

Institution: The Open University

Unit of Assessment: C22 Social Work and Social Policy

Title of case study: Applying research evidence to improve the life and end-of-life experience of older people

1. Summary of the impact

This case study demonstrates the impact of an inter-related body of research, undertaken by The Open University's (OU) Centre for Ageing and Biographical Studies, upon the ways in which older people experience everyday ageism, housing and design, and end-of-life care. The research has provided evidence for charities and non-governmental organisations (NGOs) seeking to shape government legislation, initiate action on age-friendly environments, and to change care practice. As a result it has helped inform the UK's Equality Act 2010, new guidance on toilets in public spaces, user-friendly extra-care housing and an exemplary training programme on end-of-life care in care homes.

2. Underpinning research

The research behind these impacts relates to seven projects undertaken by members of the OU's Centre for Ageing and Biographical Studies (CABS), founded in 1995.

Everyday ageism was the central concern of the 'Research on Age Discrimination' (RoAD) project (2004–07) led by Bytheway (Consultant, Senior Research Fellow, 1991–2009) with Peace (Senior Lecturer, Professor), Holland (Research Fellow) and Ward (Research Assistant). Help the Aged (now Age UK) initiated this collaborative project with the OU in 2003 to engage older people in participatory research, including online networking, diary keeping and – significantly – training older co-researchers to interview others about daily experiences of ageism. The UK-wide findings identified discrimination in public places, health service delivery, the marketplace, appearance and fashion, sexuality and sexual orientation [3.1,5.1–5.4].

Three of the projects dealt with particular concerns of ageing and the environment namely planning, housing and design. 'Social interaction in urban public places' (2005–07) funded by the Joseph Rowntree Foundation (JRF) was led by Peace who was Principal Investigator (PI) with Holland, Katz (Lecturer, Senior Lecturer) and Clark (Research Assistant). The geographical focus was the town of Aylesbury, Bucks, where trained co-researchers spent a year observing how different generations shared, contested and avoided public spaces. These observations led to recommendations that facilitate age-friendly communities through using public resources to create accessible public toilets and appropriate street furniture [3.2,5.5]. Ageing or 'staying' in place was also central to the second study, 'Attitudes of Jewish people regarding extra-care housing' (2005–06) led by Katz (PI) and Holland [3.3,5.6]. This used focus group discussions on the topics of accommodation and care, the need for support and the importance of personal space within the physical environment. Building on this work, Holland and Peace acted as consultants for *Silverville*, a television programme by the BBC about daily life in extra-care housing.

The third project, 'Transitions in kitchen living' formed part of the UK Research Councils' New Dynamics of Ageing programme, and considered the effect of contemporary kitchen design upon older people living in both supportive and normal domestic housing, alongside related experiences of kitchens from the past and the possible role of future assistive technology (2009–12). For this work, Peace (PI), Percival (Research Assistant) and Scicluna (PhD student) collaborated with colleagues at Loughborough University's Design School. Their findings show how personal mobility, reach, dexterity, vision and hearing are all impacted upon by poor design, and how kitchens can be made to enhance personal well-being [5.7].

Finally, three connected projects, all funded by the Department of Health, were concerned with end-of-life care: 'Death and dying in residential homes for older people', 'Investigating the training of staff' and 'Developing training materials' (1995–2002). These featured Katz (PI), Sidell (Lecturer, Senior Lecturer to 2003) and Komaromy (Research Assistant, Lecturer, Senior Lecturer) [3.4,3.5,5.7–9]. Involving a phased national study of one hundred care homes, the research

demonstrated how care staff need to recognise and put into practice end-of-life care for frail older people, acknowledging the importance of their personal needs and wider relationships. The findings have since formed the basis of important training materials.

3. References to the research

3.1 Bytheway, B., Ward, R., Holland, C. and Peace, S. (2007) *Too Old: Older People's Accounts of Discrimination, Exclusion and Rejection*. The Open University/Help the Aged. Available online at: <http://www.open.ac.uk/hsc/assets/h4bwtxdy7tjqvhe2.pdf>.

3.2 Holland, C., Clark, A., Katz, J. and Peace, S. (2007) *Social Interactions in Urban Public Places*. York: Joseph Rowntree Foundation. Available online at: <http://www.jrf.org.uk/sites/files/jrf/2017-interactions-public-places.pdf>.

3.3 Holland, Caroline, A. and Katz, J. S. (2010) 'Cultural identity and belonging in later life: Is extra care housing an attractive concept to older Jewish people living in Britain?' *Journal of Cross-Cultural Gerontology*, 25 (1), pp 59-69.

3.4 Komaromy, C., Sidell, M & Katz, J. (2000) 'The quality of terminal care in residential and nursing homes', *International Journal of Palliative Care*, 6 (4) pp192-200.

3.5 Katz, J. and Peace, S. (eds) (2003) *End of Life in Care Homes: a palliative approach*, Oxford University Press: Oxford, pp 205. 'Highly Commended' in the 2004 Medical Book Competition by the British Medical Journal.

4. Details of the impact

This body of work has had substantial impact, influencing policy and practice in the areas of age discrimination, design and end-of-life care.

Impact on policy

(i) The RoAD research was influential in the joint response given by Help the Aged/Age Concern, (now Age UK), first to the National Equality Panel, part of the UK Discrimination Law Review (2007/08), and second in evidence submitted to the UK Parliamentary Joint Committee on Human Rights (2008/09). The case studies and findings from the research also formed the evidence base for Help the Aged's 'Just Equal Treatment' campaign, which won a Third Sector Excellence Award in 2008 and was cited by the judging panel as 'an outstanding example of persistently promoting matters of social justice to MPs and ministers and persuading them to change the law'. During the process of bringing forward the Equalities Bill (2008), now the Equalities Act (2010), Harriet Harman MP (then Secretary of State for Equalities) referred to the campaign as 'evidence that has made it imperative for us to act' [5.1 - 5.4].

(ii) In October 2008, JRF gave documentary evidence to a House of Commons Select Committee entitled *The Provision of Public Toilets*. This cited The Open University's research into the location and design of toilets and the anxiety of some older people about encountering anti-social behaviour in such public spaces. As a result of the JRF evidence, the subsequent parliamentary report recommended that 'local authorities can and should exercise existing legislative powers to prevent anti-social behaviour', and that 'local authorities study the benefits and cost effectiveness of providing attended public toilets, or at least ensuring regular inspections, so that the public regains its confidence in using them' [5.5].

Impact on practice

(iii) When central government funding became available for the development of extra-care housing in England, local decision makers in the Jewish community were presented with the question of how to address cultural and age-friendly issues. While participants wished to live in locations close to Jewish facilities such as the synagogue, the direct influence of Katz and Holland's research can be seen in the design of a care facility by Jewish Care, which provides enhanced space standards, even within two bedroom units, making a highly positive impact upon the lives of older people and establishing a model for future design [5.6].

(iv) The capacity to influence both the setting and the design of living environments for older people is clearly evident in the ongoing outcomes of the 'Transitions in Kitchen Living (TiKL)' study.

Peace and Maguire were invited to address the British Standards Institution's B/559 Access to Buildings for Disabled People Committee, in February 2012, during its period of consultation for new guidance [5.7]. The chartered architects practice, Archadia, have used the TiKL research when developing kitchen design in supported housing for the Almshouse Associations. Renee Mascari, Chief Executive of the Kitchens Bedrooms Bathrooms National Training Group (good practice training for the construction industry) following a feature on BBC's 'You and Yours' has told us that: 'I support all you said ... and as someone who has designed kitchens for nearly forty years as well as someone who teaches the principles of kitchen design, I continually promote all efforts to support inclusive design' (5.8, email 27 April 2013).

(v) Our research on end-of-life care for people living in nursing homes led to the development of facilitated learning for those who work with older people in care homes. Training packs on palliative care and bereavement were developed in collaboration with Macmillan Cancer Support, and since 2011 there have been two print runs with over 8000 packs being distributed to hundreds of UK care homes. Adrienne Betteley, Palliative and End of Life Care Programme Manager at Macmillan, has told us that, 'some of the positive comments from the facilitators were about the ways in which the care home staff were really improving their skills, knowledge and confidence; and it was really starting to change culture within the care home sector' <http://www.open.ac.uk/health-and-social-care/main/research/research-themes/death-dying-and-bereavement>. These palliative care materials are used to support the national Gold Standards Framework for care homes, a national training programme started in 2004 and supported by the four major trade associations in this sector [5.9 and 5.10]. A group of seven homes in Midlothian, Scotland reported that as a result of using the Macmillan/OU materials 'There was a significant improvement in the following areas: care of the dying, control of symptoms, continuity of care, carer support (families) and continued learning' (Hockley et al., 2008, p. 4).

5. Sources to corroborate the impact

1. Help the Aged evidence submitted to the Parliamentary Joint Committee on Human Rights (2008–09) <http://www.publications.parliament.uk/pa/jt200809/jtselect/jtrights/169/169we29.htm>
2. Help the Aged's 'Just Equal Treatment' campaign: Jopling, K. (2007) 'Older people deserve Just Equal Treatment', *Working with Older People*, vol. 11, no. 2, pp. 24–27.
3. Third Sector Excellence Award: <http://www.thirdsector.co.uk/news/862796/> and <http://www.thirdsector.co.uk/Communications/article/862796/Third-Sector-Excellence-Awards-Big-Impact>
4. Age UK blog: <http://ageukblog.org.uk/tag/bill-bytheway/>
5. Joseph Rowntree Foundation evidence to Select Committee: <http://www.publications.parliament.uk/pa/cm200708/cmselect/cmcomloc/636/636.pdf> (Report para 32–33 and Evidence p. 30)
6. Jewish Care: <http://www.jewishcare.org/independent-living-apartments-for-survivors>
7. Invited presentation to British Standards Institution B/559 Access to Buildings for Disabled People Committee, 20 February 2012 during consultation for new standard published summer 2013 – BS9266:2013 Design of accessible and adaptable general needs housing – Code of Practice.
8. 'You and Yours' <http://www.bbc.co.uk/programmes/p01818th>
9. Macmillan/OU Palliative Care materials: <http://be.macmillan.org.uk/be/p-19455-foundations-in-palliative-care-participant-pack.aspx>
10. Hockley, J., Watson, J. and Murray, S. (2008) The Midlothian 'Gold Standards Framework in Care Homes Project', Primary Palliative Care Research Group, University of Edinburgh/St Columbia's Hospice.

Sources to verify the impact

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