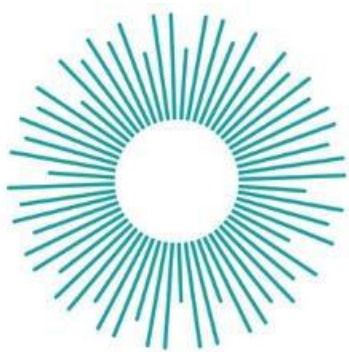




A translational case study of empowerment into practice: An evaluation of the Dementia NI Service

Executive Summary

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drill
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Background

A recent report by the World Health Organisation (WHO) and Alzheimer's Disease International suggested that the number of people living with dementia will triple by 2050. A key objective or goal of the G8 Dementia Summit (UK) is to improve treatment and preventive methods, and improve the quality of life of people living with dementia. This summary presents the story of the development of a new initiative –Dementia NI – and the extent to which it has contributed to the goal of improving the quality of life of the vast number of people living with the disease.

On 15 January 2015 Dementia NI was founded by five people living with a diagnosis of dementia. The goal was to provide a voice for people who are living with a diagnosis of dementia and to reach out to others who have dementia. This unique organisation continues to be led by people with dementia who are developing empowerment groups across Northern Ireland. These groups are based on a model of empowerment whereby people with dementia meet regularly in groups to help influence policy, practice and service delivery to meet local needs.

Aims

This evaluation helps identify and explain what it is about Dementia NI that works, how it works, and what increases the likelihood that the organisation will meet its intended outcomes. To do this we asked the following questions.

What processes and circumstances help/hinder Dementia NI meet their intended outcomes, including:

1. Improving quality of life for members?
2. Better informing policy-makers and service providers?



3. Increasing involvement of people with dementia?
4. Shaping services?
5. Improving public awareness and understanding = reducing stigma/greater social inclusion?

Methods

An organisational case study using a realistic evaluation approach to answer the question 'what works, for whom, in what circumstances?', with the aim of producing a deeper understanding of what happens in the real world of practice. Data collection included semi-structured interviews with current members (n=15), staff (n=3) and board members (n=5). Our observational engagement with Dementia NI took place in Empowerment Group meetings, public events they contributed to, and in attendance of board meetings. Exclusion criteria included those unwilling or unable to give informed consent.

Findings

Findings revealed that Dementia NI operates using three distinct, but interdependent activities – which can be derived from the organisational goals. These activities were classified early in the analysis cycle as: empowerment groups, awareness raising, and consultation.

The Dementia NI service model of empowerment revolved around the formation and maintenance of social groups of PWD. Facilitators employed by Dementia NI supported six groups, with one to four members per group, each with mild to moderate cognitive impairment. Facilitators helped expand empowerment groups, facilitate decision-making, awareness raising and consultation opportunities with group members. The 'Empowerment Groups' appeared to lead to the development of a



shared social identity and a sense of collective strength as indicated by interview and observational data demonstrating an activist mentality among group members to challenge the stigma surrounding dementia. Group members also reported improved quality of life. Widespread implementation of the empowerment model has the potential to lead to reduced stigma and greater social inclusion, increased involvement of PWD as active co-producers of policy and service development, and better services and support.

Conclusion/lessons learned

These insights provide a new model for informing similar initiatives. Within this model, we propose the following considerations for the successful implementation of empowerment initiatives for people with dementia.

- If people with dementia are provided with the opportunity to develop a shared social identity, this can create a sense of social power, generating motivation to access the required resources, and enabling members to realise group and individual goals, resulting in political and attitudinal changes

This is expanded on below in light of our findings. For example, there are a number of circumstances that make it more likely (or in some cases, less likely) that people with dementia will develop a shared social identity, and feel empowered to achieve positive outcomes at an individual, and wider political/societal level. These are outlined below.

- If group facilitators focus on encouraging members to recognise the many skills they have and can still learn, encourage shared decision making between members of the group in relation to improving services and support, provide opportunities for awareness raising and consultation with service providers and policy makers, then this is more likely to lead to improved quality of life for



members, enhanced peer networks and social activity, increased confidence and self-esteem, maintenance of cognitive abilities, more openness around their diagnosis of dementia, and improved relationships with family and friends

- If the stigma surrounding dementia is not challenged, especially in rural areas where the illness is still very much a taboo subject, then expanding empowerment groups to rural areas is severely compromised as people with dementia will be more reluctant to join a group for fear of their diagnosis being exposed, preventing sufficient numbers for peer support, and collective action

- If there is organisational and staff support to set up empowerment groups, adequate resources and expertise for media training and awareness raising activities, and positive feedback from consultation exercises, then members will be enabled and empowered to educate the public on dementia, thereby challenging the stigma surrounding dementia, along with highlighting the need to improve services. As a result, members gain satisfaction from making a difference to the lives of people with dementia, have the opportunity for civic contribution and political influence at local and national level, and can work toward improving public awareness and understanding of dementia with the aim of reducing stigma and greater social inclusion of people with dementia

- If empowerment group facilitators generate opportunities for people with dementia to consult with policy makers, health care providers, and community services; and ensure consultations are followed up with actions based on members' advice, this empowers people with dementia to have a voice, builds their confidence to challenge those with decision making power to listen and act on the advice and guidance provided by those actually living with dementia, resulting in better informed policy makers and service providers who recognise the needs and aspirations of people with dementia, increased involvement of



people with dementia as active co-producers of policy and service development, and ultimately better services and support for people with dementia

- If there is a continuing cultural shift in the health service and wider commissioning arena in relation to a greater sense of openness and interest in issues affecting people with dementia, then they are more likely to take the advice of people with dementia on board and implement change in line with the needs of those actually living with dementia.

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