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| Institution: The University of Edinburgh |
| Unit of Assessment: 22 Social Work and Social Policy |
| Title of case study: 7: Influencing dementia philosophy, policy and practice |
| <p>1. Summary of the impact</p> <p>The work of the Scottish Dementia Working Group (SDWG), a self-advocacy and campaigning group of people with dementia, has influenced the image and role of people with dementia in Scotland and internationally. Since 2005 there has been increasing engagement with, and involvement of, people with dementia in the policy process leading up to the Scottish Dementia Strategy (launched 2010). The SDWG currently has 171 members across Scotland and has acted as a catalyst for change in dementia care, as evidenced by its direct involvement and representation in influencing education, training and practice development across dementia care in Scottish and European health and social care sectors. In 2012 the European Dementia Working Group was launched based on the SDWG model. Its work is underpinned by research that rejects the exclusion of people with dementia from claiming and using a voice in policy and practice.</p> |
| <p>2. Underpinning research</p> <p>PDFs of weblinks in this section are at www.wiki.ed.ac.uk/display/REF2014REF3B/UoA+22</p> <p>Ten years ago people with dementia were invisible and silenced, stereotypically perceived as incapable, and excluded from research, policy and practice. The findings from five research projects (see section 3) challenged widely-held beliefs around the capacity of people with dementia to participate in meaningful ways. These findings were further developed and explored by a group of people with dementia, and led directly to the formation of the SDWG as a means of challenging the status quo.</p> <p>The original primary research, conducted in the course of a Royal Society of Edinburgh/Lloyds TSB Personal Research Fellowship (Wilkinson, UoE 1/07/2002 – 31/12/2003), was a longitudinal qualitative study interviewing 10 people with dementia and their family carer over a 12 month period. This work was an early contribution to research that shifted the focus onto the subjective experience of living with dementia and challenged the lack of ‘voice’ for people with dementia. The formation of the SDWG was the central outcome of discussion of the research findings with a core group of people with dementia. They decided that a formal grouping of people with dementia was the best way to ensure effective self-advocacy, campaigning, visibility and a foundation for evidencing the potential of people with dementia to influence and engage. The SDWG was co-founded by Wilkinson (UoE) and James McKillop, a person with dementia who chaired the group for its first six years. He has published with Wilkinson and others (Wilkinson et al 2004; section 3 below) has since become a member of the Alzheimer Europe Working Group on the ethical issues of dementia research and has been awarded an MBE for services to dementia.</p> <p>The core research findings that formed the basis for the SDWG were:</p> <ul style="list-style-type: none"> • people with dementia do have an important and substantial contribution to make to research (and policy and practice) • methodological and ethical challenges to their involvement can be addressed • co-production and partnership working is effective. <p>These findings challenged the widespread understanding that limited the potential contribution of people with dementia to research, policy and practice. At that time the majority of research exploring social understandings of dementia, in itself an emerging field, was from a carer’s perspective. The RSE study was one of the first to support the methodological inclusion of people with dementia, and the following four pieces of funding all took this innovative methodological and philosophical stance further (Wilkinson et al 2008; section 3 below).</p> <p>Members of the SDWG have had a sustained involvement in research in other contexts, including:</p> |

- A research subgroup that works closely with the UoE dementia research cluster setting research priorities and co-producing research bids and being part of research projects.
- The DEEP project which explored ways of empowering and engaging with people with dementia
<http://www.jrf.org.uk/publications/stronger-collective-voice> [5.4]
- A member of the SDWG is on the advisory board of Scottish Dementia Clinical Research Network
<http://www.sdcnr.org.uk/our-research/our-research-strategy>

3. References to the research

Wilkinson H, Weeks D (Editorial) (2008) Hearing the voices in the policy-practice-research nexus: the importance of the knowledge exchange process for people with dementia. *Dementia: The International Journal of Social Research* **7(4)**: 427-31, DOI: [10.1177/1471301208096627](https://doi.org/10.1177/1471301208096627).

Wilkinson H, McKillop J (2004) Make it easy on yourself! Advice to researchers from someone with dementia on being interviewed. *Dementia: The International Journal of Social Research* **3(2)**: 117-25, DOI: [10.1177/1471301204042332](https://doi.org/10.1177/1471301204042332).

Dementia: The International Journal of Social Research is one of the main peer-reviewed international social science journals in the field of dementia.

The five research projects are listed below, the first two funding the primary research, the final three supporting the ongoing development of the SDWG. The SDWG then received longer-term funding to support its development as a group from Alzheimer Scotland, Comic Relief, The Big Lottery.

- July 2002-Dec 2003. Royal Society of Edinburgh/Lloyds TSB Personal Research Fellowship £117k. New perspectives on dementia: issues of social well being for people with dementia and their carers (Wilkinson, personal fellowship)
- July 2002-July 2003. Carnegie Trust for Scottish Universities £27k. Scottish Dementia Network (Wilkinson with Dr Ailsa Cook, research fellow)
- Sept. 2009. £2,640. UoE KT Grant. Dementia Dialogues (Wilkinson)
- Sept 2008–Sept. 2009. £2,000. ESRC. ESRC Engagement Event: Creating Innovative Exchange across Dementia Theory, Practice and Policy (Wilkinson with Morton)
- July 2008–July 2009. £10k. UoE Knowledge Exchange Fund. Creating innovative Exchange across Dementia Theory, Practice and Policy (Wilkinson).

4. Details of the impact

PDFs of weblinks in this section are at www.wiki.ed.ac.uk/display/REF2014REF3B/UoA+22

Influencing policy

The SDWG has regular annual meetings with Scottish Health Ministers and their deputies [5.1]. Since the present Scottish government made dementia a priority, this has increased to 2-3 times per year. In 2007, the then Scottish Minister for Public Health set up an advisory group, the Dementia Forum, to inform and advise her of issues that needed to be addressed and to guide the development of dementia as a national priority [5.1]. Two members of the Scottish Dementia Working Group were invited to join this influential group and continue to make a contribution to this forum (*Dementia in Scotland*, Issue 60, December 2007, p. 1). During a visit by the First Minister in 2009 they discussed the importance of challenging public stigma and misconceptions of dementia (<http://local.stv.tv/edinburgh/81230-salmond-to-visit-alzheimer-charity/>).

In 2009, SDWG partnered Scottish Parliament's Cross-Party Group on Alzheimers at the launch of the Charter of Rights for people with dementia and their carers in Scotland

(<http://www.palliativecarescotland.org.uk/content/publications/charter-of-rights-launch-8thOct20091.pdf>).

This charter was to be central to the development of the first *Scottish Dementia Strategy*, which was launched in 2010. During the development of the Strategy, 10 members of the SDWG were involved in workgroups and as partners running consultation events (see Foreword of Strategy pages 6-7 by the chairman of SDWG, also page 28-29 acknowledging the impossibility of producing such a document without SDWG input [5.2]).

“The work that we have undertaken to produce this strategy would have been impossible without the direct contribution of the Scottish Dementia Working Group, whose members all have a diagnosis of dementia” (page 28/29) (Edward McLaughlin)

“securing the government’s recognition of dementia as a national priority and the development of the Scottish Dementia Strategy - would have been impossible without the active contribution of people with dementia through the Scottish Dementia Working Group” (Henry Simmons CEO Alzheimer Scotland at the inaugural meeting of the EWGPWD)

Furthermore, there are three members of the SDWG who sit on the programme board to oversee the implementation of the strategy

http://www.nes.scot.nhs.uk/media/584864/membership_list.pdf)

“Development of the Dementia Strategy included the close involvement of Alzheimer Scotland and the Scottish Dementia Working Group, both of whom endorsed our approach. It has been vital to me that, in implementing the strategy, they have both been at the heart of the large programme of work, providing expert advice and input on the services to which people are entitled, and influencing the implementation of the various strands of the strategy.” (MSP Nicola Sturgeon, Depute First Minister, *Dementia in Scotland*, Issue 75, p. 3, March 2012) [5.1]

In recognition of the contribution to policy, the Scottish Government hosted a celebration reception at the Scottish National Gallery in 2012. Nicola Sturgeon spoke in acknowledgement and praise of the work and highlighted just how far the group had influenced the shift in attitudes in Scotland. [5.1]

The Joseph Rowntree funded **Dementia Engagement & Empowerment Project (DEEP)** explored ways of empowering and engaging with people with dementia and found that the SDWG were the only activist group of people with dementia in the United Kingdom. The work recommended that the SDWG serve as a model which could be adopted and adapted throughout the rest of the UK. <http://www.jrf.org.uk/publications/stronger-collective-voice> [5.4]

Dementia policy is now directly influenced and informed by people with dementia themselves, through the representatives of the SDWG.

Influencing practice

The SDWG has been involved in many presentations and lectures to reach different professional groups. Group members have contributed to three training DVDs (*United We Stand, Listening to the Experts and Through Our Eyes*) and have worked in partnership with Health Scotland and Alzheimer Scotland to produce a DVD entitled *Living Well with Dementia*.

Group members also helped launch the NHS Education for Scotland (NES) DVD *Promoting Excellence* and worked in partnership with NES and Alzheimer Scotland. Two members of the group were on the National Integrated Care Pathways steering group (part of Quality Improvement Scotland QIS) which mapped out service needs. They also work closely with the Care Commission.

Through active, strategic involvement, people with dementia are directly influencing and informing practice directives, guidance and frameworks at national level.

International influence

In April 2012, a European Dementia Working Group was formed at a meeting of SDWG, Alzheimer Scotland and their European counterparts from Austria, Bulgaria, England, Norway, Slovenia and Spain in Glasgow. The European group is replicating the Scottish model to ensure representation of people with dementia in policy and practice across Europe. The first European group meeting was held in Vienna in October 2012, when the chair of the SDWG was elected vice-chair. The SDWG were invited to address the meeting and were cited as being a “particularly successful example” of a campaigning group run for and by people with dementia (Jean Georges, CEO Alzheimer Europe [5.3]).

SDWG members have spoken at major international conferences and have had a presence at Alzheimer’s Disease International and Alzheimer’s Europe every year (see, e.g., <http://www.alz.co.uk/ADI-conference-2012>).

Engagement with the media and public

SDWG members have given interviews to the press and interviews on radio and television to raise awareness about living with dementia and challenge stigma about dementia (e.g. The Guardian 2008, The Sun 2010, BBC).

<http://www.guardian.co.uk/society/2008/feb/06/longtermcare.socialcare>

<http://www.thesun.co.uk/sol/homepage/news/scottishnews/2838102/Charity-boss-on-life-with-dementia.html>

<http://www.bbc.co.uk/programmes/b01k67sf>

<http://www.bbc.co.uk/news/uk-scotland-scotland-politics-17665088>

Agnes Houston (member of SDWG) appeared in BBC programme, Panorama: *The Postcode Lottery: It Could Be You* (BBC One 8.30pm Monday 18 August 2008).

SDWG members have been utilising different ways of engaging with the public and have uploaded some of their training DVDs to youtube

http://www.youtube.com/watch?v=ZcM6g_B-mcs

5. Sources to corroborate the impact

PDFs of weblinks in this section are at www.wiki.ed.ac.uk/display/REF2014REF3B/UoA+22

5.1. Deputy First Minister, Scottish Government – speech at 10th Anniversary summarising impact of SDWG.

5.2. a. Chair of SDWG – can comment on membership and reach across Scotland and Europe. Scottish Dementia Strategy available at

<http://www.scotland.gov.uk/Publications/2010/09/10151751/0>.

b. CEO Alzheimer Scotland – funder of SDWG.

5.3. CEO Alzheimer Europe, can attest to development of the European Dementia Working Group – across 11 European countries.

Press release on setting up of the European Working Group of People with Dementia and the influence of the SDWG:

<http://www.alzheimer-europe.org/EN/Alzheimer-Europe/Who-we-are/European-Working-Group-of-People-with-Dementia/Activities/April-2012-setting-up-the-EWGPWD>

5.4. Programme Manager, Joseph Rowntree Foundation. Commissioner of impact study of SDWG. JRF commissioned a paper to record their 10 years of campaigning and this report was written in collaboration with its members and two of its founding professional members

<http://www.jrf.org.uk/publications/perspectives-ageing-dementia>

This Programme manager also managed the DEEP work.