Summary

Chronic Illness and Inclusion Project (CIIP) – Mobilising a Collective Voice for Social Change

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 projects 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

The project aimed to promote the framework of independent living among the chronic illness community, providing them with tools for great autonomy and dignity.

The project also explored the technological solutions to participation barriers of people with chronic illness in traditional Disabled People’s Organisations, and civic life in general.

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

Approach

The project used focus groups of 20 people, lasting eight weeks, allowed for an in-depth exploration of individual experiences and provided qualitative data. These took place on an online platform, allowing for increased participation as face-to-face focus groups would have excluded some people.

A follow up survey was produced, providing an element of quantitative data to the project. This received 2,300 responses.

Findings

The project explored the lived experiences of impairment among those who identify as having chronic illness. An array of symptoms were identified, but limited energy and fatigue were deemed the most debilitating and restricting features. Almost three quarters of survey respondents corroborated this finding, selecting these symptoms as the most restricting.

Pathological fatigue experienced by participants differed from the universal experience of tiredness, with reports explaining that ‘units of energy’ had to be rationed in order to get through each day. More than 80% of survey respondents felt that people thought ‘everyone gets tired,’ which manifests itself as denial and disbelief of their experience.

Many focus group participants felt that government departments did not acknowledge the existence of chronic illness as a type of disability. It was also felt that existing organisations of, and for, disabled people did not adequately give a voice to the experiences and needs of those with chronic illness.

Half of the survey participants felt that the legal obligation to make reasonable adjustments did not apply to them. Systems of support, such as welfare benefits, employment support and social care are not tailored to their impairment experience.

Many believed that policy priorities should be health care and social security, particularly Personal Independence Payments (PIP). Interactions with the DWP were seen to be the main source of oppressive attitudes to those with chronic illness.

Findings (continued)

Almost two-thirds of survey respondents said that improving medical treatment would be the main thing that would improve their quality of life. Four in five also agreed that a better understanding of chronic illness would also improve their quality of life.

Recommendations

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

- The World Health Organisation should review the Internal Classification of Functioning, Disability and Health to consider the wider application of fatigue and stamina
- The UK Government should recognise people living with stamina/breathing/fatigue as a discrete impairment group. They should also devote funding for biomedical research into these symptoms
- A review of the language used for the category of stamina, breathing and fatigue. ‘Energy impairment’ would more accurately reflect the preferred language of the research participants
- The disability sector must engage with the knowledge and experiences of people with chronic illness. They must challenge ableist attitudes and practices
- They must also include and represent people with energy limiting chronic illness and energy impairment in education and training on access and inclusion
- There must be support for the establishment and sustainability of a user-led organisation for people with energy limiting chronic illness.

Final report

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Please click on report name to read the full report.

Project partners

Centre for Welfare Reform