See Me as a Human Being:

How attitudes within the social care system impact on the independent living choices of disabled people

3rd December 2020

drill
Disability Research on Independent Living & Learning
Disability Action
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Disabled people co-produced this research with three partners

The DRILL National Advisory Group (NAG)

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The NAG contributes to the development and delivery of DRILL research projects in Northern Ireland by scrutinising proposals, developing research tools, critiquing work, advising, and helping with promotion and dissemination of the work. The Research Partnership is a sub-group of the NAG that oversees and provides support to this research project. The NAG is comprised of disabled people, human rights activists with expertise on disability, representatives of Disabled People's Led Organisations (DPLOs), academics, research and policy-making bodies, and practice and professional leaders. Disabled people form a majority on the NAG.
http://www.drilluk.org.uk/about-disability-research-on-independent-living-and-learning-drill/national-advisory-groups/

Disability Action Northern Ireland (DANI)

Disability Action

Disability Action is a Northern Ireland charity that works with people with physical disabilities, learning disabilities, sensory disabilities, hidden disabilities and mental health disabilities. We work to promote, protect and uphold the human rights of disabled people.
https://www.disabilityaction.org/

The Northern Ireland Social Care Council (NISCC)

Social
Care
Council

The Social Care Council is helping to raise standards in the social care workforce by registering social care workers, setting standards for their conduct and practice and supporting their professional development. https://niscc.info/about/

“**See me** – not who you think I am or who you want me to be or what’s convenient for you in the moment – but **see me**.

And if you see that I have a particular requirement or a particular ‘need’ - as everybody is fond of the word ‘need’ - then ask yourself, can you address it and if you can’t, why not? ...

But always **see me**, don’t focus on the seizure, don’t focus on the tears, don’t focus on the anguish, focus on what can be done in that moment and how can it be done humanely with dignity ...

So **see me**; and in the caring world few people **see me**. They see what they want to see but they never **see me**.”

Disabled person during interview

Contents

1. Glossary

Ableism - Ableism is the belief that people are defined by how they are disabled by a society not designed for them and are therefore inferior to abled people.

Adult Social Care – Adult Social Care is the personal and practical support provided to adults with physical or learning disabilities, or physical or mental illnesses, to help them live their lives. It should support individuals to maintain their independence and dignity.

Co-production – For the purposes of this project, co-production means disabled people being involved at every stage of a proposal and subsequent research project. This extends from identifying what is to be researched, through undertaking the research, to drawing conclusions.

DANI – Disability Action Northern Ireland. Disability Action is a Northern Ireland charity that works with people with physical disabilities, learning disabilities, sensory disabilities, hidden disabilities and mental health disabilities.

DDA – Disability Discrimination Act. This Act introduced laws and measures in 1995 aimed at ending the discrimination many disabled people faced when accessing employment, and/or goods and services.

DLA – Disability Living Allowance. This is a benefit to help people cover the extra cost of care or mobility needs due to illness or disability. For those aged 16+ it has been replaced by PIP.

DPO & DPLO – Disabled People’s Organisation and Disabled People’s Led Organisation.

DRILL - Disability Research on Independent Living & Learning.

ECHR - The European Convention on Human Rights. This Convention protects the rights of people living in the 47-member states of The Council of Europe.

EHRC - The Equality and Human Rights Commission. It enforces equality legislation to prevent discrimination on the grounds of protected characteristics, such as age, race, religion or belief, disability, gender identity, marriage and civil partnership, pregnancy and maternity, sex and sexual orientation.

ESA - Employment Support Allowance. This is a benefit for adults below the State Pension age who cannot work because they are disabled or have a long-term health condition.

Grounded theory – A research approach that allows for extraction of themes across the data gathering and analysis process, under which data can be usefully grouped.

HSC - Department of Health and Social Care (in Northern Ireland). The role of this department is to make sure that people with disabilities or long-term health conditions receive the support they need to live as independently as possibly in a dignified manner.

ILF – Independent Living Fund. An organisation that provides funds to help disabled people live as independently as possible.

Independent Living – Independent living means “all disabled people having the same choice, control and freedom as any other citizen – at home, at work, and as members of the community. This does not necessarily mean disabled people 'doing everything for themselves', but it does mean that any practical assistance people need should be based on their own choices and aspirations” (Morris, 2003, p. 4).

Lived Experience – This refers to a representation of the experiences and choices of a given person (in this case disabled people), and the knowledge that they gain from these experiences and choices.

Multiple identities / Intersectionality – This describes the interconnectedness and overlapping of different social categories by which people define themselves. such as disability, gender, sexuality, class or race as they apply to an individual or group. These social and political identities can combine to create unique and interdependent systems of discrimination and marginalisation.

NISCC – Northern Ireland Social Care Council. This organisation is concerned with raising standards in the social care workforce by registering social care workers, setting standards for their conduct and practice and supporting their professional development.

Non-disabled person – A person who is enabled by society due to being either physically and/or sensorially typical, or neurotypical.

RQIA – Regulation and Quality Improvement Authority. An independent organisation that monitors and inspects the health and social care system in Northern Ireland.

UC – Universal Credit. This is a benefit for people who are unemployed or who are on a low income.

UNCRPD – United Nations Convention on the Rights of Persons with Disabilities. This is an international human rights treaty designed to protect disabled people against discrimination and abuse, while promoting their rights to inclusion and equitable treatment.

2. Introduction

This research tackles two major issues which significantly impact on disabled people's daily lives: **adult social care, which exists to support people to live as independently as possible**, and **attitudes towards disabled people**. It is concerned with finding out what happens in practice, not just what is written in policy. It was inspired by discussions with disabled people themselves during DRILL's Northern Ireland roadshows and with the Disability Action Advocacy Team.

Time and time again, disabled people would begin a question or comment with the words "Is it me?" when reporting a negative experience in the social care system. While some disabled people recognised that the problem was with the system and/or with individual workers, others were left with the feeling that they were the problem – in part because attitudes can be difficult to pin down. "Is it me?" too readily became "it must be my fault."

Over the course of this research, it became clear that the central problem was one of society not seeing disabled people as equal, and the casual denial of their rights was tantamount to seeing them as less than human. To move away from the notion that disabled people were inherently at fault for what was happening to them, the name of this project evolved to become **See Me as a Human Being**. It reflects something fundamental that emerges from this research - that disabled people want to be seen, listened to, and treated as human beings. They want to be seen as people equal to any other, with the right to equal respect.

Attitudes matter to disabled people. Negative attitudes which imply that disabled people are lesser, "other", or a burden, impact on all aspects of their lives - housing, relationships, public life, education, employment, and the adult social care system. Attitudes such as these can underpin bullying, harassment, and discrimination against disabled people. They can adversely affect mental health and lead to disabled people internalising ableist views about themselves (Linton, 1998, p. 9). Therefore, it is important to understand how attitudes impact on disabled people's experiences of the social care system and how these attitudes impact on their independent living choices and experiences.

This research explores the attitudes and behaviours that disabled people experience from individual social care staff and considers how policies and practices affect attitudes within the social care system. It allows space for people to talk about the impact that attitudes have on their experience of social care. Along with the moral and legal arguments, there is a strong economic case to be made for the value of consulting disabled people. Disabled people live with their impairments or health conditions. They are the experts on their own lives and know the most about what they need.

This report also investigates the experiences of social care workers, social workers and others who work in the social care system to better understand the challenges they face in their work. Their experience of providing social care, their own attitudes to disabled people, and their experience of how attitudes impact on policy and practice within the system can provide valuable insight into how to improve adult social care.

See Me as a Human Being delivers key findings about what is working well and should be supported, what is not working well and needs to be addressed, and evidence-based recommendations for change. This research is intended to be a tool for disabled people, their allies and organisations, health and social care workers, policy makers, funders, and government departments to improve attitudes within the social care system. It aims to improve disabled people's right to access choice and control and discover how their independent living choices and rights can be more effectively realised.

Underpinning all of this are the fundamental human rights that disabled people are entitled to, but so often are unable to access. The general principles in Article 3 of the United Nations Convention on the Rights to Persons with Disabilities (UNCRPD) are "respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons" (2006). These are the standards towards which we, as a society, should be striving to create true equality for disabled people.

3. Co-production

Co-production is built into this research project, as both a fundamental methodology and a practical way of implementing the disability movement's principle of *nothing about us without us*. The aim of co-production is to ensure that research is sustainably led by disabled people throughout the lifetime of the project.

The aim of DRILL is to ensure disabled people are "empowered to have direct influence on decisions that impact on their independent living, particularly in relation to policies, legislation and services" through co-produced research (DRILL UK, 2019, p. 10).

DRILL projects are not undertaken "on" or "for" disabled people; they are undertaken "with" and "by" disabled people. This research was led by disabled people, right from the initial idea for the project, through the development of the research questions, the methodology, the data-gathering, report-writing and editing, until the project's conclusion, and the dissemination of the findings.

Human rights activists and academics with expertise on disability were recruited to two advisory boards. The Northern Ireland DRILL National Advisory Group (NAG) fed into and supported the DRILL research projects in the region. The Research Partnership, a sub-group of the NAG, specifically informed and supported the **See Me as a Human Being** research project. Some individuals sat on both boards. These boards met regularly throughout the life of the research projects, and funding was allocated to support disabled people to be able to attend and fully participate. The NAG and the Research Partnership ensured that the research questions were informed by the key issues facing disabled people. Disabled people formed the majority on both advisory groups. They also regularly critiqued and supported the work produced by the researcher, providing invaluable expertise on subjects such as disability policy, activism, academia, and from lived experience of being disabled.

The DRILL co-production research process has embedded the following principles into practice:

Accessibility

Research is co-produced in ways that are accessible and understandable to all involved. Research findings are made available in a wide range of accessible formats and in places that disabled people can access.

Experts by lived experience

Research respects the value of academic, professional, and experiential knowledge and requires the active use of all these forms of knowledge.

Collaboration and shared goals

Each step of the research process is undertaken in equal partnership. A mutual understanding of what the research question is, why the research is being done, and what the aims, objectives and desired outcomes of the research are, provide a sound basis for working in an equitable partnership.

Equalising power relations

Disabled people's priorities steer the research process. Power and responsibility are shared equally and constantly reviewed, and all partners can influence decisions throughout the process, with opportunities for reflection and learning from experience.

Impact

Research outcomes have real impacts, which improve independent living for disabled people beyond the life of the DRILL Programme.

Co-production can be implemented to various degrees in practice, from "fairly tokenistic user-involvement all the way through to a complete transformation of power relationship within services" (Nesta, 2012, p. 6). When fully realised and placed within a practical context, for example, a study of an aspect of the adult social care system, co-production could have a transformative effect. Indeed, “the people who use services … can help to improve those services” if they are effectively and consistently involved in the co-production process of both research and service creation and delivery (Needham & Carr, 2009, p. 1).

This co-produced research project aspires to “create room for rhetorical agency – giving space for a greater diversity of voices – within our discourses” (Bone, 2017, p. 1311). It strives to create equality in the research process, prioritising lived experience and expertise. It takes a critical and innovative approach to examining attitudes within the adult social care system and how they impact on independent living choices.

4. Methodology

The voices of disabled people are central to this research and co-producing this research with disabled people is an essential part of the methodology. Prioritising what disabled people say is essential to acknowledging the expertise that they have from their lived experience as disabled people.

Those who work in the social care system also provide a very useful understanding of the challenges they face in their work and the attitudes they see in practice. Collecting information from social care workers, social workers, social care managers added another perspective from those who work in the social care system.

Both quantitative and qualitative methods were used, including:

- A review of existing research related to attitudes and social care
- Four focus groups with disabled people
- One focus group with social care managers
- Fourteen in-depth interviews with disabled people
- An online survey of social care workers and social workers which elicited 550 responses

Interviews and focus groups were digitally recorded and transcribed, apart from two interviews that were received by email or post (which better met the needs of the interviewees) and one interview where the interviewee requested that they not be recorded.

4.1 Review of relevant material

Relevant research and policy reports, as well as news reports on current affairs, attitudes, and human rights in the areas of social care were reviewed. The literature review provided useful context around current policy, practice, and mainstream understandings of disability and social care.

4.2 Focus Groups with Disabled People

Four focus groups were conducted with disabled people between October and December of 2018 in Belfast, the Northwest, and rural Northern Ireland. Altogether, 24 people participated in these focus groups. Their function was to clarify the key issues relating to attitudes and adult social care. Four clear themes emerged from thematic analysis (which means looking at the main issues people were talking about) of the transcripts:

- Availability of information
- Acknowledging lived experience as expertise
- Attitudes and stereotyping
- Lack of quality and continuity of care

These themes were then used to develop the interview and online survey questions.

4.3 Focus Group with Social Care Managers

One focus group was conducted with seven social care managers. The aim of the focus group was to learn from those working within social care about attitudes within the sector. This included how policy filters down in practice and the challenges facing frontline staff and the social care system.

4.4 Interviews with disabled people

Interviews were conducted with 14 disabled people across Northern Ireland between January and August of 2019.

The interviews gave them the space to talk in greater depth about attitudes and experiences of adult social care and independent living choices. They shared their ideas, experiences, and understandings of attitudes within the social care system and how they impacted upon their independent living. Grounded theory (Heydarian, 2016) was used to identify themes from the transcripts of the interviews.

While four of the themes overlapped with those that emerged in the focus groups, two additional themes were identified as important to disabled people:

- Dignity, trust, and value
- Choice and control

These additional themes were then applied across all data, including the focus groups and the online survey.

4.5 Online Survey with workers in the social care system

A questionnaire was developed, using the themes that came out of the focus group to inform the questions, for people working with disabled people in social care. The survey was distributed through NISCC, which is the regulatory body for all social workers, social care workers and social care managers.

The aim of the online survey was to triangulate the research (see it from different angles), investigating the dynamics of the caring relationship from those who work in the field of adult social care. With 550 respondents, it was designed to provide both quantitative and qualitative material.

24 people participated in focus groups.

14 in-depth interviews with disabled people

4.6 Who are the research participants?

The disabled research participants (in the interviews and the focus groups) have a diverse range of impairments and health conditions, including physical disabilities, learning disabilities, sensory disabilities, hidden disabilities, and mental health disabilities. There is a mix of women and men, adults of various ages and a number of lesbian, gay, bisexual or transgender respondents. Black or minority ethnic (BME) people are not represented amongst the research participants, despite attempts to recruit through BME voluntary organisations.

The workers in the field of social care who completed the survey are mostly social care workers (66.32%) social workers (12.15%) and others (2.08%) include social care managers and students.

They work in Trusts (44.95%), the private sector (30.66%), the voluntary sector (13.94%), a combination of the above (7.32%), or other (3.14%). A small minority of all respondents are disabled themselves (7.64%).

4.7 Ethical considerations and limitations of the project

An excess of paperwork proved to be a barrier for some of those taking part in the interviews and focus groups. Filling in equality and diversity forms and consent forms was time and energy consuming. This was especially difficult when interviewees were already emotionally and physically exhausted by the interview process. Coupled with the effects of people's health conditions or impairments, it meant having to concentrate for longer to fill in paperwork. While gathering information, particularly about equality and diversity, is essential, it could be carried out with greater sympathy to these issues.

The online survey was anonymous. This may have encouraged people who work in the social care sector to be candid in a way that might not be possible for them in their workplace. However, the provision of anonymity means there is no way of verifying who is taking the survey. In addition, the survey was, mistakenly, designed in a way that meant questions could be passed without an answer. That means while 550 people completed the survey, each question did not necessarily have 550 responses. While being able to skip questions may have allowed people to focus on the issues that were most relevant to them, it means that not every participant answered the questions about equality and diversity and where they worked. The data are therefore presented in percentage form.

66.32% of those who completed the survey are social care workers

5. Literature review: The context for this research

Attitudes towards disabled people impact significantly on every aspect of their lives. This is because attitudes impact upon how people are seen, thought of, and interacted with. One metric by which quality of life for disabled people is measured is the extent to which they are able to live it independently. When people rely on the social care system to determine how independent they can be, the role attitudes play within this system must be addressed: how do attitudes towards disabled people within the social care system impact upon their choices around independent living? This literature review explores relevant, current material to provide an up-to-date context for this question.

5.1 Fresh challenges

At the time of writing, the UK is facing unprecedented levels of political and social turmoil. The devolved executive and Northern Ireland Assembly returned to work in January of 2020 following a lengthy hiatus since January 2017. Not only has the health and social care service atrophied without a minister in place in the intervening years, it must also face up to dealing with the impact of Brexit. Although the UK officially exited the European Union on the 31 January 2020, the effects of leaving will not really be apparent until after the transition period, in December of 2020. While research has shown that “all forms of Brexit are bad for health”, leaving the EU without a deal is by far the most damaging (Fahy, et al, 2019, p. 949). With negotiations making slow progress and the prospect of an extension rejected, a no-deal Brexit is still a real possibility. Perhaps the most pressing issue for the adult social care services is the ability to recruit and retain staff from the EU as the UK government’s attitude to immigration hardens. It was estimated in 2017 that EU workers made up to 90,000 of the UK’s 1.6 million social care workers, a figure that will be harder to sustain as the UK government rejects the EU's principle of freedom of movement (Marnoch, 2018, p. 87) and proposes stricter criteria for people wishing to live and work here.

As momentous as the Brexit situation seems, it has been all but eclipsed in 2020 by the emergence of a novel Coronavirus at the close of 2019. The spread of the virus has caused over 11 million cases of the illness COVID-19, leading to over 500,000 deaths globally as of 7 July. At the time of writing, the UK alone accounts for over 44,000 of these deaths (World Health Organisation, 2020). The availability of statistics across the four nations is patchy, but combined they paint a devastating picture of the effects the pandemic has had on disabled people across the country.

The Office for National Statistics suggests that almost 60% of deaths from COVID-19 in England and Wales between the beginning of March and mid-May were disabled people (2020b). Northern Ireland recorded the highest rate of deaths taking place in care homes between the beginning of March and end of April, at 44% (Office for National Statistics, 2020a). Close to 4,000 of the 24,000 domiciliary care packages across Northern Ireland were put on hold by disabled people and their families who feared they were at risk of contracting the virus, leaving family members and the community to take the strain of extra caring responsibilities (Cullen, 2020). Healthcare workers in Northern Ireland and across the UK faced the prospect of working without personal protective equipment vital to their safety (Davies, 2020).

In terms of attitudes towards disabled people and those with long-term health conditions, the crisis has been revealing. Particularly in the early days of the pandemic, the message emerged that “only” those with pre-existing conditions or impairments were at risk. While this may have been intended to reassure the general population, for those that fall within the high-risk category “there's a natural concern about framing a pandemic in the belief that disabled people's lives aren't as valuable as everyone else's” (Ryan, 2020). There is also a possibility this message could erode the general public's resolve to keep up basic hygiene practises and social distancing if they believe they are not personally at any great risk, increasing the risk for sick and disabled people.

In June 2020, Health Minister Robin Swann took stock of the situation in Northern Ireland as it emerged from the initial wave of the pandemic: “Our health and social care system was in very serious difficulties long before Coronavirus reached these shores. The virus has taken the situation to a whole new level” (Northern Ireland Executive, 2020). On top of the pre-existing problems, he recognised the fresh challenges that are facing the services, such as a renewed emphasis on infection control and the threat of a possible second wave. A new report, *Rebuilding health and social care services: Strategic framework,* was published, with a focus on rehabilitating health and social care in the wake of the pandemic. Within this report, The Department of Health acknowledged that there may be greater demand for social care from those who have contracted COVID-19 so far (and those who will in the future), suffering its long-term effects and creating new service users or more reliance from pre-existing ones (2020, p. 11). Given the strain the system was under prior to the pandemic, it is not easy to see where the resources required to provide this increased capacity will be found.

The Department of Health’s new strategic framework recognises the importance of implementing recommendations made to reform health and social care by the *Systems, not structures* (Bengoa, et al, 2016), *Health and wellbeing 2026* (Department of Health, 2016), and *Power to people* (Kelly & Kennedy, 2017) reports (Department of Health, 2020, p.15). Although they all predate the emergence of COVID-19, they point to issues such as an ageing population, workforce pressures and long waiting lists that not only endure but are compounded by the pandemic. This report, also based on research conducted pre-COVID-19, joins these important pieces of work, calling for reform that centres the voices of disabled people and recognises them as experts of their own experience, at a critical moment for the future of social care.

5.2 Health and Social Care in Northern Ireland

The UK has four health care systems, one controlled centrally by the UK government to serve England, while power over health policy has been devolved to the other three nations, Scotland, Wales, and Northern Ireland. In Northern Ireland, this service is collectively known as Health and Social Care in Northern Ireland (HSC).

The Minister of Health heads the Department of Health, which is responsible for forming policy and legislation (Health and Social Care

Online, 2020b). The Health and Social Care Board (HSCB) commissions health and social services in Northern Ireland, distributing funding received from the Department of Health, and directing Northern Ireland's six Health Trusts. These include The Belfast HSC Trust, the Northern HSC Trust, the South Eastern HSC Trust, the Southern HSC Trust, the Western HSC Trust, and the Northern Ireland Ambulance Service Trust. The five regional trusts direct the running of "hospitals, health centres, residential homes, day centres and other health and social care facilities and they provide a wide range of health and social care services to the community" (Health and Social Care Online, 2020a).

With each nation following its own path for the 20 years since devolution, significant differences have developed between them (Bevan et al., 2014). While in England and Wales social care is provided by local authorities, Scotland and Northern Ireland offer an integrated health and social care service. This has been the case in Northern Ireland since 1973, as religious and political divisions lead to "systematic discrimination by local governments, which was one of the factors causing the troubles" (Greer, 2004, p. 165). England has a significantly higher rate of use of private services as it is "less generous" in its offer of social care support, whereas "Wales, Scotland and Northern Ireland offer additional support outside of the means test" (Oung et al, 2020).

When a person in Northern Ireland is assessed and found to be in need of social care, it is provided through Self-Directed Support (SDS). SDS is intended to maximise choice and promote independence by allowing individual to choose to use their Personal Budget in various ways:

- Direct Payments to pay for relevant goods or services
- A Managed Budget, held by the Trust, but spent as the individual sees fit
- Services arranged by the Trust

Or, as another option, the individual can pick and choose from all three, creating a tailored package unique to them (Health and Social Care Board, 2020). However, in the course of this research it will become clearer just how well this system works in practice as disabled people, the end-users of the services, discuss just how much "choice" and "independence" they feel is available to them in reality.

The Independent Living Fund (ILF) is another layer of social support, supplementing “resources provided by local Health and Social Care Trusts (HSC Trusts) for individuals with the highest levels of assessed social care needs” (O’Neill & Fitzpatrick, 2020, p. 4). The ILF aims to help people exercise choice and control over their life preferences, maintain their mental and physical wellness, and support their societal interaction to the fullest in work and leisure (p. 17). Unfortunately, the UK Government closed the ILF UK in 2015 after years of changes to eligibility and budget cuts, stating that it was “no longer a financially sustainable model in light of significant changes to social care policy and provision since the inception of the fund” (p. 14). It was decided that existing recipients of funding in Northern Ireland were to continue to benefit from the fund on the formation of the Independent Living Fund Scotland that same year. Research on the impact the Independent Living Fund has had on the lives of recipients in Northern Ireland shows how their journey to independence changed their lives, adding value to the lives of people around them and their community, bolstering the case for the Independent Living Movement in and of itself (p. 46-47). It is a strong argument for finding a way to open the fund for new applicants again, so all eligible disabled people can fulfil their potential to live independently.

5.3 Attitudes towards disability

There are many kinds of impairments – physical, mental, sensory, intellectual, hidden and invisible, and long-term health conditions – that affect how an individual engages with the world around them. This combination of impairment and level of engagement identifies an individual as disabled, and how disability is understood generally can affect attitudes towards disabled people (Levitt, 2017, p. 510). These attitudes are influenced by two schools of thought: the medical model and the social model of disability. The medical model sees an individual’s health condition or impairment as the root cause of their disability. It views a disabled person’s impairment as something “wrong” with them (based on an unfavourable comparison with a hypothetical “non-disabled person”) and assumes the individual needs medical correction.

Disabled people’s organisations consider the medical model to be outdated and argue in favour of the social model of disability. This model recognises that society and its institutions are disabling, as they create barriers to the inclusion and participation of disabled people (2010 to 2015 Government policy, 2015). It acknowledges that many physical and social barriers can make it impossible or difficult to access jobs, the built environment, or services. However, according to recent research by the Trades Union Congress on the disability employment gap, “the biggest barrier of all is the problem of attitudes to disability” (Roache, 2019, p. 3). The scope of the social model encompasses attitudes and stigma as impediments in the lives of disabled people, but there is a gap in the knowledge as to what this means in reality: “what we need, both in policy and in research, is some action both at the micro level of support interactions and at the macro level of attitudes and understanding” (Williams & Porter, 2015, p. 106). In the context of this research, a clear picture needs to be developed of what happens in the relationships between care workers and disabled people in the social care setting (micro level) and how this corresponds to societal depictions of and attitudes towards disabled people generally (macro level).

Research has shown that disabled people are viewed in very particular ways by the public, few of them flattering. A survey of perceptions of disabled people by Scope in 2018 found that a third of disabled people felt that there was a lot of prejudice against disabled people in Britain (Dixon et al, 2018, p. 5). Only 22% of non-disabled people agree, illustrating a significant gap in perception between the groups. Three quarters of people thought disabled people needed to be cared for some or all of the time (p.10), and a third thought of disabled people as less productive than non-disabled people (p. 11).

The kind of attitudes revealed by the 2018 Scope survey are akin to those that Philomena McCrory, founding member of The Centre for Independent Living Northern Ireland, has observed in her work as an activist and through lived experience as a disabled person:

> **“We still have a tendency to see disabled people as a financial burden, and sometimes it is only if you are economically active that you have a right to have a say, and that other people should be grateful for what they get. It’s part of a general political context outside where disabled people have been portrayed in recent years as benefit scroungers, so there’s always the assumption that maybe you’re not**

> **willing to work or you're expecting too much, that maybe you're not grateful enough for what you get. And that is disappointing."** (Disability Action, 2018)

Mapping the kind of attitudes held by the general population, such as through the Scope research and the testimony of disabled people, is useful for contemporary disability research because "[attitudes] may translate into behaviour towards individuals and groups in society which have negative consequences (such as discrimination and hate crime)" (Staniland, p. 15). They can have real practical dimensions when they influence the planning and delivery of an adult social care service that is supposed to facilitate independent living choices.

5.4 Attitudes in practice

Negative perceptions of disabled people mean they have frequently been treated as "other" and lesser than their non-disabled counterparts. Disabled people are still often dealt with in a paternalistic fashion, with other people or organisations making decisions on their behalf. Until relatively recently, many disabled adults, especially those with mental health conditions and learning disabilities, were placed in institutions where they had little or no choice about how they conducted their lives. This was sometimes called "warehousing", a dehumanising term used to describe disabled people being gathered under one roof to reduce the expense of caring for them (Ryan, 2019a, p. 83).

While more disabled people may now live in the community than they did mere decades ago when institutionalisation was the norm, attitudes have been slower to catch up with this progress. Prejudice remains and can show itself in the harassment and exploitation of disabled people, as The Equality and Human Rights Commission's (EHRC) *Hidden in plain sight: Inquiry into disability-related harassment* (2011) discovered. In the context of this inquiry, a broad spectrum of behaviours were categorised as harassment, from seemingly mild actions such as "being ignored or overlooked; stared at; called names; asked intrusive questions, offered offensive advice, patronising comments or jokes" through to serious incidents of "invasion of personal space, touching, pushing, being spat at or hit or being the target of thrown objects; sexual harassment and assault; damage to property; and actual or attempted theft or fraud" (p.

66). Harassment is a commonplace experience for some disabled people, and those with mental health issues or learning disabilities were more likely to be targeted than people with other impairments (p. 108). The EHRC inquiry ruled that “attitudinal barriers are some of the most pervasive barriers that need to be tackled if we are to address this issue effectively” (p.135).

The effects of these attitudinal barriers can be seen in the rate of disabled people’s participation in public life. According to the Department of Culture, Media and Sport, in 2010 disabled people were still less likely to enjoy cultural, leisure and sporting activities than non-disabled people (2010, p. 39). Despite the hope that the 2012 Olympic and Paralympic Games in London would encourage disabled people to take part in sport, the rate of participation has since fallen, likely due to underfunding and inaccessible facilities (Pring, 2015). This underfunding and inaccessibility is part of a wider, systemic attitude that does not value disabled people equally and, coupled with the behaviours described by the EHRC inquiry, sends an implicit message that they should stay away. While the shifting of emphasis within the adult social care system to enabling disabled people to live within the community is to be welcomed, it is clear that disabled people will not reach the point of full integration in public life until both physical *and* attitudinal barriers are overcome.

5.5 Disabled in Northern Ireland

According to the Northern Ireland Statistics and Research Agency, one in five people in Northern Ireland identifies as disabled (NISRA*,* 2012, p. 4). There are relatively few disabled people’s organisations that are pan-disability, and many disabled people’s organisations or disabled people-led organisations tend to focus on campaigning or providing services for a narrow range of impairments or health conditions. This means as a sector, and as a political movement, focus and momentum can be quite fragmented, with few cross-cutting calls for action. In recent times those working in the disability sector have

1 in **5** people in NI identify as disabled

adopted a rights-based framework in greater numbers, but this approach has yet to fulfil its potential (Disability Action, 2018).

The fractured political situation in Northern Ireland reflects a society habitually segregated along traditional nationalist/Catholic, unionist/Protestant lines. The focus on segregation results in the neglect of other forms of difference, such as disability or ethnicity (Potter, 2018, p. 334). In 2007 it was calculated that sectarianism in Northern Ireland cost up to £1.5 billion every year, through policing, segregated housing, and duplicated services for the two communities (Gordon, 2008). In the intervening years little has changed, and more contemporary research confirms that this costly sectarianism “shows no sign of going away” (Morrow, 2019). In her 2013 study of the interplay between conflict and disability, Stephanie Kerr notes that “available resources go to segregated groups, thus ignoring individuals with a disability and hereby limiting or depriving the individual with the disability of both their resources and their voice” (p. 828). The conflict has dominated the narrative on inclusion and societal participation for so long that disabled people have not been prioritised in terms of policy and available resources. This seems even more counterintuitive when considering that 500,000 people were directly affected by the conflict through bereavement, experiencing a traumatic event, or sustaining a physical injury (Cunningham, 2011).

Further research into the ramifications of the conflict shows it continues to have an indirect effect on society through transgenerational trauma (Fitzgerald et al., 2017) and a hostile environment for mental health (O'Reilly & Stevenson, 2003). A report from the Northern Ireland Affairs Committee (NIAC) on funding for the health service has demonstrated that Northern Ireland has the highest incidence of post-traumatic stress disorder in the world, a 25% higher rate of depression when compared to England and the highest suicide rate in the UK (2019). Despite all of this, a comparatively low percentage of the Department of Health’s overall budget is spent on mental health services. This deficit means that “those in need of mental health services have struggled to access the same quality of care as those with physical health needs”. The NIAC has called for greater investment in mental health services (and social care services generally), as well as consultation with professionals, service users, staff, and the community and voluntary sector to evaluate how best to distribute this funding.

A survey of the relevant literature shows a tendency to come to separate but similar conclusions: we need to "re-conceptualize what it means to be included in a deeply divided society" (Potter, 2018, p. 334). Increased funding is desperately needed, but it must be allocated with due regard to the expertise of disabled people's lived experience, recalibrating priorities and addressing inequalities and deprivation.

5.6 Legislation in Northern Ireland

In comparison to other areas of the United Kingdom, Northern Ireland differs in terms of disability legislation and policy in relation to disability. This is due to the devolution of equal opportunities law to the Northern Ireland Assembly in 1998. For example, the Equality Act, which "provides a legal framework to protect the rights of individuals and advance equality of opportunity for all" (Equality and Human Rights Commission, 2019) in the rest of the UK, does not extend to Northern Ireland. It retains the Disability Discrimination Act, amended in 2008 (Equality Commission for Northern Ireland, 2013). The DDA protects disabled people from discrimination in areas of employment, and the provision of goods and services. This includes requiring employers to make reasonable adjustments for disabled people in their workplace. It also states that public authorities must "pay 'due regard' to the need to promote positive attitudes towards disabled people and to encourage the participation of disabled people in public life" (Equality Commission for Northern Ireland, 2011).

The Equality Act provides greater protection to disabled people than the DDA does, as in Northern Ireland disabled people are not protected from indirect discrimination. The DDA allows employers to ask applicants in Northern Ireland about their disability, and how it impacts on them. Employers in the rest of the UK cannot do so under the Equality Act, leaving disabled people in Northern Ireland more vulnerable to discrimination during the employment process.

The Mental Capacity Act (NI) 2016 draws together legislation regarding mental health, and when certain actions and behaviours can be applied to people with mental health conditions in social care and the criminal justice system. This act has been criticised for breaching key human rights under both the UNCRPD and The European Convention on Human Rights (Potter, 2016). The areas highlighted for breaching rights include substituted decision-making, deciding what the best interests of others are, the capacity test and deprivation of liberty.

In Northern Ireland, reports of practices breaching the human rights of patients with mental health conditions and learning disabilities started to emerge from Muckamore Abbey Hospital in 2017. Photographs were released of sparsely furnished “seclusion rooms”, used to implement “a policy based on national guidance to contain behaviour likely to cause harm to both the patient or to others” (BBC News NI, 2018). One mother of a resident there described the room as “a dark dungeon” with no access to drinking water or toilet facilities. Her son, who has “autism and epilepsy and cannot speak or feed himself”, was locked in the seclusion room for up to two hours on more than one occasion (Connolly & Smyth, 2018). Evidence suggests abusive practice was routine, as CCTV captured 1,500 suspected criminal assaults in a six-bed ward (McHugh, 2020). Research into a similar case in Bristol at a facility called Winterbourne View describes a “slippery slope to abuse” when “organisational culture supports abusive practices” (McDonnell et al, 2014, p. 36). When legislation such as the Mental Capacity Act fundamentally fails to protect the human rights of disabled people, it is not surprising this “slippery slope” forms between organisational polices and the reality of situations found in Muckamore Abbey and Winterbourne View:

> **“Such abuse is likely to emerge in settings where people are devalued, unreasonably restricted, denied freedom and choice, and where staff and cultures are unreflective, poorly led, afraid of risk and lacking in perspective”. (p. 39)**

Research into “informal cultural aspects”, such as that undertaken for this report, “represents one way to avoid such abusive care and potential gaps developing between policy and actual practice” (Deveau et al, 2020, p. 88). Including disabled people in the dialogue and hearing from them about the reality of their experience is key to filling the “gaps” that allow dehumanising treatment and the denial of basic rights to become routine.

5.7 Multiple identities/ Intersectionality

Disabled people are not a homogenous group. They come from every ethnicity, age, gender, sexual orientation, community background and all the equality groups which are protected under legislation. Acknowledging the intersection of identity factors is important because they play out in disabled people’s lives and there needs to be adequate provision in social care policy to ensure all disabled people’s rights and needs are met.

People are living longer than ever before, and an aging population means increasing demand for care services for older people. The demands of providing for an older population’s need for social care can oftentimes eclipse disabled people’s needs in the public debate (Ryan, 2019b). Age and disability need to be approached differently when providing care services, as people’s needs can vary depending on their life stage.

A major point of intersection is that of class or income. Nearly half of people living in poverty are either disabled or living with a disabled person (Disability Rights UK, 2020). This is disparity is due in no small part to the higher cost of living disabled people endure, barriers to paid employment, lack of qualifications (although disabled people with equal qualifications to non-disabled people still tend to be paid less) and the impact of government austerity measures. The intersection of disability and poverty will be further developed under the examination of the impact of austerity on disabled people (section 5.8) and the benefit system (section 5.9), while the particular challenges faced by disabled women will be addressed under independent living and human rights (section 5.10).

5.8 The impact of austerity on disabled people

The UK government began its austerity programme in 2010 in response to the global financial crisis of 2007 and the period of economic recession which followed. This included the implementation of welfare reform as well as cuts to public services. Although it is widely agreed that the blame for the financial crisis lay with irresponsible practices within the financial sector on an international scale, disabled people have been one of the groups disproportionally affected by its consequences due to subsequent austerity measures that still reverberate through society.

This is a fact recognised by the UN Special Rapporteur on Extreme Poverty:

> **“Those with disabilities are also highly vulnerable to cuts in local government services, particularly within social care, which has left them shouldering more of the costs of their care. This has driven many families with a person with a disability to breaking point.”** (Alston, 2019)

However, some commentators have noted a focus and a rhetoric from the UK government and the media that indicates that disabled people are more than just collateral damage in the dispassionate pursuit of asceticism. As a group, they are nine times worse off than before under austerity, rising to 19 times worse off for the most severely disabled people since austerity began (Duffy, 2013). This “jaw dropping” discrepancy “laid bare the spuriousness of any claim that cuts and reforms to the welfare state were equitable” (O'Hara, 2015, p. 140).

The UK Secretary for Work and Pensions from 2010-2016, Iain Duncan Smith, argued that alleged fraud and cases of overclaiming justified the focus on reforming disability benefits, saying they were motivated by a sense of fairness to the taxpayer and concern for those “trapped” on benefits (Smith, 2012). This rhetoric suggests an “adversarial” dynamic between disabled people and the rest of society. It was mirrored by an increase in language depicting disabled people as scroungers, cheats and burdens, and a decrease in sympathetic content about disability discrimination (Jolly, 2011). Tabloid newspaper *The Sun* launched a campaign in 2012 called “Beat the Cheat”, encouraging people to “name and shame fiddling scroungers” by calling “the national benefit fraud hotline” (Dunn, 2012). Iain Duncan Smith was quoted therein endorsing the campaign, using some ironically ableist language to do so: “We must create a new culture where working hard and standing on your own two feet is something to be proud of”. Disabled people watched as a new narrative was formed: “It was not a global economic crash that had caused a recession but the supposedly bloated welfare bill covering the needs of supposedly disabled people” (Ryan, 2019a, p. 4).

Despite this rhetoric, benefit fraud around the time of the “Beat the Cheat” campaign was really very low. The Office of National Statistics reported incapacity benefit fraud at 0.03%, and The Department of Work and Pensions put Disability Living Allowance fraud at 0.05% (Jolly, 2011). However, as Jolly outlines, research at the time revealed the disproportionate political and media focus had hardened public attitudes against disabled people, leaving them with the impression that rates of fraud were more like 50-70%. More recent research in Northern Ireland shows that these attitudes are tenacious, with one in seven believing disability benefits were not distributed correctly, the assumption being that those who need support are not getting it and those getting it did not need it (NISRA, 2018).

As mentioned previously (section 5.7), almost half of people in poverty in the UK are either disabled themselves or live in a household with a disabled person. The rate of employment has an important influence on poverty rates, and at 53.8% for disabled people, is much lower than that for abled people (81.8%) across the UK (Office for National Statistics, 2019b). The situation is particularly bad in Northern Ireland, which has the lowest employment rate for disabled people in the whole of the UK at only 34.8%. This exacerbates and perpetuates poverty, and means these people are particularly vulnerable to the hardships imposed by austerity measures as public services are cut back.

Excluding disabled people from the labour market prevents them from forming a key facet of their identity. In the UK, as with other western capitalist societies, “employment has a particular cultural significance as it is often used as the marker for an individual’s social class and social status” (Runswick-Cole & Goodley, p. 176). For good or ill, employment determines an “active citizen” and a measure of an individual’s social value, to the exclusion of others who do not fit this mould. Disabled people are trapped in a cruel cycle in which attitudes decide the resources that contribute to their personal care. As we will hear from the disabled people who contributed to this research, this is rarely of a quality that allows or encourages them to pursue paid work. Without the social status afforded by a career and the “active citizenship” this endows, attitudes are unlikely to change and the desire of disabled people to live independently will continue to be deferred. In an ideal world, disabled people (and people in general) would be free of this metric. They would have social status and active citizenship conferred upon them automatically by virtue of being human. However, while we must “resist the pressure to abandon the values embedded in a politics committed to exposing and challenging disablism” (p.178), Runswick-Cole & Goodley suggest “working the spaces” of services, employment and self-advocacy with the expertise that comes with lived experience (p. 180). While far from ideal, we will see how the disabled people interviewed for this research work the space of social care to get what they need from staff who are short on time and resources. Unfortunately, this can come down to a choice between eating and toileting, a choice no human being should ever have to make.

5.9 Financial support to live independently

Benefits such as Employment Support Allowance (ESA), Disability Living Allowance (DLA) and Personal Independence Payment (PIP) (sometimes under the umbrella benefit Universal Credit) support disabled people who work, or do not, to live independently. While they do not form part of the framework of the social care system, they are essential for disabled people who cannot work to live independently. This puts these forms of financial support relevant within the remit of this research. Under Article 28 of the UNCRPD, the state is obligated to ensure that disabled people are awarded an “adequate standard of living and social protection” as a human right. (2006).

According to the Northern Ireland Human Rights Commission and Equality Commission, the introduction of welfare reform has had devastating impacts on many disabled people across Northern Ireland, impeding their ability to afford food, heat homes, and take part in society (Northern Ireland Human Rights Commission, 2017). A much higher proportion of Disability Living Allowance claimants had their claims disallowed in Northern Ireland (36%) than in Great Britain (27%). Although arrangements made by the Northern Ireland Executive provided a mitigating period of a year for a claimant who had lost their benefit, it still left Northern Ireland with a larger contingent of vulnerable disabled people, leading the Human Rights Commission and Equality Commission to repeatedly call on the government to outline a strategy to protect these people when support is removed.

Last year, then-Work and Pensions Secretary Amber Rudd announced yet more changes to the benefits system, promising to “change the landscape” for disabled people in the country (Bloom, 2019). The proposals include fewer and less rigorous reviews for certain claimants, changes to the assessment process and sanctions, and a plan to merge assessments for ESA and PIP benefits. While some DPOs cautiously welcomed parts of the proposals, they voiced concern over merging the assessment process for two separate benefits. Although this has the potential to reduce the stress of going through what could be very similar assessments on paper and in person, it could increase the likelihood of disabled people losing both benefits in one assessment process, leaving them without an income (Winchester, 2019).

Due to the high number of successful appeals overturning decisions made to reduce or deny benefit claims altogether, there is little faith in the assessment process as it stands. It is estimated that in as many as four out of five cases, the decision to deny a claimant disability benefits is overturned on appeal, suggesting the processes are “inherently flawed” and decisions and assessments are not being completed properly in the first place (Butler, 2017). Genevieve Edwards of the MS Society conveys the dismay felt by disabled people at the idea of combining two such problematic systems and the unrealistic expectations of policy makers with this vivid comparison: “like harnessing two donkeys to a farm cart and expecting it to transform into a race chariot” (Bloom, 2019).

A group of charitable organisations and the Royal College of Psychiatrists released a statement expressing “concern that shortcomings in Department for Work and Pensions policies and safeguarding processes are linked to avoidable deaths” (Butler, 2020). This came in the wake of the well-publicised case of Errol Graham, a 57-year-old man suffering from mental illness, who starved to death in 2018 after his benefits were stopped. The signatories of the statement questioned whether the Department of Work and Pensions had learned lessons from the catalogue of errors made in Graham’s case, or indeed any of the 69 cases ending in suicide that were subject to internal investigation. As of January 2019, 17,000 people had died while going through the process of claiming PIP, which took an average of 14 weeks (Bulman, 2019). This statistic prompted former Shadow Minister for Disabled People Marsha de Cordova to conclude that the benefits system was creating a “hostile environment for disabled people”. The UN Special Rapporteur on Extreme Poverty also criticised the UK government’s austerity approach. He stated that “It is hard to imagine a recipe better designed to exacerbate inequality and poverty and to undermine the life prospects of many millions" (Office of the High Commissioner for Human Rights, 2019).

5.10 Independent living and human rights

Article 19 of the UNCRPD stresses the importance of disabled people's right to independent living. It recognises "the equal right of all persons with disabilities to live in the community, with choices equal to others" (2006). It places the onus on governments and public bodies to "take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusions and participation in the community".

In accordance with the UNCRPD definition, DRILL defines independent living as:

> **"All disabled people having the same choice, control, dignity and freedom as any other citizen to achieve their goals at home, in education, at work, and as members of the community. This does not necessarily mean disabled people doing things for themselves but it does mean having the right to practical assistance based on their choices and aspirations."** (DRILL UK, 2016, p. 8)

This definition was originally developed by the Disability Rights Commission in 2002 and was also used in the UK Government report, *Improving the Life Chances of Disabled People* (Prime Minister's Strategy Unit, 2005, p. 58).

The Committee for the Rights of Persons with Disabilities addressed the Northern Ireland government in 2017, highlighting what the NI Government need to do to meet their legal obligations. They raised a concern over the transfer of responsibility for ensuring independent living in Northern Ireland to devolved administrations "without providing appropriate and earmarked budget allocation". They were also dismayed at the closure of the Independent Living Fund, and the Committee requested that it be re-opened.

The Committee felt that legislation fails to recognise living independently as a human right, and they required Northern Ireland to ensure “the right to living independently and being included in the community as a subjective right”. This means that Northern Ireland needs to adopt rights-based policies, and back this up with guidance and regulation, to make sure they are properly implemented. In addition, the Committee also wanted to ensure that all institutional abuse of disabled people is investigated and eliminated. Northern Ireland has seen large-scale abuse within institutions, such as the continuing investigation into institutional abuse of disabled people at Muckamore Abbey. The committee questioned why the practice of institutionalising disabled people continued at all.

The lack of adequate, accessible housing to meet the current needs of disabled people partly accounts for the continuation of institutionalisation across the country, and it is detrimental to their ability to live independently. Indeed, listening to the lived experience of disabled people living in unsuitable housing while waiting for a more accessible home clearly shows it can cause physical and mental harm (Anderson et al, 2019, p. 89). This contravenes Article 19 of the UNCRPD, which secures disabled people’s rights “to live independently and be included in the community and to exercise their right to choose their place of residence and where, and with whom to live” (2006).

The provision of supportive, accessible housing is also integral in the protection of disabled people, especially disabled women and children, against domestic physical and sexual violence. Disabled women are twice as likely to experience domestic violence as women who are not disabled (Safe Lives, 2017, p. 6). They typically stay in abusive relationships for longer and are more likely to report violence from multiple perpetrators than in the general population of women (p. 9). As research shows that disabled women are over five times more likely to have experienced sexual assault in the past year than disabled men (Office for National Statistics, 2019a), it is imperative that they have access to support to help them escape their abuser.

A lack of accessible housing can mean that victims are trapped with their abuser, and perhaps reliant on them for access to personal and medical care and financial support (Safe Lives, p. 18). The Committee for the Elimination of all forms of Discrimination Against Women (CEDAW) also raised concerns that women and girls are not protected effectively in Northern Ireland because the Equality Act does not extend to them and because Northern Ireland lacked a functioning government at the time. It stated that the public sector duty needs to address intersecting forms of discrimination, including the additional challenges faced by disabled women when seeking protection and justice for gender-based violence, particularly when perpetrated by their carer (2019, p. 4).

Sexual and physical abuse is a significant risk, given that personal care is often intimate in nature and the setting is often domestic. The Committee argued that disabled people need to have access to assistants of their own gender - this is particularly important for women and girls. Evidence suggests that women-only services are safe and effective for vulnerable women, including those who have experienced gender-based violence (Corry, 2018, p. 30).

5.11 Adult social care

This report, along with Kelly and Kennedy's *Power to People*, concurs with the Social Care Institute for Excellence's (SCIE) definition of adult social care, recognising that "Excellence in social care is rooted in a whole-hearted commitment to human rights" (2010, p. 4). SCIE states that social care should improve lives by delivering "choice and control over day-to-day and significant life decisions", helping to maintain "relationships with family, partners, friends, staff and others" and promoting the ability to "purposefully and enjoyably [do] things that bring … pleasure" (p. 5). It also alludes to a fourth pillar relating to "organisational and service structures" which supports the first three. All four interact and enhance the others to provide excellence in social care. However, "excellence" seems very far removed from a social care system widely acknowledged to be "collapsing in slow motion" (Kelly & Kennedy, 2017, p. 6) and "forced into unplanned change through fire-fighting and crisis" (Bengoa et al, 2016, p. 11). The long-term impact of austerity has left a system chronically under-funded, with projections that this will only get worse as pressures on the system increase in the context of greater demand due to an aging population and longer life expectancy (Kelly & Kennedy, p. 16-17). Now, as mentioned previously, the COVID-19 pandemic has added yet another unbearable load on a crumbling system (section 5.1).

The impacts of a failing social care system are often much less visible publicly than the pressures facing health care, where much of the political and financial focus is on decreasing Accident and Emergency waiting times and reducing waiting lists for consultant-led appointments and operations. Yet health is inextricably linked to social care, a link coming most "sharply into focus when people are unable to be discharged from hospital" due to a substandard level of care at home (Kelly & Kennedy, p. 17). There is a fundamental and illogical inequity between health care being free at the point of delivery and social care being means tested – an inequity that disproportionately affects disabled people.

Key principles of the *Transforming Your Care* policy model for the HSC in Northern Ireland, published in 2011, outline ways to improve adult social care and the lives of disabled people. These include promoting independence and control for disabled people, using outcomes and quality evidence to shape services, and focussing on tackling inequalities, placing the service user at the heart of adult social care (p. 137). It also suggests enabling balanced risk-taking for disabled people to ensure the greatest level of independence possible.

The recommendations outlined above, and in the *Power to People* report, are very positive. However, the disabled people interviewed for this research say they have not yet seen them translated into practice. They want policy makers to listen and work with them and their organisations to improve disabled people's experiences of social care and choices in independent living. They have been waiting a long time for change, and have endured the disappointment of promises of "citizenship, empowerment, community, social action and a route out of (or protection from) poverty" repeatedly deferred, only "enhancing the weight of the problem" rather than solving it (Runswick-Cole & Goodley, 2015, p. 168).

5.12 Conclusion

This project is being produced at a crucial time for adult social care in Northern Ireland, when the system is under unprecedented pressure and scrutiny. The specific context of Northern Ireland, both political and practical in terms of the nature of adult social care here, are important factors that must be considered in our examination of attitudes. This co-produced approach to disability research and the commitment to prioritise the lived experiences of our participants and research partners will ideally make a key contribution to the discussion of how attitudes as an explicit barrier can impact on the independent living choices of disabled people in the context of adult social care. Given the ongoing tragedy of the COVID-19 pandemic for disabled people, applying the lessons learned from engaging disabled people in this work could provide a real opportunity to contribute to social care’s positive reform with disabled people at the forefront.

6. Introduction to the Research Findings

The data collected from the interviews and focus groups were analysed and arranged to create an accurate representation of adult social care today.

Six key themes emerged:

1. Availability of information about independent living choices
2. Attitudes and stereotyping
3. Acknowledging lived experience as expertise
4. Lack of quality and continuity of care
5. Dignity, trust and value
6. Choice and control

The data on each of these themes are outlined and the issues and experiences explored in the following sections.

6.1 Theme One

Availability of information about independent living choices

> **“Adult social care system is not working. Not enough caring people work in it. It has been left for too long. I was registered as a blind person for 10 years before I knew I had a social worker.”**
>
> Focus Group with disabled people

The disabled people who took part in the interviews and focus groups for this research talked about the varying degrees of difficulty they encountered when exploring the services available to them and what their rights are in relation to social care. Some described frustration and embarrassment when having to “chase” for information and appropriate social care packages. Some said they were unaware of social workers assigned to them who could have provided information, and some described these figures as “gatekeepers”, who decided how much information the disabled people should or should not get. Participants claim that the information they receive very much depends on what resources are available, creating a service based on existing funding rather than genuine need.

Accessing information

Access to information is a necessary step in the process of living independently. Yet this step is often hard to take, with nearly all the research participants describing the process of accessing information as not particularly straight forward. One participant said they make independent living choices “with great difficulty”. Finding the right information can be complicated, time-consuming, and the cost needs to be considered, not just in terms of money, but in time and energy, too:

> **“Independent living choices are very important, so I consider them day and night**

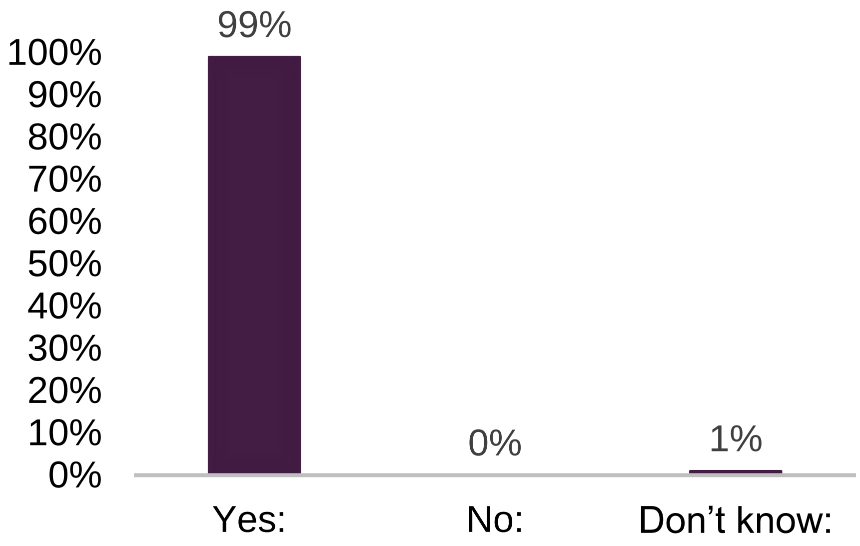
> **for however long it takes to come to a decision. This process includes listing the pros and cons and having conversations with my trusted confidants.”** Interview with disabled person

Sometimes the search for information can be made more complicated and difficult by a person’s impairment:

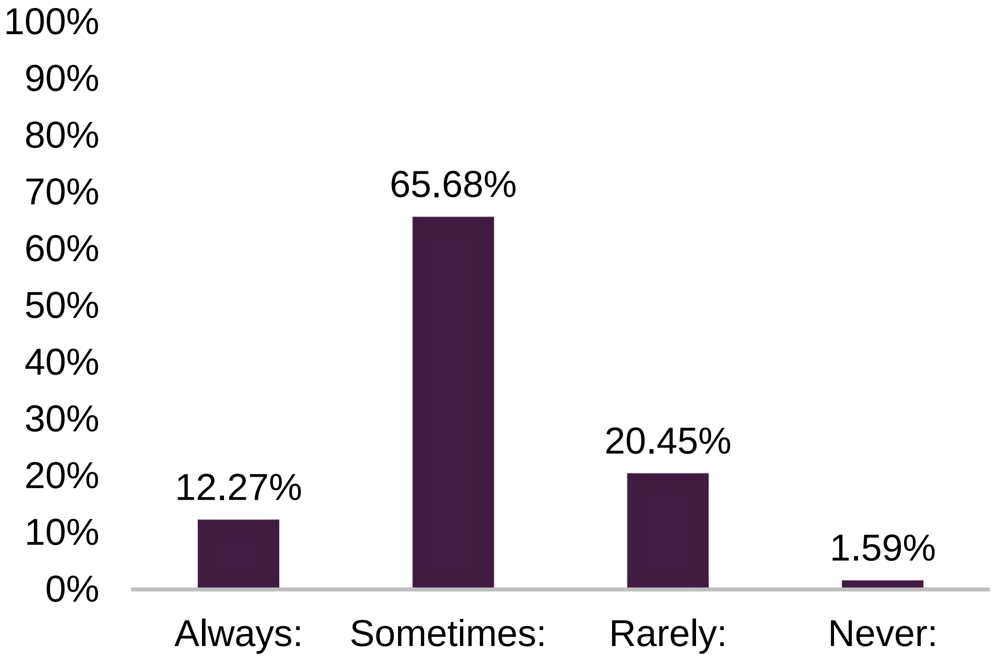
> **“I look online and I do research but I don’t really know what I'm looking for because of my disability. It’s hard, it’s a nightmare because I don’t really understand and you might click on something you shouldn't… then it’s causing more stress, which is a big trigger for my condition.”** Interview with disabled person

In the online survey created for this research and completed by social care workers, social workers and other workers in the field of social care, the following questions were asked:

Do you think disabled people using adult social care should be informed about their independent living choices?



Do you think disabled people receive enough information about their independent living choices in the adult social care system?



A significant majority of workers in social care thought disabled people using adult social care should receive enough information about their independent living choices to make informed decisions. Yet when asked if disabled people receive enough information about their independent living choices in the adult social care system, only 12% said they always receive enough information. This means that most of the time disabled people are not guaranteed adequate levels of information about their independent living choices. There is a gap between what information levels the service providers aspire to and the reality of how often disabled people get the information they need.

Only **12%** of disabled people said they receive enough information about their independent living choices

Gatekeepers

Some research participants talked about “gatekeepers”, who are people that make it more difficult for them to access information. They can take the form of people in positions of power who should be providing information, such as care managers, social workers and occupational therapists. “They are the first gatekeepers of your whole package,” said one disabled interviewee. This adds another frustrating obstacle in the disabled person’s path to independent living:

> **“The social worker and the care manager first tell you everything you are not entitled to. That is their attitude. It is a script written by the providers. The attitude is forced by the lack of resources and time. The attitude is how quickly they can get out!”** Focus Group with disabled people

This can create a difficult situation for people trying to live independently. They should be at the centre of the decision-making process, but “sometimes the very people who are supposed to help are a deterrent and cause more problems” (Interview with disabled person). Some of the interviewees said that they have had to turn to other sources for information, such as their doctor, counsellor, Citizens Advice, social workers, and the internet.

Other people listed members of their family as sources of both information and practical support, despite having other caring commitments or being elderly or infirm themselves: “My parents had ten in the family, two boys and eight girls, and when they got older and older, they helped me to make decisions” (Interview with disabled person).

Resource availability determining information provision

Workers in social care consulted for this research talked about how disabled people and their families are not always told about all the independent living choices that are available to them to avoid overstretching an ailing service already under extreme pressure. One worker in social care claimed that “the Trust will force the cheapest option available on you” due to limitations on the social work department’s budget (Online survey). This has wide-ranging ramifications for disabled people relying on social care, as “independent living choices are curtailed by funding and staffing levels” (Online survey). The reality as people working in social care see it, is that “there are simply not enough facilities to accommodate those capable of independent living” (Online survey).

6.2 Theme Two

Attitudes and stereotyping

"I am not an illness or a disability, those are just things that make up who I am as a person."

Interview with disabled person

The disabled people who contributed to this research spoke about how damaging societal attitudes towards disability can be, sometimes leading to exclusion and abuse. They said they often encounter an assumption that disabled people are all the same, with the same needs and desires, especially when it comes to social care and health services. They discussed the rigidity of attitudes and care plans that do not allow for fluctuations in conditions and impairments. The attitudes of family members can be a barrier to truly independent living. All of this can lead to disabled people having negative feelings towards themselves, internalising society's pervasive ableism.

Societal attitudes and assumptions

Many of the research participants talked about how frequently assumptions and judgements are made about them within society. How they present with their impairment can be mistaken for something else, such as drunkenness or substance abuse. This can lead to isolation, ostracisation, and even abuse and violence, as two participants explain:

> **"Going out, people think I'm drunk, the way I walk and sometimes I wish I was drunk. People don't understand unless they've been there, unless they have it themselves."**
> Interview with disabled person

> **"I was bullied as a school child, beaten up, called a cripple. The vast majority of employers see you as an obstacle, liability.**

> **What would you expect of him, look at the shape of him?"** Focus Group with disabled people

People who work in social care acknowledged the negative attitudes towards disabled people in society, especially those with hidden or invisible disabilities with which the public are unfamiliar or do not understand. The medical model often still prevails over the social model, meaning "People do still have an attitude, 'So what's wrong with you?'"(Focus group with social care managers) Social care workers broadly agree more needs to be done to challenge this "medical model-thinking" and promote inclusion and opportunities for those with disabilities: "The community still needs a lot of education about disability… Attitudes about disability are still very bad in our society" (Online survey).

Social care stereotyping

Some of the disabled people interviewed for this research felt burdened with "the assumption that because of the wheelchair you cannot be truly independent and can't aspire to do the things [non-disabled people] aspire to do" (Focus Group with disabled people). They cannot imagine "how much you have achieved, maybe more than they have." This participant goes on to say:

> **"For me independent living is about how you live your life, and to aspire to be as independent as you can be. Not just about what you can and can't do. They are not carers. If they do their job properly they [should] enable me to be the best person I can be. I very much go against the idea of them caring for me. Terminology is important."** Focus Group with disabled people

That "us and them" divide that this person says makes them feel diminished in the eyes of society because they require personal care is also noted by those working in the social care system. According to the online survey, 82% of those working in social care think the attitudes of those delivering care to disabled people are either positive or very positive, with time and effort “spent on trying to give service users a human rights and caring-based experience.” However, some have seen other workers in social care who behave in “negative and derogatory” ways. This can result in disabled people being disrespected or denied the dignity they deserve, as staff overlook them while using their home as “a social arena” with their colleagues, treating “the clients… as an inconvenience” (Online survey).

Some workers in social care also mentioned how disabled people are judged as pushy or demanding if they try to assert their right to control their own care. This speaks to systemic negative attitudes within the social care system:

> **“I think the perceived personality and behaviour of the disabled person impacts on [the] attitude of those delivering care. When somebody tries to exert choice or have control over the help they receive this can be perceived as being ‘difficult or awkward.”** Online survey

This can impact negatively on how care workers behave towards the disabled people they work with and discourage disabled people from exercising their freedom of choice for fear of retribution.

Assumption of a “usual” baseline

Participants talked about the rigidity of their care plan, and how it could not be easily changed or amended. This approach does not consider how conditions can fluctuate and demonstrates that people making decisions about a care plan do not always listen to what disabled people are telling them. Living with an impairment or condition can mean dealing with near constant change:

> **“My reality on Wednesday is very different from the life I'm going to have on Friday. My life is different each day, it’s not the same and my needs are different each day.”** Interview with disabled person

This can be made even more difficult when in “private care or public care, people tend not to talk to you, they tend to get a baseline and then just work off that basis” (Interview with disabled person). This can mean people do not get the consistent support that they need.

Disability often entails a degenerative condition, with the possibility of mobility, cognitive ability or communication decreasing and pain increasing over time. One service user interviewed spoke of ability being taken for granted because carers assume “he’s been doing it for years”. But his carers “don’t really see” what he is going through because he puts on a brave face to protect his dignity and his privacy:

> **“You keep a lot of your pain, your physical pain, your trauma private, nobody sees how difficult something is.”** Interview with disabled person

Surveying workers in the social care system revealed that three-quarters of the time disabled people may not regularly be asked questions about the suitability of their care provision. This means that their changing ability levels or needs are not always being acknowledged or monitored.

A prevailing view emerged from the survey among those working in social care: “Each time an individual comes into contact with the service they should be reassessed” (Online survey). Social care workers recognised the importance and value of the review process but did not think it is carried out regularly enough, as “they tend to be either six monthly or annual.” Some social care workers said they would like to have the option to amend care plans “as and when required” to give disabled people the most flexible and appropriate level of care (Online survey).

Assumptions by relatives

Along with health professionals and social care workers, sometimes relatives can make unhelpful assumptions about the disabled people in their family. The disabled people interviewed say they can be risk-averse, and their instinct to protect their disabled family member can clash with that family member’s desire for independence and life-experience. One interviewee describes how her mother had misgivings when she expressed an interest in learning to drive on turning 21. “It took me longer because of my disability," she said. "But anyway… I went and done my theory, failed it the first time, got it the second time" (Interview with disabled person). A less confident or determined person could easily have been deterred by family disapproval, especially if they relied upon them to provide care.

People working in social care acknowledge the need to work with both the disabled person and their family with a sensitivity that respects the family unit but keeps the best interests of the disabled person at heart. When opinions differ between the family and the disabled person around independent living options, staff must be trained to support service users and their families "to start challenging the notion that if the service user wants to take part, whether they should be allowed" (Focus Group with social care managers).

Disabled people's own attitudes to receiving social care

Disabled people can internalise ableist messages amplified by the media and by some public figures, suggesting even the most basic standard of care is a luxury, not a right. One disabled person recognised how "we are prepared to accept more than any other group, because of internalised shame" (Focus Group with disabled people). A tendency to minimise one's own situation, to shift focus from one's own needs to those who are needier, due to this shame and stigma is very much in evidence when talking to disabled people:

> **"Probably I have been very lucky because a lot of other people need a lot of things and they don't get them, and that's what I don't agree with, there's people who are a hell of a lot worse than me, an awful lot worse than me, I should be very lucky, and for those people, I would be out shouting, very much so, for them to get more support, because people aren't getting what they really need, but for me, at the moment, I suppose I'm okay."** Interview with disabled person

This research participant went on to say how she should be having physiotherapy, and how the absence of this basic service and the participant’s learned deference has drastically affected her level of independence and quality of life: “I have gone downhill, I don’t walk as well as I used to, I've stopped driving, which I miss terribly” (Interview with disabled person). Her internalisation of society’s ableism and shame is preventing her from advocating for her own needs. The care she should be receiving is deferred, depleting her physical and mental health, demonstrating the devastating impact negative attitudes can have on disabled people.

6.3 Theme Three

Acknowledging lived experience as expertise

“You’d be spoken for.”
Interview with disabled person

“First you listen to them…LISTENING is the key.”
Online survey

The disabled people who took part in this research are the experts of their own experience, and stress how important it is for them to feel listened to when it comes to independent living. This is the vital first step when participating in decision making and building relationships with service providers based on trust, allowing disabled people to experience the calculated risk-taking that is a normal part of life.

Being listened to

Participants talked about what it is like when social care works well for them – it always involves being listened to. It does not necessarily mean people become friends with their carers; it is more that carers hear what the person’s needs are. One participant talks about how they educated the carers and other social care staff, “so their understanding of my needs is quite good now” (Interview with disabled person). This is a good start on the journey to receiving quality support.

Yet many of the research participants share adverse experiences when they were not listened to, especially when communicating essential medical information:

> **“I have seizures. You don’t want to have to keep repeating that.”** Interview with disabled person

Many more describe not being listened to during assessments and reviews about their care packages by professionals who do not appear to respect their lived experience. One interviewee describes confronting this attitude: "'Hey Mr Senior Social Worker, I'm right here sat in front of you… I can speak.' That happened at one review meeting, I said, 'I can speak, you know, if you want to speak to me.'"

There is some acknowledgement in the social care system that disabled people's lived experience is not only valid, but valuable. One social care manager recognised that, while most training is delivered by professionals with no lived experience of disability, it really needs "to be inclusive with the people with the disability, otherwise I don't think [care workers] really get the sense of what [disability] is" (Focus Group with social care managers). Disabled people are not only willing and able to educate others on disability, they often provide the more constructive and efficient experience for those trainees.

Participating in decision making

While some participants felt that they have been part of the decision-making some of the time, many also talked about how they have not been included in the decision-making process, their voices noted only as an afterthought. "You'd be spoken for", says one. Another interviewee felt exclusion from the decision-making process and gatekeeping are indicative of a disrespectful attitude towards the expertise of disabled people:

> **"Some support and respect me but others keep information from me and don't include me in the decision-making."** Interview with disabled person

Some research participants felt that staff (and sometimes family members) excluded them from the decision-making process because of assumptions based on their disability:

> **"You've a learning disability, you don't know anything", that's my point of view, that was the way I felt."** Interview with disabled person

One interview participant listed a variety of reasons that are presented to disabled people to explain why their wishes are not followed through and translates the hidden meanings behind them:

> **"'They already have something in place'" -** *the decision has been made and it is too much trouble to change it*.
>
> **'It's based on what the social worker said' -** *the disabled person's expertise has been overruled*
>
> or
>
> **'There's somebody more urgent than you, so you're taking away someone else's time' -** *you should count yourself lucky and stop wasting resources."* Interview with disabled person

It can be exhausting to be continually confronted with excuses why your needs are not being met, just as it is exhausting trying to gain access to the decision-making processes that govern your life. The disabled people interviewed recognised the disproportionate "energy and effort you have to put in to get what you really need' and the confusing bureaucracy, disappointment, and depersonalisation when 'the computer says no, it doesn't tick the right boxes" (Interview with disabled person).

One interviewee described her battle to gain access to consultations that would decide whether the day care centre she attended would remain open or not. This is an important social outlet for her, a way to get out, participate in the world and be seen. She wants to do all of these things, and her frustration (not to mention vivacious personality) is clear:

> **"It's difficult for me to be sitting at home and looking at four walls and looking pretty!"** Interview with disabled person

Building relationships

Both disabled people and workers in the social care system talked about the importance of building relationships with each other. This is an essential foundation for a positive working relationship where the disabled person is listened to and involved in decision making, and the process supports them to get their needs met:

> **“Knowledge of the social care system has helped me throughout my life as a disabled person living in supported living. Also, I have worked hard to develop a reasonable working relationship with the people making decisions so as to maximize my ability to take control.”**
> Interview with disabled person

Workers in social care also recognise the importance of relationship building “by giving [disabled people] choices, talking to them, not at them. Keeping them involved in as much of the decision making as possible” (Online survey). They realise the value of spending time with disabled people using the social care system as “you get to know them and how their needs change by talking to them and observing changes in behaviour” (Online survey). This allows social care workers to optimise the service they provide.

Calculated risk taking

Health and safety policy has been implemented in social care to keep people safe. However, disabled research participants talk about the ways in which it restricts them. One interviewee describes the frustration of being unable to make choices based on their own evaluation of risk while at a day centre:

> **“There is this whole idea that, ‘While you're here, you're at least technically a vulnerable adult,’ so that’s that.”** Interview with disabled person

An over-emphasis on health and safety can encourage a paternalistic attitude among care workers, leading them to do things for disabled people, instead of supporting disabled people to do things for themselves when they choose to. A disabled person's right to self-determination can be easily undermined by risk-averse health and safety regulations.

This can happen with something simple, a freedom that many people take for granted, such as sitting in the sunshine. One interviewee was sitting in the sun when they were asked by a member of staff to come back inside. The person asked, "Why?" and was told, "It's in case you fall, if you fall out here, nobody sees you" (Interview with disabled person). The person accepted this reasoning but missed out on the benefits to their health and wellbeing of spending time outside, and their right to exercise a simple act of self-determination.

Those implementing social care also recognised problems with the balance between risk and independence. The system has "become so risk averse, sometimes we stifle the person in terms of the services that we provide" (Focus Group with social care managers). There is a growing acknowledgment that "promoting positive risk taking" is beneficial, "enabling people to reach and fulfil their optimum".

6.4 Theme Four

Quality and continuity of care

“I have never been in a situation where I have been the carer’s priority. Their priority is to get to the next client or to get the job done as quickly as possible and everything is about time.”

Interview with disabled person

All research participants identify both quality of care and continuity of care as issues in their pursuit of independent living. This is mirrored by the responses of workers in social care to the online survey, who cite staff turnover as the main cause of the problem. Participants say that this turnover means that new care workers or social workers do not know enough about them or their lives and conditions, disrupting the continuity of care. Cuts in social care services and the provision of equipment due to a lack of funding also impacts on the lives of the research participants. This lack of funding reduces the most precious resource of all for the research participants: time. When carers are under pressure to save time, participants have had to make agonising decisions between eating or toileting.

Quality of care

The quality of social care reported by the disabled people who contributed to this research differs dramatically, with some receiving good quality care, some less good and some saying that social care workers have been abusive towards them.

One praised staff for providing a positive, supportive, and respectful experience:

> **“The carers themselves, they're just great, they come in, they're very friendly, they're**

> **understanding of my needs ... They'll discuss things with my wife, with me, and generally I have to say they're very good."** Interview with disabled person

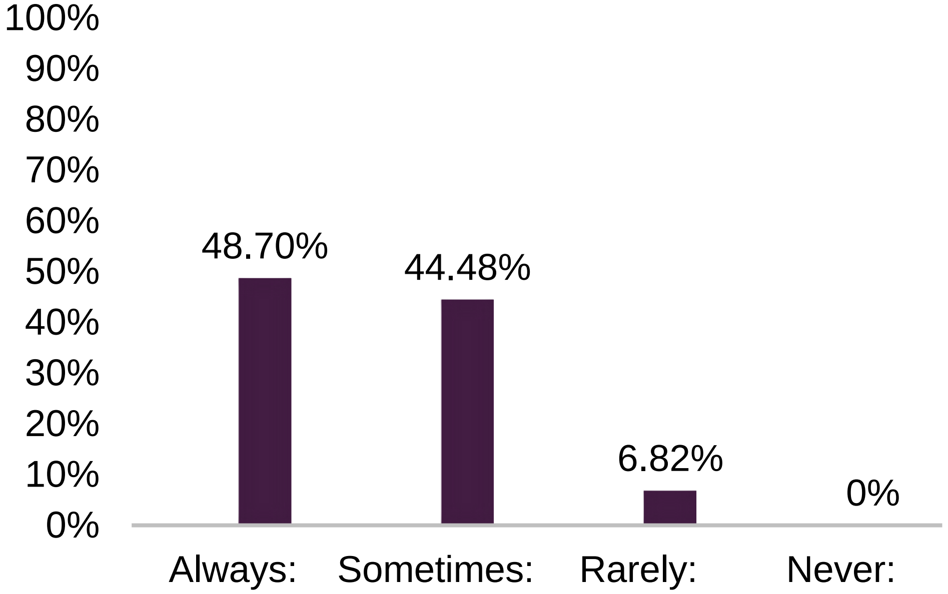
However, many of the research participants have a negative experience to describe. One encountered staff with an "absolute disinterest in caring," who "wouldn't know your name, what your condition was." One says they even witnessed "criminal behaviour from more than one person." This might seem like reasonable grounds for complaint, but some disabled people fear the consequences of this kind of action:

> **"You were scared witless to say you don't want this person anymore because they might bring a worse one in."** Focus Group with disabled people

Continuity and change

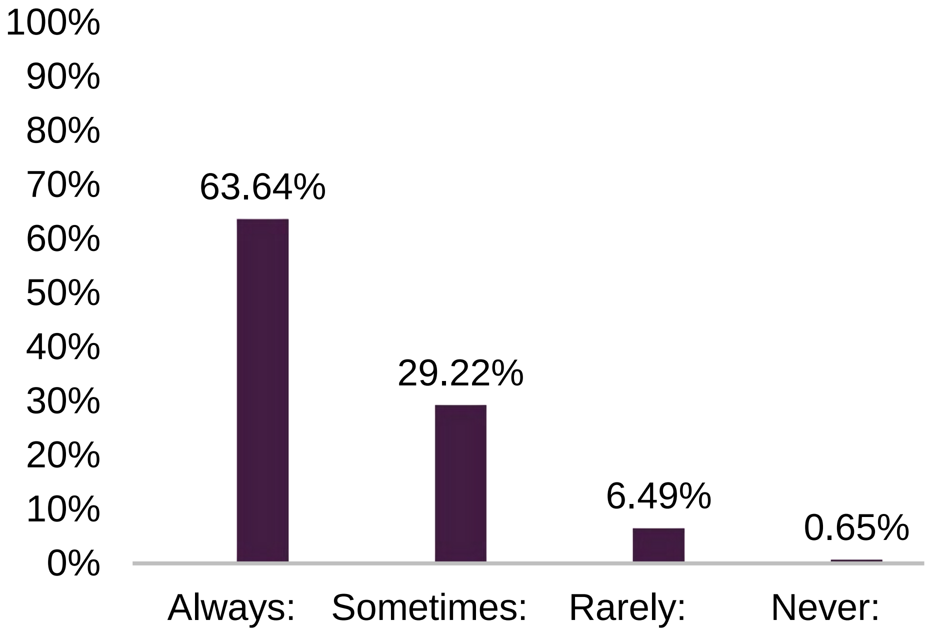
One of the biggest issues the disabled people who took part in this research had was inconsistencies in social care services and changes made without due notice. These inconsistencies are borne out by the online survey, in which workers in the care system were asked:

What proportion of the time are you able to provide services to disabled people at the time arranged?



The online survey also asked:

What proportion of the time are you able to tell disabled people if there are changes made to a care plan?



The results show that people relying on social care, according to those who provide it, are not always guaranteed to receive assistance when they are expecting it, nor are they always aware of when changes are made to their care plan. This has real consequences in their private and family lives. One interviewee described when an important family occasion “was ruined because of the social care provider”. This woman had to cut Christmas with her family short and inconvenience family members who had to get her home early, so she would not miss her bedtime slot, which had been changed at short notice. She was informed by email that her curfew was early because of Christmas, but not given a specific time. When she asked for more detail, the issue was still not clarified.

Another interviewee explains how they had found their life severely restricted due to time constraints imposed by “the care provider [who] changed my back-to-bed call to an earlier time to suit one of their workers better” (Interview with disabled person). This person had not been consulted about or informed of this change before it was implemented.

Disruption such as that described can be upsetting and stigmatising, eroding trust in the social care system and those who work within it. As one research participant commented:

> **"To me, consistent care means that the workers try to fit into *my* routine."** Interview with disabled person

Barriers to continuity of care

Workers in the social care system were asked, "What are the barriers to disabled people having continuity of care?" Some of the main issues they raise are about staffing problems. Poor terms and conditions mean that staff will often leave their jobs when they find something better. It is difficult to retain good staff in roles that are often under-paid and under-valued. This high turnover is stressful not only for disabled people reliant on social care, it is stressful for the care workers who are stretched to bridge gaps when the "Trust [is] not filling vacancies for months on end". These shortages result in "over working and burn outs" (Online survey). The current political situation all but guarantees that the recruitment issue will get worse, as "Brexit has caused some EU workers to leave", further depleting a workforce already under pressure (Online survey).

These barriers to providing continuity of care inhibit relationship building, and this has not escaped the notice of social care workers. When they are "unable to forge trusting relationships", it is "harder for the disabled person to communicate any personal changes which may be occurring" (Online survey). Poor communication and "constant changes may lead to depression and loneliness. Disabled people may feel rejection, leading to lower self-worth and esteem" (Online survey). This is in alignment with the thoughts and feelings described by the disabled peopled interviewed for this research.

Empathy for the disabled people they work with is evident in the words of many social care workers. They realise how difficult it is for disabled people to form trusting relationships with care workers who are assisting with intimate care. After all, says one care worker, "who wants to have a stranger helping them in the shower?" (Online survey). The use of unfamiliar agency staff is "very unsettling and unfair" for disabled people in this kind of situation.

Social care workers blame inefficient management for many of the problems, including high staff turnover and poor communication between staff members and service users. Rotating through “different staff with different approaches and beliefs about what is best” can lead to “disregard for care plan” (Online survey). Under these conditions the wishes of disabled people may be ignored, they may be put in danger, and they may have their dignity violated.

Consultation with people working in the social care system for this research reveals that managers are often under pressure to fill vacant roles quickly. They are aware that some people are not suited to working in social care as they “haven’t got the right mindset… we think we can train them to do everything, we can’t… unless you want to help and you’re compassionate, you may as well forget about it” (Focus Group with social care managers). Despite this, these people can be recruited to positions that desperately need to be filled due to high turnover and staff shortages, leaving disabled people with a substandard and possibly dangerous service.

Lack of training for staff, especially new staff coming in, is an important issue for social care workers. They believe there is a “lack of training on handling behaviour which may challenge”, which is essential for the safety and wellbeing of disabled people and those that work with them (Online survey). They want more specialist training provided so they can more effectively communicate with people with various impairments, such as autistic spectrum disorder, speech impairments, or hearing difficulties.

Cuts in services and equipment

Some research participants said they have had their services cut off in the past, some without warning or explanation. This includes losing social workers, disability coordinators and occupational therapists. Some were told this was due to a lack of funding. They found they suddenly had no support, with one interviewee attributing a steep decline in their mental health to the resulting social isolation:

> **“All support stopped a number of years ago and directly as a result of that, I am bordering on agoraphobia.”** Interview with disabled person

Some research participants have had very good experiences of equipment to support them to live independently. One says their Occupational Therapist “couldn’t be any more helpful… they were very attentive to what I needed” (Interview with disabled person). Others had negative experiences regarding equipment that was old, rusty, or dirty.

One interviewee was sent contaminated equipment by the Trust. Attempting to clean it made her ill, and the Trust began demanding that staff gain entry to her home to check on it, even though she had already cleaned it and sent it back. This was a very stressful, invasive experience for this research participant, which seriously impacted upon her mental health:

> **“I can only hope my interaction with this Trust and its agencies is unusual. My experience has been the exact opposite of helping and caused me quite serious physical and mental harm. As a result I am loathe to ask help of anyone – due to the adverse way I have been treated.”** Interview with disabled person

Time, and how it impacts on quality of care

Time, or the lack of it, was brought up repeatedly by the disabled people and workers in the social care system who participated in this research. Lack of control over times social care workers were due to arrive (or instances when they did not arrive at all) had a huge impact on those who experienced this. They lost control of their day, meaning they were forced to remain at home and cancel whatever plans they might have had, be they medical appointments or social engagements, key to warding off social isolation.

Research participants frequently raised how the lack of time to perform tasks significantly impacts on the quality of social care that is provided. They described how they adjust their expectations and learn to ask for what they are more likely to be given, rather than what they need or want:

> **“What you do is, you figure out what you can get and you go for that, you go for the lower apples instead of the higher apples on the tree**

> **and generally, I tend to go for the lower apples because the last thing anybody wants is to be a hindrance or a nuisance to somebody.”** Interview with disabled person

One interviewee described making the agonising decision between eating and using the toilet because the time they are afforded with their carer is so short:

> **“I know he’s only got 10 minutes … what are you going to pick? Are you going to pick getting a sausage sandwich or are you going to pick going to the toilet because you can’t move the top part really that well and you need help standing up?”** Interview with disabled person

Inevitably, this leads to some of the inhumane conditions described by the disabled people spoken to for this report, from urinating in a chair and having to sit in it until someone comes to help, to being returned to a still-wet bed because the carers only have 20 minutes to spare on each call (Interviews with disabled people).

One research participant reflected on the change they noticed when a private company was contracted to take over the delivery of their care. They talked about the practice of “call cramming”, booking more clients in a time frame than is realistically manageable in the name of profit. Such micro-management of time is “so constraining that you get nothing done” (Interview with disabled person).

Socialising

The research participants discussed the importance of being part of a community, whether that be going to a day care centre or joining support groups or social clubs, allowing them to feel connected to other people with similar impairments or health conditions. As with many of the research participants, having a social structure in place is vital to their wellbeing.

Some people seek out community groups that they feel a sense of connection to, such as people with the same impairment or health condition, or people who have similar interests to themselves. They could have conversations about sensitive topics, such as continence, with a guarantee of understanding and confidentiality:

> **“They all understand, the fact that they’re running to the toilet every so often, everyone understands that, there’s no problem, we can talk deeply with each other about it, male and female, it’s a confidential group where you listen and you're not going to go out and tell that somebody else, ‘John done this and John done that’.”** Interview with disabled person

However, some of the disabled people interviewed are unhappy that they have not been permitted to socialise when and with whom they want. One research participant talked about being told he had to stay with the group while on an outing, when he wanted the freedom and space to buy a present for his granddaughter. This affected his experience and discouraged him from taking part from then on: “I haven't gone on any of the community trips since… It certainly demonstrated to me that, ‘We’re in charge, you're not’, and I was quite unhappy about that” (Interview with disabled person).

One interviewee described effectively being forced to go on a community trip with other disabled people. “One particular member of staff was almost pushing me out of the door to get into the mini-bus to join them.” He resisted, saying: “I have the right to make the decision whether I go there or not, and I have sufficient stuff to do here, there are sufficient staff here to be aware of what I'm doing, etc, so I'm not being pushed around” (Interview with disabled person).

Family support

Many research participants said they rely heavily on family support. Even those who use social care regularly still depend on family members for cooking meals, checking on them, taking them to appointments, etc. Some rely on family members to support them in challenging inadequate social care. One interviewee stopped ominously short from speculating what befalls disabled people without that form of support: “If people have families that can fight their corner, they will be ok. If they don’t…” (Interview with disabled person). This goes to show how low levels of trust in the social care system are among the disabled people who need to use it.

Some research participants felt guilty over how much support they were getting from their family, that they are somehow a burden. One disabled person spoke lovingly of the role their sister plays in their life, caring and cooking for them, especially while their mother was in hospital: “She's great, she's like a little tornado… she does everything, I'm sitting, I'm like, ‘I could be doing that’” (Interview with disabled person). Again, this guilt is evidence of the ableism disabled people have internalised for not being seen as “self-sufficient” or “useful” by society.

Social care in rural areas

Living in a rural area significantly impacts upon what kind of support is available to those using social care. Participants talked about having no local services at all, or having to travel a long way, which is difficult for some because they cannot use public transport or because there is no toilet available along the journey. Toileting came up in more than one interview, and it was a source of embarrassment for the interviewees, restricting where they can go and what activities they can engage in: “It all depends on the toilet. Everything depends on the toilet. I mean everything, that’s for sure, if I could sort that out, life would be much better” (Interview with disabled person).

“Toilet mapping” (researching and making mental notes on where the nearest toilets are and the quickest way to get to them) is just one part of the extra mental load disabled people must take on just to engage with the world in the same way non-disabled people do. This arduous process, and the general lack of convenient or accessible toilets can discourage disabled people from engaging in society in many ways, leading to social isolation and mental health problems.

6.5 Theme Five

Dignity, trust, and value

"I used to lay there looking at the clock and I didn't know who was coming – and what they were going to do to me."

Interview with disabled person

The disabled people who contributed to this research value their dignity, see the need for trust in care, and appreciate feeling valued. This is important as care that allows a person to maintain their dignity, fosters trust in the caring relationship, and leaves disabled people feeling that they have equal worth as human beings makes a real difference to the experience of disabled people.

Closely related to these topics and often not explicitly acknowledged in policy is the issue of power. In accordance with the social model, disabled people are made vulnerable not by their impairment or their health, but by the powerlessness they have in the specific situation of care provision. People who are paid to provide care or manage carers have more power than those being cared for. This can make it very hard, if not impossible, to raise issues of concern and report undignified treatment or conduct that makes disabled people question their self-worth.

Value could be understood in a number of ways: how disabled people are valued, how workers in the social care system are valued and how social care itself is valued. All of these are inter-related.

Dignity

Dignity is an issue for several research participants, both in what supports it and what takes it away. Having a person present in intimate situations takes some getting used to and therefore needs to be handled with sensitivity:

> **"One thing that I'm still getting used to is having to shower with a woman in uniform. And at first … uniform or not, [it was] a stranger, it was that whole thing about privacy, dignity and whatever else, but they were very respectful, and that was important, because that got me over that hurdle."**
> Interview with disabled person

The impact of intimate care on each disabled person's dignity is different. The cost feels too high for some, especially when care is inconsistent and the disabled person in question cannot be guaranteed they will see someone they know and trust each time. In the words of one interviewee:

> **"I couldn't trust my state of being to a stranger and waiting on a private nursing agency to come up and send a nurse… If you're lying on the ground on the hallway floor or whatever, or you've peed yourself or you've pooped yourself or things are going difficult or you're in pain… my dignity would be at stake."**
> Interview with disabled person

Trust and the balance of power

Some research participants vividly described the power dynamic in the relationship between recipient and carer. This is important because it is often not apparent in current policy frameworks, but it is very much present in practice. One interviewee described feeling "guilty" for modifying their behaviour to please carers in a more powerful position and feeling "grateful" for basic, humane care:

> **"You be grateful for what you can get and then you have this mentality where – and I have it – I'm guilty of it just as much as anyone else, what can you ask for so you don't lose Brownie points? Because you can ask for too**

> **much, so it ends up happening, no matter how educated you are, no matter how smart you are, no matter how much you analyse, is when you're in pain, it doesn't matter what you know, it doesn't matter what your experience is, it doesn't matter what your rights are, your entitlements are, you will ask for as little as possible because you want at the end of the day, the pain to go, so you'll take what you can get, not what you need or is better for your care, it's an absolute fact.”** Interview with disabled person

One research participant was taken into residential care as a very young child, and described the powerlessness they experienced along with their family when the situation was not quite what was promised:

> **“They said I was going to get an education, mummy and daddy wanted me to get an education. But it wasn't an education at all and I stayed there for 17 years… It was all keys and locked doors.”** Interview with disabled person

When the imbalance of power in the caring relationship leads to the kind of mistreatment described by the disabled people interviewed for this research, trust in the social care system as an institution is eroded. Without trust, fear rushes in to fill the vacuum.

Many research participants felt they have been mistreated within caring relationships in the past. They found themselves the recipient of harsh, abrupt, invasive, or abusive treatment. They said that they were afraid to report such treatment because they felt powerless over the outcome and feared retribution or punishment at the hands of the offending carer. Abusive behaviour by care workers is of course criminal and illegal, and there are protections in place, as social care is a regulated occupation monitored and inspected by the Regulation and Quality Improvement Authority (RQIA). Yet, at the time, these disabled people felt they had no recourse.

The fear experienced by one interviewee at the hands of care workers still haunts them:

> **"I used to lay there looking at the clock and I didn't know who was coming – and what they were going to do to me."** Interview with disabled person

This interviewee said their social worker was aware of the abuse but took no action. Abuse of this kind was not an isolated occurrence for interviewees, with a number of research participants reporting abusive treatment.

One interviewee described a rotating ensemble of carers who "cut corners" and were not performing the tasks they ought to. They recalled the carers "getting impatient and nasty" as they tried to remember what they needed help with (Interview with disabled person). Interviewees have also been treated with disbelief with they did try to complain:

> **"When someone has a genuine and serious complaint it should be treated with concern and respect, not 'between the lines' call the person a liar."** Interview with disabled person

The fears that many disabled people have around being critical of the care they receive were manifest during the interview process. Some research participants were initially afraid to say anything negative about past or present treatment, fearing reprisal. One research participant did not want their interview to be recorded because they were afraid that at some point someone involved in the provision of their care service would hear the recording and it would adversely affect how they were treated.

Safety

The uncertainty over who was going to arrive from one day to the next to provide personal care is an important issue for disabled people feeling safe in their own homes. This is especially important for women, as well as men and women who had experienced early trauma (such as childhood sexual assault).

One research participant had requested only female assistants/carers and was denied this request. At a review, the care manager told one research participant that it was her fault that her care had changed to single slot. He told her, “I can’t get you another provider because you won’t accept men” (Interview with disabled person). Given that we know that rates of sexual violence against women and girls who are disabled are higher than average, as are rates of violence against disabled people generally, there needs to be a greater level of sensitivity in this area to help people feel safe in their own homes.

For research participants who had experienced trauma as a child, including physical or sexual abuse, this protection of dignity and control is essential to feeling safe. One participant described how they were “terrified of losing control, probably more than the average person”, and would sooner endure physical pain than have their privacy and dignity violated:

> **“If the pain’s going to last a couple of hours longer then fine, but don’t take away my privacy and don’t take away my dignity and for God’s sake, don’t take away complete control.”** Interview with disabled person

A sense of value

The difference between the mistreatment described here and supportive assistance to live independently is life-altering for the research participants. One who has experienced both put it this way: negative attitudes from social care workers were disabling because it literally brought home “all the things you can’t do, frustration because you can’t sort it out, feel utterly worthless, that no-one is listening, you don’t know where to turn. You feel so isolated” (Interview with disabled person).

On the other hand, positive attitudes from social care workers are very empowering – for the research participants, this means they are listened to, looked at and treated as if they are human beings. One interviewee described how this changed her life. She was able to sit up more, started to study and began to campaign for equal rights for disabled people: “All that because I had a care package that worked” (Interview with disabled person). With good quality care, she came to feel valued, capable, and able to contribute to and be part of society.

The disability benefits which support independent living, such as Universal Credit, Employment Support Allowance or Disability Living Allowance / Personal Independence Payments, are a major source of anxiety and negativity for the people interviewed for this research. One recounted their experience of applying for Employment Support Allowance:

> **“Going through ESA… It was so humiliating to prove I couldn’t work when all I wanted to do was work. You’re made to feel like a lazy sponger.”** Interview with disabled person

Cuts to social care services contribute to the feeling of worthlessness disabled people experience. A research participant who said her care was removed with no explanation feels that no one was listening to her, and she had a sense that, rather than progressing, disabled people were being pushed backwards to a time when they had even less value in society:

> **“We’re nothing anymore. Disabled people are just going to be left all on their own, the way it was in the 70s, where you're just pushed to one side. That’s how I felt when I was growing up in the 60s and 70s.”** Interview with disabled person

Disabled people are concerned about how other people value them and, consequently, how they value themselves. They feel pressure to underplay the realities of disability or long-term health conditions.

With good quality care, she came to feel valued, capable, and able to contribute to and be part of society

One interviewee describes going to meetings “in excruciating pain” for fear of losing their “value to the outside world”. This person was afraid of having their identity erased by the encroachment of disability. Our societal values suggest that a person must be economically active to prove their value as a human being. Poor quality care exacerbates this feeling, limiting disabled people’s potential and making them feel inadequate in the face of this value system: “you become useless then and you have no value. And the caring system tells you that on a constant basis” (Interview with disabled person). This is clearly contrary to the ethos of the human rights framework, which affords every person respect and value simply by virtue of being human.

Along with the disabled people they work with, social care workers said they do not feel valued. They felt they are underpaid, undertrained, and expected to cope within a system that is not functioning. In their view, “managers are so far removed from the staff working on the ground and they don’t see what they see”. With this disconnect separating “decision makers from those who not only need support but those who also provide support”, disabled people are ultimately the losers as their basic human rights are compromised (Online survey).

6.6 Theme Six

Choice and control

“I do suspect that duty to save money has replaced duty of care.”

Interview with disabled person

The choice and control disabled people have over living their lives independently is ultimately based on two key inter-related factors. One is money – that is, the resources available, and how these resources are used. The other is attitudes towards disabled people, and how these attitudes filter down through the care system, affecting their daily lives. The two factors are linked but need to be distinguished from one another. The impact of negative attitudes cannot simply be collapsed into an issue of resources.

Money: choice and control

> **“Sometimes it feels like the whole system is just about money and less about service users.”** Online survey
>
> **“Without more investment in supported living options, the choices are so restrictive; it is no choice for the individual.”** Online survey

Many research participants talked about severely restricted resources for health and social care, and how this curtails their independent living options. One participant with Multiple Sclerosis requires catheters to empty their bladder. They called their GP to order more, only to be denied because the doctor thought they were using too many. This person was then asked to record how many times they urinated (possibly to compare to other patients using catheters). They had an infection at this time and needed to urinate frequently to help clear the infection. Another health professional explained to this person that the doctor withheld the extra catheters because the cost would come out of their funding (Focus Group with disabled people). Not only is it humiliating and invasive to force a person to count used catheters in the name of cost-cutting, it is clearly a false economy. Denying this person the catheters they need could make their health situation worse, possibly leading to the expense of hospitalisation to treat them.

Another disabled person interviewed talked about how he was refused a chairlift because he has diabetes and that might make it unsafe for him to use. He was suspicious of this reasoning and speculated on what the decision makers might really be thinking in his case: "'Can we use health and safety as a very good reason not to spend the money on this man's needs?'" (Interview with disabled person)

One interviewee felt disrespected by the "empty gestures" offered by care workers pushed for time who have already made clear the limitations of the service they are able to provide. Just as they are leaving, the care workers asked, "is there anything we can do for you?":

> **"How do you sum that up? Like what is the answer? You've told them what you want, they've told you what you're getting and now they're asking - 'Is there anything we can do for you?'"** Interview with disabled person

Most of the disabled people asked mentioned a lack of resources as a factor when determining the quality of their care: "At every level, social care, medical care and everything, the first thing they say to you is, 'We have to watch the taxpayers' money'" (Interview with disabled person).

Workers in social care talk frankly about how a lack of adequate resources is affecting the independent living options disabled people have access to, with 86% believing there should be more independent living choices available to disabled people. But the reality is that workers are under pressure to meet demanding targets with limited resources and this can have a detrimental impact on morale, breeding a "cynicism [that] has become a detrimental characteristic [as] the 'care' is fading from 'social care''.

86% of workers in social care believe there should be more independent living choices available to disabled people

Social care workers also noted a regression in the provision of specialist services for different types of disabilities, described as “a poor move by some trusts” (Online survey). They claimed disabled people are no longer guaranteed to have a specialist social worker focussed on developing services to meet their needs. There can be major differences between the services someone with a physical disability needs, compared to someone with a learning disability, for example. Much of the time services are “provided based on critical need, [making] it difficult to secure support services for long term situations, especially if the needs are more about support than essential day to day care needs” (Online survey). This creates a hierarchy in which some disabled people are deemed more worthy of support than others.

Oftentimes disabled people must reach crisis point, compromising their health and wellbeing, to qualify for basic levels of support. Either that or, as one respondent to the online survey for social care workers admitted, “we have to have people pass away or move to nursing care for places to become available”. These workers recognised that families with aging carers struggle greatly and cannot afford to rely on this unpredictable system. They are clear in their criticism: “funding is the biggest obstacle that support services need to overcome in order to provide the optimum standard of support tailor-made for each individual” (Online survey).

Workers in social care see their vocation as “the poor cousin” in the partnership that is health and social care. Care workers also have an unobstructed view of the effects of austerity on disabled people. One suggested that society needs “to ensure that government understands the detrimental impact its approach to benefits has on those within the care system” (Online survey). A better, more humane benefits system would help to relieve pressure of disabled people and the social care system alike.

Attitudes: Choice and control

Disabled people see how ingrained attitudes, ignorance or narrow-mindedness in the social care system make their lives so much harder:

> **"If I got the few things that I need doing, it would make life a hell of a lot better. It'd be less stressful… at the moment, it's confrontational, everything you want or everything you try and do, it is confrontation, you have to battle for it and that's the way the system's set up."** Interview with disabled person

Even without the intrusive negative attitudes of others and the endurance of substandard care, the day-to-day reality of living with an impairment or disability can become overwhelming on its own. One interviewee describes experiencing depression in the face of these challenges:

> **"Some afternoons you just want to go back to bed, some mornings you don't want to get up. In fact, this morning, if I wasn't seeing you, I don't think I would have come here."** Interview with disabled person

While disabled people want understanding of and sensitivity towards their impairments and disabilities, they do not want to be reduced to or defined by them. "I am not an illness or a disability," says one interviewee, "those are just things that make up who I am as a person." Disabled people want to be acknowledged as unique, fully rounded individuals with interests and personalities. They do not want their identities collapsed by disability. This diminishes their ability to exercise choice and control.

Many workers in social care already have an understanding of how crucial positive attitudes are to disabled people, to help facilitate them to live as independently as possible and can see things from their perspective: "Ask the disabled person what they want and need. What are their goals for themselves? What would make life easier or more enjoyable for them?" (Online survey). Others believe practical solutions to ensure the right people are employed in social care are necessary: “Strong value-based recruitment would promote more positive attitudes” (Online survey). Ensuring both existing staff and new recruits have the right values to promote a positive attitude in social care would make a significant difference to disabled people’s experience.

Sometimes very small things, ultimately produced as a result of seeing people as more than just their impairment, can make a very big difference to their choice and control. One social care manager, who has experience working with people with learning disabilities and challenging behaviour, explains how a simple assessment of the caring practice resulted in moving service provision for these people so it did not clash with the time of their favourite television programme. This helped reduce instances of challenging behaviour, creating a more settled environment for both clients and staff. “You know,” said the social care manager, “even those tiny things make the world of difference.” He said it was not an easy adjustment for some of the care team as “they really struggled with the idea that interrupting somebody’s TV programme could be a difficulty for them and would actually impact their quality of life” (Focus Group, social care managers). A shift in perspective, to see things the way disabled people do and acknowledge their viewpoint as valid, can improve their lives and, by extension, the lives of those who live and work with them.

7. Conclusions

It is widely acknowledged that the social care system is in crisis, by both service users and those who deliver that service. This is the result of both a lack of funding to run the services, as well as poor pay rates for those who work on the ground in social care. The current welfare system that supports disabled people to live independently is also failing them in many cases.

This evidence clearly demonstrates that this is not a 'simple' matter of a lack of money. Attitudes towards disabled people, by staff working on the ground and by decision makers, are impacting negatively on the lives of disabled people, and are fundamentally contributing to why they are not having their needs met or their rights addressed.

The disabled research participants spoke eloquently about the most basic things they should be able to expect to have more control over their independent living choices. They talked about the need for education (for society generally and specifically for care workers) around the impact of impairments and health conditions on a person and what kinds of support they need. They observed how disabled people are dehumanised by the media and how they are devalued within the care system, and they want to challenge this. They explained how negative attitudes to disabled people are not rare or trivial – they see them again and again, as carers, workers, and society views them as lesser human beings. Disabled people have the same clear message for the social care system and social care workers – "**See Me as a Human Being**".

It is understandable that disabled people in this position would ask "to be seen as a person and not as a reference number or a statistic*"* and *"*as a person rather than an object*"* (interviews with disabled people). They want to be spoken to, to be listened to, as "if you were a person and another person was talking to you, then they'd want to know what would make your life better" (Interview with disabled person). It is in this exchange that disabled people see the key to being seen as human.

Disabled people need to be valued as members of society. To that end, adult social care also needs to be more valued and better funded than it is currently. The government has legal obligations to meet disabled people's human rights and the shortfall should be urgently addressed.

The following key findings and recommendations are drawn from the evidence produced by this research and framed under existing human rights and health legislation and policy frameworks.

8. Key Findings

Disabled people are consistently not having their human rights or needs met in adult social care.

Negative attitudes are fundamental to why disabled people are not living as independently as they could be.

These are the over-arching findings, supported by the source material:
- 14 interviews and four focus groups with disabled people
- A focus group with social care managers
- An online survey with 550 workers in the social care system
- A comprehensive review of relevant literature

Disabled people who receive social care regularly experience negative attitudes and behaviours. This is two-pronged. Some of this is about attitudes and behaviours of individual workers. Some is more systemic – how attitudes towards disabled people within the system of social care itself impacts on both policy and practice.

Action is needed across six key areas:
1. Information about independent living choices
2. Negative attitudes and stereotypes
3. Acknowledging lived experience as expertise
4. Lack of quality and consistent care
5. Dignity, trust, and value
6. Choice and control

Key to these recommendations are the Articles of the UNCRPD, as well as the *Concluding Observations* of the UNCRPD Committee in 2017. Relevant health and social care policy, including the *Transforming your Care*, *Health and Wellbeing 2026*, and *Power to People* reports, have also been drawn upon in developing these recommendations. Some of the recommendations below are adapted from the Citizen’s Assemblies, in Northern Ireland and in England.

1. Information about independent living choices

Disabled people are often not given enough information about independent living choices. Gatekeepers in the system focus on telling them “what they are not entitled to”. Sometimes information is kept from them because the resources for independent living choices were not available.

Workers in the social care system confirm that most of the time disabled people are not guaranteed to receive enough information about their independent living choices.

2. Negative attitudes and stereotyping

Disabled people experience negative attitudes and stereotyping within the social care system, which has several negative effects. It can affect their care plan by assuming a “usual baseline” that does not consider the fluctuation of their impairments or health conditions. Disabled people also reveal how they are made to feel like “tasks” or “objects”, and not seen as people or not seen at all.

Decisions about care packages to support independent living can be made based on stereotypes or assumptions about a condition or impairment, without talking to the person about what their needs are. Almost three quarters of workers in social care said that disabled people are not asked questions regularly about their care provision. This contributes to lack of recognition about changes in disabled people’s needs.

3. Acknowledging lived experience as expertise

Disabled people need to be listened to. They should be part of decision making about their care. Building working relationships between the disabled person and their support worker is essential. This message is clear from both disabled people and workers in the social care system.

Disabled people have a unique lived experience of their own impairments or health conditions, but that knowledge is often not accepted as expertise within the social care system. Disabled people say they are spoken for, talked at, and their care taken over, without regard for their own views about what is best for them.

There is a paternalistic attitude that is pervasive in adult social care, which assumes that other people know what is best for disabled people and has entrenched health and safety rigidly in practice. This sometimes impacts on supporting and encouraging people to do what they can for themselves in the pursuit of independence. While the safety of disabled people receiving care is important, so is the role of care in enabling people to live as independently as possible. There needs to be a balanced approach to ensure that risk aversion does not stifle disabled people's independent living choices.

4. Lack of quality and consistency of care

Half of the time disabled people are not provided with services at the time arranged, according to workers in social care. They also say that in more than a third of cases disabled people are not told of changes to their care plan. Disabled people talk about the impact such inconsistent care has on their lives, to have care workers providing intimate care change, and to have their care plan or times for care change, often at very short or no notice. Many disabled people experience wide disparities in the quality of care, from good quality care to very poor.

Workers in the social care system raise a number of factors contributing to poor quality and inconsistent care, including poor conditions for staff. Staff morale is low and burn out common. This leads to staff shortages, a situation that may get worse as Brexit causes some EU workers to leave. This high staff turnover combined with a lack of funding can lead to workers receiving less training and not adhering to care plans. Time spent on heavy paperwork loads leaves less time and energy to meet the needs of disabled people to live independently.

5. Dignity, trust, and value

The power of both individual workers and the social care system can make disabled people feel disadvantaged and vulnerable in situations where they are receiving care (often of an intimate nature) in their own homes. Many disabled people find it difficult to raise any complaints about poor quality care, for fear of retribution. And many feel they should "be grateful for what you can get". Disabled people who experience poor quality care are often left feeling worthless. Those who experience abusive care can be traumatised by the experience.

For women and for anyone who experienced early trauma, such as childhood sexual abuse, feeling – and being - safe in their own home is crucial. This research shows that women have had their care provision cut for requesting only female care workers. This should be a valid request, given the higher rates of violence against disabled women, and the higher rates of violence against disabled people than the general population.

6. Choice and control

Many disabled people talk about how little choice and control they have over their independent living choices. One key reason is a lack of available resources. Most workers in social care believe there should be more independent living choices available, and this is often curtailed by a lack of funding. Faced with a culture of austerity within social care, both service users and care workers are left feeling devalued and demoralised

However, choice and control could include relatively small things, such as consulting disabled people about the timing of services, treating disabled people with respect, and seeing things from their perspective. Pervasive negative attitudes within the social care system can be challenged by prioritising value-based recruitment and the training of existing staff to cultivate this type of positive, person-centred behaviour.

9. Recommendations

1. Cross Government and decision makers on social care:

It is time to address the crisis of under-investment and the poor management of resources in social care and develop a social care system that works more efficiently and meets the human rights of disabled people. A rights-based approach should be adopted in social care, rather than one based on budget restrictions.

Ensure that social care:

- Is sustainable and for the long term – with a protected funding solution
- Is fair and equal – guaranteeing a minimum level of care for everyone
- Is universal – not creating a postcode lottery
- Is high quality – providing consistent and high-quality care
- Treats people with dignity and respect – giving people choice and control (Involve & House of Commons, 2018)

It is critical that the voices of disabled people are listened to and that they help shape all relevant policy, practice, service planning and delivery. Disabled people should be acknowledged as experts in their own lives, and in living with their impairments. The State must "closely consult with and actively involve persons with disabilities" (UNCRPD, *Article 4*, 2006).

2. For the Department of Health and Social Care:

- Ensure that disabled people's views are consistently listened to in decision making about their care, including assessing need, planning care and support services, delivery of these services, and ongoing evaluation of social care services (Department of Health Social Services and Public Safety, 2011, & Kelly & Kennedy, 2017).
- Ensure that the *Concluding Observations* from the UN Committee on the Convention on the Rights of Persons with Disabilities (UNCRPD) from 2017, including implementing a human rights framework, are fully embedded in all social care policy from now on.

- Ensure that the Mental Capacity Act (NI) 2016 is amended so as to be compliant with the UNCRPD, that it is adequately funded, and brought into force as soon as possible.
- Develop a holistic model of social care that considers how an individual's needs change across their life span, with a specific emphasis on tackling poverty & inequality (Involve & House of Commons, 2018).
- Ensure disabled people receive enough information about their independent living choices. Access to this information should be based on need and not dictated by the availability of resources.
- Enable disabled people to take calculated risks as part of a balanced health and safety policy that supports people to live independently as fully as possible.
- Review the assessment process, with the aim of moving towards continuous assessments which are needs-based and not resource-led. Learn from good practice from Trusts developing co-assessments with service users and carers. The process of assessment and service allocation should be transparent.
- Ensure that all processes involved in putting social care work out to tender are robust. Social value should be built into all contracts as part of the assessment criteria, rather than just the financial cost. Human rights obligations must apply to all work put out to tender for social care by the Health and Social Care Department.
- Provide training for all workers within the social care system, from those working on the front line to decision makers, about the importance of applying a human rights approach within their work. This must include key principles of listening to disabled people, treating them with dignity and respect, and giving them as much choice and control as possible. It must challenge the widespread negative perception of disabled people as “other” or “less than”, or that they are an economic burden.
- Collect data on all Section 75 groups (not just disability) and be able to disaggregate these data against people's multiple identities. This is crucial to ensure needs are identified and rights are addressed.
- Ensure that workers in social care are paid fairly, with progression linked to skills, experience, and qualifications. Include payment for travel time, mileage, and expenses in addition to salary, and end compulsory zero-hour contracts.

3. For the Department of Communities:

- Develop and implement a fairer application and review process for disabled people accessing benefits to support them to live independently, including, but not limited to, Personal Independence Payments, Disability Living Allowance, Employment Support Allowance and Universal Credit
- Reopen the Independent Living Fund for new applicants
- Increase the amount of suitable and accessible housing and accommodation for disabled people under the Supporting People programme, to support them to live independently
- Ensure the Disability Strategy currently being developed is implemented as soon as possible

4. For the Regulation & Quality Improvement Authority (RQIA):

- Improve regulation to ensure a consistent provision and quality of social care, to a minimum standard, across all providers. This should include Trusts, voluntary sector and private companies. It should also include all work commissioned or procured, as well as all agency workers
- Ensure that the Police Service of Northern Ireland and the RQIA work together on a fully collaborative basis to ensure vulnerable people are fully protected

5. For the Social Care Council:

- Develop and promote value-based recruitment to ensure we have the right people working in social care
- Develop a career structure for social care that provides opportunity for development and progression
- Promote social care as a valued and prestigious career

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11. Appendices

There are also a number of appendices to this report, which are all online at DRILL www.drilluk.org.uk and Disability Action Northern Ireland www.disabilityaction.org

- Appendix 1 - DRILL NAG and Research Partnership members
- Appendix 2 - Sample Interview Transcript
- Appendix 3 - Focus Group Transcript, Social Workers
- Appendix 4 - Online Survey Questions

DRILL (Disability Research on Independent Living and Learning) is an innovative UK wide programme led by disabled people for disabled people. DRILL is a Four Nation Research Project (across Northern Ireland, Wales, Scotland and England) which delivers the world's first major research programme led by disabled people. Disability Action Northern Ireland leads the DRILL programme in partnership with Disability Rights UK, Disability Wales and Inclusion Scotland. Launched in 2015, DRILL concludes in November 2020. The National Lottery Community Fund (NLCF) funds the DRILL Programme.

The 32 DRILL projects across the UK have completed or are completing DRILL research. The Four Nations project is unique in the sense that Northern Ireland, Wales, Scotland and England have come together to conduct research on the same key topic: attitudes to disabled people. Inclusion Scotland leads on bringing together the learnings of the Four Nations research.

For more information about the other DRILL research projects, please go to www.drilluk.org.uk

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