





Summary

A translational case study of empowerment in practice: an evaluation of the Dementia NI Service

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 provides an evaluation of the Dementia NI Service, exploring the impact of their involvement at individual, dementia community and social levels.

The project also looks at empowerment of people living with dementia and how this can be enabled through the organisation.

Approach

The project used semi-structured interviews with 15 current members, 3 staff and 5 board members.

Observational engagement of the Dementia NI Service took place in empowerment group meetings, public events that they contributed to and in any board meetings.

Findings

Dementia NI uses three distinct activities – empowerment groups, awareness raising and consultation.

Empowerment groups meet fortnightly to provide peer support and to promote better practice in relation to dementia care.

The model of empowerment revolved around the formation and maintenance of social groups. Facilitators of this were employed by Dementia NI and supported six groups, of 1-4 members per group. Each member had mild to moderate cognitive impairment.

The empowerment groups lead to the development of a shared social identity and a sense of collective strength.

Members of empowerment group reported improved quality of life.

Implementation of the empowerment model has the potential to lead to reduced stigma and greater social inclusion of individuals with dementia.

An improved knowledge gave people with dementia the confidence to talk about their illness with family and friends, which helped them improve these relationships and reduce their fears about their future with dementia

The stigma that exists around dementia, and the taboo that this creates, could create barriers to people with dementia from joining these empowerment groups.

Dementia NI provided resources to support members with dementia in awareness raising. This included branding, organisational skills, contacts, media training and transport to events.

Findings (continued)

Awareness raising activities generated an 'activist' mentality for members. They were able to draw on their new found confidence, collective strength and their motivation to reduce the stigma around dementia and highlight the need to improve services.

Recommendations

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

- Provide people with dementia the opportunity to develop a shared social identity to create a sense of social power and generate motivation to access the required resources
- Empowerment group facilitators should focus on encouraging members to recognise the skills they have and can still learn
- The stigma around dementia must be challenged
- There must be adequate resources for training and raising awareness of empowerment groups, especially in areas where dementia is still a taboo
- Opportunities for people with dementia to consult with policy makers, health care providers and community services will empower them to have a voice and build their confidence
- Providing these opportunities will result in better informed policy makers and service providers who recognise the needs and aspirations of people with dementia
- There must be a cultural shift towards a greater sense of openness and interest in the issues affecting people with dementia.

Final report

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Please click on report name to read the full report

Project partners

Queens University Belfast



Dementia NI



Ulster University

