



See Me as a Human Being: Executive Summary

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**



**COMMUNITY
FUND**

We have also produced an Easy Read version of this Executive Summary.

If you would like this research in an alternative format, please get in touch with us.

Disability Action Northern Ireland
Telephone: 028 9029 7880
Textphone: 028 9029 7882
Website: www.disabilityaction.org

This report is published by DRILL©

For more information about DRILL go to:

Website: www.drilluk.org.uk
Twitter: @drill_uk #seemeasahumanbeing
Telephone: 028 9029 7880

Disabled people co-produced this research with three partners

The DRILL National Advisory Group (NAG)



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 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.
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>

Photo Credits: Disability Action NI and
Brian Morrison Photography@Disability Action Northern Ireland



1. Introduction

This co-produced research tackles two major issues:

1. Attitudes, which significantly impact on disabled people's daily lives
2. Adult social care, which exists to support people to live as independently as possible

The aim of the research was to understand how attitudes impact on disabled people's experience of social care and, in particular, how these attitudes impact on their independent living choices and experiences.

Attitudes matter to disabled people. This research allowed space for people to talk about the impacts that attitudes have on their experience of social care. It 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. This work is driven and underpinned by fundamental human rights.

2. Co-production

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

3. Methodology

Co-production of this research with disabled people was a central part of the methodology.

Both quantitative and qualitative methods were adopted. The following research methods were used:

- 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

4. Key Findings

The over-arching findings, supported across the interviews, focus groups, and online survey responses, are:

- Disabled people are consistently not getting their human rights addressed or their needs met in adult social care
- Negative attitudes are fundamental to why disabled people are not living as independently as they could be

Disabled people spoke eloquently about the ways in which their basic human rights and needs were not met in social care. They also talked about how this came not just from negative attitudes by individual workers, but through the application of policies that were unjust, unfair, paternalistic or resource-led above rights-led. This speaks to a systemic problem in which it could be argued, based on evidence provided by research participants, that attitudes towards disabled people do impact

on both policy development and implementation within social care, for good or ill. Data collected from workers in the social care system support the findings from disabled people.

The data collected from the interviews and focus groups were explored to determine what kind of issues and experiences participants encountered in their contact with social care.

Six key themes emerged, which were then applied across the interviews, focus groups and online survey responses. These themes are:

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

5. Conclusions

Evidence gathered in this research is revealing:

- Disabled people feel “Social care is currently not fit for purpose”
- Adult social care should be better valued and better funded than it is now
- Disabled people should be better valued and better treated than they are now

The government has legal obligations to meet disabled people’s human rights. The United Nations Convention on the Rights of Persons with a Disability (UNCRPD) requires the government to protect the “human rights and fundamental freedoms by all persons with disabilities”, and “to promote respect for their inherent dignity” (*Article 1*, 2006).

See Me as a Human Being is designed to be a useful tool to improve attitudes within the social care system, and to improve how disabled people's right to choice and control over their independent living can be more effectively achieved. More work needs to be done in co-production with disabled people, their organisations and allies on the issue of attitudes.

6. Key Recommendations

Please see the full **See Me as a Human Being** report for the full list of recommendations.

Government departments and decision makers on social care should:

- Address the crisis of under-investment and the poor management of resources in social care
- Develop a social care system that works more efficiently and meets the human rights of disabled people
- Ensure a rights-based approach be adopted in social care, rather than a financially based approach

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
- Provides 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 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).

Ensure that the Concluding Observations from the UN Committee on the Convention on the Rights of Persons with Disabilities (UNCRPD) are fully embedded in all social care policy from now on (Committee on the Rights of Persons with Disabilities, 2017).

7. References

Committee on the Rights of Persons with Disabilities. (2017). Concluding observations on the initial report of the United Kingdom of Great Britain and Northern Ireland.

<http://docstore.ohchr.org/SelfServices/FilesHandler.ashx?enc=6QkG1d%2fPPRiCAqhKb7yhspCUnZhK1jU66fLQJyHlkqMIT3RDaLiqzhH8tV Nxhro6S657eVNwuqlzu0xvsQUehREyYEQD%2bldQaLP31QDpRcmG35KYFtgGyAN%2baB7cyky7>

Involve & House of Commons. (2018). *Citizens' Assembly on Social Care: Recommendations for Funding Adult Social Care*.

<https://publications.parliament.uk/pa/cm201719/cmselect/cmcomloc/citizens-assembly-report.pdf>

United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). (2006). *Article 1 – Purpose*.

<https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-1-purpose.html>

United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). (2006). *Article 4 – General obligations*.

<https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-4-general-obligations.html>

This is a DRILL research project.

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 August 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 on attitudes towards disabled people.

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



“To be seen as a person and not as a reference number or a statistic.”

“The most fundamental thing I would change would be for them to treat me as a person rather than an object.”

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

Quotes from disabled people during interviews