disabled people with other characteristics.

Our research also suggests, however, that a lack of knowledge and understanding seemed to sometimes be used as an excuse by service providers to avoid having to deal with some disabled people.

3. What are service providers' understandings of intersectionality and how do they make services inclusive for all disabled people?

Our research shows that service providers seem to be aware of the importance of person-centred services. While the term intersectionality was not as familiar, discussions around person-centredness included an awareness of the need to consider the whole person, including their different characteristics, relationships and life circumstances.

Our findings highlight that service providers work in challenging environments where they are constrained by various issues including reducing or stagnant budgets, issues with staff and recruitment and reputational risks.

Services seem to be aware of the need to tackle issues around staff attitudes and assumptions and lack of knowledge and understanding. However, the extent to which they feel able to do this while operating within challenging environments and using existing service processes was limited.

Overall conclusion

What are the experiences of disabled people with other characteristics when they access services?

Overall this research suggests that disabled people with other characteristics do experience distinct forms of unfair treatment when accessing services because of their intersectional identities. This unfair treatment is underpinned by negative attitudes, assumptions and a lack of knowledge and understanding from service providers. Service providers do show an awareness of the importance of person-centred services, however putting this into practice seems to be challenging particularly because of constraints around staff, resources and risk aversion.

Disabled people make up one fifth of the Scottish population and each disabled person has different combinations of characteristics and lives in different circumstances. It is therefore imperative that service providers see and treat disabled people as individuals with individual needs and preferences. To do this service providers should adopt a genuinely person-centred approach to how they deliver their services. They must also ensure that staff are trained and are given the right support and supervision to be able to develop their knowledge and continuously challenge their own beliefs and assumptions about disabled people. Only once negative attitudes towards disabled people are effectively challenged and eliminated will services be able to be genuinely inclusive of all disabled people.

Recommendations

These are the actions we believe are necessary to overcome the barriers identified by the disabled people who participated in the research.

These actions will require long-term commitment from the Scottish Government and service providers to tackle negative attitudes towards disabled people and to move to a genuinely person-centred approach to service provision.

Scottish Government

1. **The Scottish Government sets out in A Fairer Scotland for Disabled People that Scotland wants "Improved awareness and understanding of discrimination, prejudice and barriers faced by disabled people including the physical environment, stigma and negative attitudes".**

To do this, the Minister for Older People and Equalities and the Scottish Government should gather evidence about negative views towards disabled people, how these are formed and the most effective ways of challenging them.

Once there is a more robust evidence base about negative attitudes, the Minister for Older People and Equalities and the Scottish Government should use the best methods to challenge these. For example this could be a public campaign to challenge negative attitudes towards disabled people or an educational programme for school pupils.

2. **In A Fairer Scotland for Disabled People the Scottish Government commits to "explore how disability impacts different equality groups and what this means for our policies, services and communities".**

To address this the Scottish Government, public bodies and inspectorates should take steps under their Public Sector Equality Duty obligations to build a more comprehensive evidence base on disabled people. This requires that:

- Data is routinely collected across all protected characteristics and that intersectional analysis is undertaken and published.
- Qualitative research is carried out to explore the issues highlighted by the data and which disabled people with other characteristics report are hindering their right to live independently.
- The data and research findings are used to inform policy development and service design.

3. **The Scottish Ministers should amend the Public Sector Equality Duty regulations (The Equality Act 2010 (Specific Duties) (Scotland) Regulations 2012) to require public services, when carrying out Equality Impact Assessments, to consider the impact of policies and services on people with more than one characteristic.**

Taking an intersectional approach to Equality Impact Assessments will ensure that they more accurately reflect the reality of disabled people's lives and lead to a greater understanding of intersectional issues.

Services

4. Human Resources managers (including those in NHS Scotland, care providers, Social Security Scotland, social work departments, education providers, transport providers and housing providers) should ensure that all staff receive equality training which:

- Is underpinned by intersectionality and a person-centred approach and provides accessible explanations of what these concepts mean and how they can be put into practice.
- Is designed and delivered by people who use the service, including disabled people.
- Provides an understanding of the social model of disability.
- Challenges negative attitudes and assumptions towards different groups.
- Is kept up to date.

Human Resources managers should also consider how equality issues can be embedded throughout their organisation, for example through updates or notices in staff newsletters, via leadership programmes, through staff networks etc.

5. Chief Executives (including of NHS Scotland, care providers, Social Security Scotland, social work departments, education providers, transport providers and housing providers) should actively prioritise the voices of those who use their services by ensuring:

- A range of disabled people are involved in designing services through co-production. This means that disabled people should be meaningfully involved at every stage of the process.
- The services and products are tested by the people who will use them.
- A proportion of the workforce are disabled people.
- Policies and practices are reviewed to make sure they do not prevent people from getting involved.

6. Chief Executives (including of NHS Scotland, care providers, Social Security Scotland, social work departments, education providers, transport providers, housing providers) should ensure that they have an accessible and transparent information/ communications policy that is applied consistently. This should include:

- Actively providing disabled service users with information about entitlements (as required by Article 21 of the UN CRPD), which is not based on availability of resources.
- Communicating why things are done in a certain way and where flexibility is permitted or required.
- Consequences for services which fail to give out relevant information or supress information.
- A clear and accessible complaints procedure requiring that complaints are investigated by independent boards which include disabled people.

7. Chief Executives (including of NHS Scotland, care providers, Social Security Scotland, social work departments, education providers, transport providers, housing providers) should ensure that staff have good working conditions and foster a positive organisational culture by:

- Providing support for staff, including opportunities for reflective practice.
- Ensuring that staff are not overworked and that their concerns are listened to.
- Ensuring the workforce is reflective of society, including employing disabled people.

Funding and resources

8. **The Scottish Government should ensure all services are sufficiently funded so that they can deliver person-centred services which enable independent living. This requires that the Scottish Government:**

- Reviews its approach to person-centred services to ensure that it encompasses intersectional issues.
- Regularly discusses with services it funds any barriers that prevent them from providing person-centred services.

9. **Public bodies should ensure that they use their funding and resources in a way that enables the provision of person-centred services and independent living.**

Future research

10. **Organisations involved in research and data collection (including the Scottish Government, funding bodies, universities, third sector organisations) should promote and/or undertake further research on intersectional issues.**

11. **This research report highlights some specific areas that would benefit from further research:**

- The meaning of person-centred services for service users, policy makers and service providers.
- The connection between intersectionality and person-centred services.
- Methods for embedding person-centred services.
- The experiences of people with multiple impairments.
- Disabled people's understanding of their characteristics and how these impact on their experiences.
- Negative attitudes towards disabled people with other characteristics.

Third Sector Organisations

12. **Third sector organisations should recognise and take account of intersectionality to ensure that people with multiple characteristics can benefit from their services. Taking account of intersectionality can also enable third sector organisations to challenge intersectional discrimination and contribute to the evidence base on the experiences of disabled people with other characteristics.**

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