

Institution: University of Edinburgh		
Unit of Assessment: UOA20 Social Policy and Social Work		
Title of case study: Enhancing policy, services, and public perception to benefit people living with dementia		
Period when the underpinning research was undertaken: 2010-2016		
Details of staff conducting the underpinning research from the submitting unit:		
Name(s):	Role(s) (e.g. job title):	Period(s) employed by submitting HEI:
Charlotte Clarke	Professor of Health in Social Science	1/8/11 to 15/9/19
Heather Wilkinson	Professor of Dementia Participation and Practice	1/12/05 to present
Sarah Keyes	Research fellow	1/8/11 to 15/9/19
Eva Joanna Alexjuk	Research fellow Lecturer Counselling, Psychotherapy and Applied Social Science	1/6/12 to present
Period when the claimed impact occurred: 1 Aug 2013- 31 December 2020		
Is this case study continued from a case study submitted in 2014? No		
1. Summary of the impact		
<p>Dementia research and public engagement by Edinburgh researchers has challenged societal views of people with dementia, and brought to light the value of peer support and social networks by:</p> <ul style="list-style-type: none"> • Influencing ministerial views and UK Government recommendations to support new 'dementia-friendly' community policies in England. • Leading to 91% of Commissioners of Social Services in England implementing the recommended dementia services, benefitting an estimated 1 million people. • Informing policies, strategies and practices in Wales and Scotland to improve dementia support services in devolved administrations. • Increasing awareness among the public, and health and social care practitioners, of the challenges and opportunities of living with dementia through a series of influential performing art outputs. 		
2. Underpinning research		
<p>Edinburgh researchers have examined the experiences and lives of people with dementia. Their research findings emphasise the importance of creating an environment in which people with dementia can live more inclusive lives. Three projects have led to changes in policy, practice, and public awareness based on these findings.</p> <ol style="list-style-type: none"> 1. Funded by the Department of Health Policy Research Programme, the Healthbridge research project (2010-2012) analysed the impact and sustainability of services recommended by the National Dementia Strategy for England (2009). Clarke, Wilkinson, Keyes, and Alexjuk undertook a major analysis of 40 pilot services across England, which claimed to offer an innovative approach, designed to empower the people they sought to serve. They used a large mixed-methods design of surveys, workshops and 155 interviews. 47 people with a diagnosis of dementia and 54 carers were interviewed on up to three occasions. The research provided strong evidence of the value of peer 		

support and 'Dementia Advisors' (professionals who are experts in living with dementia and accessing local support). Specifically, the research identified how the creation of Dementia Advisor positions and support services provided substantial benefits for people with dementia (and their families). These benefits were achieved through building social networks and sharing information, supporting the re-narration of people's lives, and enhancing people's control of their lives and their dementia. The research advocated for such approaches being located in a broader public health policy framework (3.1, 3.2, 3.3, 3.4).

2. Building directly on this research, Clarke, Wilkinson, and Keyes were awarded an ESRC grant (2014-2016) to conduct a secondary data analysis of the Healthbridge interview dataset. The project **Inciting Dialogue and Disruption in Dementia (IDDD)** analyzed the data with input from 34 people with dementia at eight workshops. Partnered with Alzheimer Scotland and the Mental Health Foundation, the project highlighted and articulated the subtle and often hidden shifts that can occur in relationships, which can lead to people with dementia experiencing social exclusion (3.5). Key findings included:
 - Dementia can compromise the ability to adhere to presumed but unspoken social expectations, leading to a gradual withdrawal of friends and withdrawal of oneself culminating in social exclusion (3.5).
 - Peer support, which is underpinned by a set of social expectations of peer identity and mutual self-support, can restore a sense of social inclusion (3.5, 3.6).
 - In order to better support social inclusion, more attention should be given to the collective nature of care, including peer support, families, communities and professionals, with people with dementia recognised as playing an active role within this network (3.5, 3.6).
 - New social expectations based on co-operative listening, co-operative action, and co-operative caring lead to enhanced solidarity with people with dementia and a society where they can be included in community, social and public life (3.5, 3.6).
3. Clarke led the **Risk & Resilience in Dementia (RRD)** project, funded by North of Tyne Primary Care Trust (2011-12). The project examined dementia in everyday life and involved interviewing people with a diagnosis of dementia, their family carers and professional staff in rural and urban areas, and asked about their understanding of risk in everyday life. The research team found that people's familiarity with people and place helps to nurture a "narrative citizenship" in which they can tell a story of being included in society. However, they note that this familiarity with place may also create a social barrier and a sense of estrangement leading to social and psychological detriment. Clarke and Wilkinson coined the term "silent harms" to describe how risk perception and efforts to safeguard people with dementia can limit or remove choices and activities, reduce well-being, and disenfranchise people with dementia (3.6, 3.7). They proposed a range of factors that impact on the development of dementia friendly communities. (PI Clarke Northumbria University 1/7/11-31/7/11, Edinburgh University 1/8/11-31/12/12).

3. References to the research

3.1 Clarke, C.L., Keyes, S.E., Wilkinson, H., et al. (2013) *Healthbridge: The National Evaluation of Peer Support Networks and Dementia Advisers in implementation of the National Dementia Strategy for England*. A Department of Health Policy Research Programme Project (Ref: 025/058). <https://www.gov.uk/government/publications/peer-support-networks-and-dementia-advisers-evaluation>

3.2 Keyes, S.E., Clarke, C.L., Wilkinson, H. et al. (2014) "We're all thrown in the same boat...": A qualitative analysis of peer support in dementia care. *Dementia: the international journal of social research and practice*. Published online 17/4/14. DOI: <https://doi.org/10.1177/1471301214529575>

3.3 Clarke, C.L., Keyes, S.E., Wilkinson, H., Alexjuk, J., Wilcockson, J., Robinson, L., Corner, L. & Cattan, M. (2014) *Organisational Space for Partnership and Sustainability: Lessons from the Implementation of the National Dementia Strategy for England*. Health &

Social Care in the Community. Published online: 22 SEP 2014 DOI:

<https://doi.org/10.1111/hsc.12134>

3.4 Clarke, C.L., Keyes, S.E., Wilkinson, H., Alexjuk, J., Wilcockson, J., Robinson, L., Reynolds J., McClelland S., Hodgson P., Corner, L. & Cattan, M. (2016) "I just want to get on with my life": A mixed methods study of active management of quality of life in living with dementia. *Ageing & Society*. DOI: <https://doi.org/10.1017/S0144686X16001069>

3.5 Clarke, C.L., Wilcockson, J., Watson, J., Wilkinson, H., Keyes, S., Kinneard, L. & Williamson, T. (2018) Relational care and co-operative endeavour: Reshaping dementia care through participatory secondary data analysis'. *Dementia: the international journal of social research and practice* DOI: <https://doi.org/10.1177/1471301218795353>

3.6 Clarke, C.L & Bailey, C. (2016) Narrative citizenship, resilience and inclusion with dementia: On the inside or on the outside of physical and social places. *Dementia: the international journal of social research and practice* 15(3) 434-452 DOI:

<https://journals.sagepub.com/doi/10.1177/1471301216639736>

3.7 Clarke, C.L., Wilkinson, H., Keady, J. and Gibb, C. (2011) *Risk Assessment and Management for Living Well with Dementia*, London, Jessica Kingsley (Can be supplied by HEI on request)

4. Details of the impact

The NHS estimate that one in 14 people over the age of 65 in the UK have dementia, and the condition affects one in six people over 80. By 2025, the number of people with dementia in the UK will be more than one million. Edinburgh researchers have raised awareness of living with dementia and associated service needs, and improved the design and availability of dementia services for people in the UK and beyond.

Reforming policy and service delivery in England

Dementia Advisors help people to come to terms with a diagnosis, and to navigate the care and support that is available. The Healthbridge research project evaluated and identified the effectiveness of the Dementia Advisor role (3.1), and the findings substantially influenced government policy and action. In Oct 2013, Norman Lamb MP, then the Minister of State for Care and Support, wrote to all social service commissioners of dementia services in England to recommend implementation of the research findings: "*In my view, the report provides strong evidence of the value of both measures as part of a program of post diagnostic support for people with dementia and their carers*" and stated, "*These evaluation findings provide important evidence in pursuing the improvement needs. The information will I believe be of considerable value to local commissioners in taking decisions on local dementia service*" (5.1).

As a result of Lamb's recommendation to service commissioners, by 2016, 91% of commissioners (81 of 89 commissioners who responded to an IPSOS MORI survey) across England provided Dementia Advisor services (5.2, p.5). There are no formal records of the number of Dementia Advisors across England. However, based on the IPSOS MORI survey, Clarke and Wilkinson estimate that 207 services have been commissioned over five years, each with an average of two Dementia Advisors (who worked with between 100 and more than 2000 people living with dementia per year). As such, the large-scale implementation and expansion of Dementia Advisor services (based on the Healthbridge evaluation) could provide support for approximately 200,000 people with dementia each year in England (over one million people since 2014) (5.2).

The Healthbridge research evaluation provides evidence of the value of peer support and social networks and has contributed to shifting policy ideas towards expanding models of social support. In November 2013, the National Clinical Director for Dementia and Older People Mental Health, NHS England and NHS Improvement wrote a blog for the NHS identifying the need to increase diagnosis and post-diagnosis support. He promoted the Healthbridge research stating: "*The evaluation provides positive evidence on the value of*

these services. It shows that dementia advisers and peer support networks have benefits to the wellbeing and quality of life of people with dementia and their carers” (5.3, p.2).

The Healthbridge evaluation also directly influenced local commissioning and service decisions in regards to peer support networks and interventions. For example through:

- Informing the Kingston Upon Thames’ dementia strategy 2015-2020 by underpinning the commitment to sustain local peer support and training networks (5.4, p.9), and increasing support in the community.
- Commissioning peer support and befriending services in Hammersmith and Fulham, Kensington and Chelsea, and Westminster (5.5, p.70) and in East Sussex County Council (5.6, p.91).
- Effecting the prioritisation of the need for people with dementia to play an integral part in commissioning, training and providing support to other people with dementia in Camden (5.7, p.5). Camden Council put plans in place to address the need for face to face, word of mouth communication with people with dementia and their care partners, as well as regular e-bulletins to be disseminated through groups or Dementia champions (5.7, p.31).

Advancing Policy and Practice in Wales and Scotland

Research findings on risk and place from the RRD project (3.6, 3.7) contributed to shifting policy and service debates at the sub-national devolved level in two influential ways. First, through adoption in the Care Council for Wales’ “Dementia Learning and Development Framework for Wales” (2016), a framework which guides learning and development across all health and social care services to improve professional practice in Wales (5.8). The framework drew directly on the research into “silent harms” (3.7), and adopted Clarke and Wilkinson’s terminology to state that it is “*unacceptable*” for services who support people with dementia to be risk-averse and preoccupied with physical safety, rather than the achievement of meaningful quality of life (p.33). It also states that care professionals must understand the concept of “silent harms” and the implications for practice (p.32).

Second, RRD research (3.6, 3.7) influenced the views of the Care Inspectorate in Scotland regarding risk and subsequently how it trains inspectors. According to the Dementia Lead, Care Inspectorate:

“The predominant mind set among service providers has been risk averse with a worry about getting into trouble. The Care Inspectorate have tried to open up the discussion about sharing risk - so that risk taking doesn’t just fall on individual services but is shared with families and the wider health and social care team. Thinking about ‘silent harms’ has been a very important aspect of this and shifting thinking away from focussing on stopping physical risk to other harms that might be caused e.g. due to a lack of activity, or the risks for people who are very withdrawn which are not necessarily obvious - this is new thinking for service providers and the Care Inspectorate. Thinking about risk, influenced by Charlotte’s work, is also now part of the Short Observational Framework for Inspection (SOFI) training for inspectors” (5.9).

Shaping public and practitioner perception through performing arts

Shaping public perception is critical to creating an environment in which people with dementia can live more inclusive lives. Clarke and Wilkinson partnered with Skimstone Arts to create films and plays based on the RDD and IDDD research findings (3.5, 3.6). Based on RDD, the play *Jack and Jill & The Red Postbox* (and linked film titled *Jack & Jill*) addressed risk in everyday life and the importance of place and familiarity for people living with dementia. Based on IDDD, the film *Michael’s Map* (and linked play titled *The Ties That Bind*) addressed the importance of social relationships and risk theory for the care by, for and about people experiencing dementia.

The play **Jack and Jill & the Red Post Box** was performed 34 times (including in the August 2013 Edinburgh Fringe Festival) to 896 audience members: *“This was a moving and educational experience, encouraging empathy and an understanding of the experience of dementia that just wouldn’t be possible with more traditional-style lectures or publications. It is easy to see how this performance can work in a variety of settings, from theatres and art spaces to care homes and hospitals”* (CEO from Partnership for Palliative Care) (5.10, p.3). *“A sensitive performance about a sensitive subject. The cast managed to bring a sense of realism about what it’s like to live with someone who has dementia... I manage a nursing home and feel all my staff would benefit from watching it”* (Edinburgh Festival website comments) (5.10, p.3). The play was the focus of an ESRC Festival of Social Science event in Nov 2013 and was subsequently selected as a case study in the 2015 independent review of the impact of the Festival for the ESRC (5.11, pp.28-30). The associated/subsequent film **Jack & Jill (2015)** has been viewed 994 times on Vimeo (5.10, p.6).

Through the collaboration with Skimstone Arts, Clarke and Wilkinson shared key messages from the IDDD project (3.5, 3.6) about the subtle ways in which the early stages of dementia begin to insidiously affect close relationships, contributing to gradual social exclusion, but also how a meaningful and hopeful life with dementia can be re-narrated within co-operative caring relationships. The film **Michael’s Map** (launched October 2016) was viewed 756 times on Vimeo in addition to five screenings to a total of 279 audience members (5.10, pp.8 - 9). This included a dementia conference in Sweden (approximately 100 delegates), two screenings to 90 student nurses and 20 members of staff respectively at Peking University, and a screening at the Scottish Dementia Congress (approximately 40 delegates). The play **The Ties that Bind** was performed 15 times to audiences in Keswick, Thirsk, Northallerton, Hexham and at the Edinburgh Fringe Festival 2017 (5.10, p.13).

As a result of connecting with the public through films and live performances, the research has generated awareness and increased capacity building and skills to understand and respond to dementia in local communities (5.10). Through this collaboration, Skimstone Arts has also been able to develop as a small business. They were awarded a grant of GBP33,350 by the Arts Council of England for further business development, mentoring, and to develop a national tour of **Jack and Jill & the Red Postbox** (5.12, p.3).

5. Sources to corroborate the impact

5.1 Letter from Norman Lamb MP to all Chairs of Local Government Association and Heads of Adult Social Care in England (October 2013)

5.2 IPSOS MORI survey

5.3 Blog by National Clinical Director for Dementia and Older People Mental Health, NHS England and NHS Improvement

5.4 Kingston Upon Thames Dementia Strategy 2015-2020

5.5 Dementia A Joint Strategic Needs Assessment (JSNA) Report for Hammersmith and Fulham Kensington and Chelsea Westminster

5.6 Dementia Joint Strategic Needs Assessment November 2016 Public Health Department East Sussex County Council

5.7 Review of the Dementia Care Pathway in Camden (August 2014-February 2015) Sophie Cottrell and Barbara Wilson

5.8 Good Work. A Dementia Learning and Development Framework for Wales

5.9 Care Inspectorate in Scotland statement

5.10 Skimstone Arts productions and feedback: (<http://skimstone.org.uk/>)

5.11 ESRC Impact of the Festival of Social Science

5.12 Skimstone Arts Evaluation of Grant for the arts funded development activity