Summary

Barriers and enablers to employment: black disabled people living with Sickle Cell Disorder

About the DRILL Programme

DRILL (Disability Research on Independent Living and Learning) was an innovative 5 year, UK wide programme led by disabled people, for disabled people and funded by the National Lottery Community Fund.

Launched in 2015, the programme was managed by a partnership of Disability Action Northern Ireland, Disability Rights UK, Disability Wales and Inclusion Scotland.

The aim of the programme was to build better evidence about approaches which enable disabled people to achieve independent living. The findings from the projects it funded can be used to inform future provision across a wide range of policy areas, and give a greater voice to disabled people in decisions which affect them.

This is one of a series of summaries of the project supported by DRILL. Final reports, toolkits and summaries of all the projects are available from the DRILL website at **www.drilluk.org.uk**.

Overview of the project

This project identified enablers and barriers to employment of people with Sickle Cell Disorder (SCD), the most common single-gene condition in England.

Written and designed by **www.furnercommunications.co.uk**

Approach

The project was co-produced with people with lived experience of people with Sickle Cell Disorder (SCD). Two focus groups were carried out, in London and Birmingham, led by people with SCD.

Interviews were also conducted with 47 adults by academics. Participants had an average age of 41, and were primarily employed, or had been in paid employment.

Findings

People with SCD had experienced various forms of discrimination in employment, work and welfare.

SCD is a mostly invisible chronic condition. A lot of employers have very little knowledge of it.

People with SCD often don’t view their condition as a disability and do not understand the services available to them, or the legislation which protects their rights.

SCD affects mainly people from ethnic minorities in the UK, which meant experiences of both indirect and direct racism were discussed. This included bullying, harassment, marginalisation and micro-aggressions.

Women with SCD explained that they also encountered sexism and sexual harassment in the workplace.

Individuals with visible manifestations of SCD discussed experience of disablism, such as not being invited for interviews, not being accommodated for and explicit hostility towards their impairment.

Medical leave was often denied, with individuals having to take annual leave instead.

Employers often struggled with how to implement reasonable adjustments which employees are entitled to under the Equality Act 2010.

Some participants did recall positive experience such as adjustments being made including specialist equipment, allocated parking spaces and flexible working times.

Findings (continued)

Participants managed their lives by restricting leisure activities, such as socialising with colleagues, to remain healthy for work and stay out of hospital.

Many participants had their benefits removed after Work Capability Assessments and had to go to benefit tribunal. They felt as if they were being singled out by the welfare system.

People with SCD were also carrying out important voluntary and community work. However, this was seen as invisible work and they were not recognised for it.

Recommendations

The project outlined many recommendations, some of which are listed here. All recommendations are included in the full report, which is linked below.

- Ensure the Equality Act 2010 is being complied with, both in relation to discrimination based on a protected characteristic, and implementing reasonable adjustments
- More must be done to ensure diversity and equality in all workplaces, regardless of the type of contract an employee is on
- Employers must ensure accessibility and transparency in recruitment
- There must be clarity around processes of disclosure for people living with fluctuating conditions, chronic illness and/or invisible impairments when applying for a job
- Employers should recognise travelling to work as an issue, as the fatigue caused by SCD can be worsened by a commute. Employers should make reasonable adjustments where necessary
- Unions must ensure that information about their work is made available to people with SCD, and that they are prepared to support a diversity of people with multiple impairments and conditions.

Final report

Barriers and enablers to employment: black disabled people living with Sickle Cell Disorder

Please click on report name to read the full report.

Project partners

De Montfort University

Sickle Cell Society

Organisation for Sickle Cell Anaemia Research Sandwell Company Ltd