A rights-based approach to dementia-inclusive public spaces

People living with dementia and their carers in rural and regional areas face particular challenges around loneliness and isolation, heightened by a lack of access to dementia-inclusive outdoor and public spaces. **Carmela Leone**, **Rachel Winterton** and **Irene Blackberry** are undertaking a study in rural and regional Victoria exploring the rights of people with dementia and carers to participation, inclusion and access to public space

Without access to public spaces, people living with dementia and their carers are denied opportunities to create and build social relationships and participate in their communities. For those living in rural areas, the combination of a rural setting and dementia symptoms can lead to further exclusion (Forbes *et al* 2011).

People living with dementia have a right to participate in community life (Downs 2013), and dementia-friendly communities need to ensure they are inclusive of and accessible for people living with dementia – otherwise they inadvertently encourage segregation through defining people merely by a diagnostic label (Rahman & Swaffer 2018).

This article argues for a rights-based approach to dementia-inclusive spaces in response to the stigma, isolation and social exclusion experienced by both people living with dementia and carers, with a focus on those living in rural and regional communities.

Adapting streets to include distinctive landmarks such as street furniture or gardens to act as visual cues can contribute to creating 'dementia-friendly' public spaces

Stigma and social exclusion

People living with dementia often experience social exclusion due to predominantly negative public perceptions (Biggs *et al* 2019). Stigma associated with dementia contributes to social exclusion and isolation, even though people living with dementia are able to perform usual activities in the early stages and, with some adaptation of activities, in the middle and later stages (Alzheimer's Disease International 2012). Despite heightened public awareness campaigns, many people are still unaware of the progression of dementia and hold inaccurate assumptions about its effects, as well as negative stereotypes about behaviours associated with dementia (Alzheimer's Disease International 2012).

Attitudes and assumptions about people living with dementia contribute to the way that public spaces are designed, planned and used. Misconceptions that dementia is a normal part of ageing, and that nothing can be done to improve the wellbeing of people living with dementia, have resulted in less prioritisation and action among policy makers (Banerjee 2010). Outdoor environments and public spaces such as parks and shopping centres, are rarely thought of as spaces where people living with dementia might spend time and thus, accessibility and amenities for people living with dementia are often neglected (Blackman *et al* 2003).

A lack of understanding around the effects of impairment and the practical difficulties experienced by people living with dementia has resulted in the failure to adapt or design outdoor environments like streets and gardens to enable people living with dementia and carers to remain active and engaged (Milligan & Thomas 2016).

Ensuring footpaths are wide, flat and not slippery, and adapting streets to include distinctive landmarks such as street furniture or trees at junctions (Mitchell & Burton 2010) and gardens to include distinctive entrances, with ornaments and bright or scented plants as visual cues (Mitchell *et al* 2003) can contribute to creating 'dementia-friendly' public spaces. Public spaces that are unsafe or inaccessible for people living with dementia are not only due to a neglect of accessibility needs, but also because of ableist values, that is, discriminatory attitudes and assumptions that exclude people with disability, which are reflected in the spaces created by designers and planners (Blackman *et al* 2003).

Perceptions and responses to dementia in the public domain generate their own forms of exclusion and disadvantage, both for people living with dementia and their carers (Biggs *et al* 2019). Stigma associated with dementia can negatively affect people living with dementia and their carers (Phillipson *et al* 2018), and for both parties, their roles within their communities and social networks are threatened early in the dementia journey (Henwood & Downs 2014). Furthermore, people living with dementia and their carers experience social exclusion through the loss of friends and shrinking social circles (Biggs *et al* 2019).

Just as people living with dementia are at risk of exclusion and isolation in their communities (Miles & Pritchard-Wilkes 2018), so too are their carers (Greenwood *et al* 2018). In rural areas, carers of people living with dementia can face particular challenges around loneliness and isolation (Keating *et al* 2011), and the lack of anonymity often characteristic of rural communities may limit their participation in local support groups and carer activities (Forbes *et al* 2011).

For people living with dementia in rural communities, the combination of a rural setting and dementia symptoms can lead to further exclusion (Forbes *et al* 2011). Issues such as distance and relative isolation, access to services, a lack of resources, and a fear of stigmatisation associated with living in small communities, exacerbate the exclusion experienced by people living with dementia (Forbes *et al* 2011).

Dementia-friendly communities

There are dementia-friendly communities around the world, addressing the stigma and social exclusion experienced by people living with dementia and their carers (Phillipson *et al* 2018). Definitions of 'dementia-friendly' and 'community' are varied, and a dementia-friendly community can cover a diverse range of activities, projects and/or initiatives (Williamson 2016). It may be a place or culture, an organisation, a group of individuals, a virtual community, or social and physical environments (Lin 2017).

Dementia-friendly communities can be geographical communities or communities of interest with the aim of including, empowering and supporting people living with dementia and their carers in all areas of life, from services to public transport (Buckner *et al* 2018). Another recent research project undertaken by our team aimed to bridge the geographical barriers faced by those living in rural areas, by creating a virtual dementia-friendly community called Verily Connect (www.verilyconnect.org.au) (Blackberry *et al* 2019). This is an online meeting place for carers to support each other in a dementia-friendly community.

Despite their growing popularity, there is no single model for what a dementia-friendly community looks like (Biglieri 2018; Williamson 2016), no one template, and definitions of 'dementia-friendly' are varied (Williamson 2016). Diverse models of dementia-friendly communities reflect the reality that each community is in itself diverse and made up of different histories, cultures and perspectives (Williamson 2016).

While the lack of a standard approach to establishing a dementia-friendly community might invite criticism, there are advantages as one size does not always fit all. A diversity of approaches to dementia-friendly communities can inspire different ways of thinking about dementia, particularly where models emphasise participation, inclusion and access for people living with dementia (Williamson 2016).

The rights-based approach

A rights-based approach to dementia considers:

- Human rights
- Inclusion
- Equality
- Participation
- Social justice
- Personhood
- Social model
- The collective
- Home
- Capabilities
- Assets

(Cahill 2018)

Violation of rights

The exclusion of people living with dementia from public spaces and neighbourhoods essentially violates their rights to participation, inclusion and accessibility (Steele *et al* 2019). Moreover, while the rights of people living with dementia are often cited as the foundational basis for dementia-friendly communities, a political understanding of genuine participation is often lacking (Williamson 2016).

Few dementia-friendly communities explicitly identify human rights as a theoretical underpinning (Hebert & Scales 2017), and few focus on rights as a starting point or make explicit reference to a rights-based approach (Buckner *et al* 2019). Consequently, some researchers have suggested that dementia-friendly communities fail to achieve genuine rights-based environments for people living with dementia (Alden *et al* 2018). Notably, some communities aim to be 'dementia-inclusive' as distinct from 'dementia-friendly', aiming for greater depth of activity than initial public engagement and awareness-raising (Chadborn & van der Marck 2019).

A rights-based approach

Calls for a rights-based approach to dementia (see box this page) recognise that people living with dementia face challenges due to social and material/built environments (Alden *et al* 2019; Milligan & Thomas 2016; Thomas & Milligan 2018). Discriminatory attitudes coupled with outdoor environments/public spaces that fail to accommodate the needs of people living with dementia create barriers to social inclusion and community participation.

A rights-based approach to dementia aims to remove socially imposed barriers and challenge human rights violations (Shakespeare *et al* 2019). Furthermore, it repositions the person living with dementia as a citizen, invoking words such as 'entitlement, 'fairness' and 'justice', which can reframe the needs of people living with dementia as legitimate and having value (Bartlett & O'Connor 2010).

Recognising people living with dementia as citizens with rights can help challenge the attitudinal barriers and ableist values that influence the design, planning and use of public space.

A rights-based study

Research currently being undertaken by our team at the John Richards Centre for Rural Ageing Research, La Trobe University in Bendigo, Victoria, uses a rights-based approach to explore attitudes and assumptions towards rights to public space for people living with dementia and carers. The PhD study, which is being funded by, and conducted as part of the Webster Rural and Regional Dementia Care Project, focuses on the rights to participation, inclusion and access, with a view to building a foundation for developing dementia-inclusive environments.

The study involves community stakeholders, people living with dementia, and carers as research participants, and is part of a larger, ongoing project which involves consultation with carers, and working with key stakeholders and community members in the City of Greater Bendigo to improve dementia care pathways within rural and regional Victoria.

The study addresses a knowledge gap relating to understanding attitudes and assumptions that contribute to the lack of access to public spaces for people living with dementia, as while access to the outdoors is essentially a matter of human rights and social justice (Argyle *et al* 2016), people living with dementia continue to be 'left behind' in terms of inclusion and access to built environments (Swaffer 2020).

The study will involve participants from both the regional centre and outer rural areas of Bendigo. In rural communities, strong social networks and informal social support can play an important role in creating dementia-friendly communities (Wiersma & Denton 2016). Social networks are also important to the uptake of care services, as they can facilitate the collection and sharing of health-related information and have the potential to change patterns of access to health care (Griffiths *et al* 2012). Public spaces facilitate social connection (Clark 2009), and as spaces for dialogue and exchange, public spaces are therefore important for people living with dementia and their carers (Charras 2020).

The study is seeking to attract participants (see below) from diverse social networks in regional and rural areas, including Heathcote, Victoria, where a dementia-friendly village project is currently being planned (with Irene Blackberry as advisor, who is currently working with Rachel Winterton to develop a research program for the Heathcote project).

Findings from the City of Greater Bendigo PhD study will inform rights-based dementia education and awareness-raising programs. These will be aimed at Bendigo community stakeholders and community groups that play a role in the design/planning of public spaces, such as local government, or that are involved in the use of public space, by way of commercial or community activities, such as businesses that operate shopping centre cafes or organisations that conduct walking groups. The implementation of these programs can then form the foundation for a rights-based dementia-friendly community in the City of Greater Bendigo. The PhD study will be completed in 2022. ■

To hear Carmela Leone discuss the project described in this article, visit: https://youtu.be/bt_ly8RncBI. For more information about The John Richards Centre for Rural Ageing Research projects visit www.latrobe.edu.au/jrc

References

Alden S, Wigfield A, Kispeter E, Karania, V (2019) Changing The Narrative: The Role Of Frontline Worker Attitudes And Beliefs In Shaping Dementia-Friendly Services In England. *Disability & Society* 34(5) 775-796.

Alzheimer's Disease International (2012) *World Alzheimer Report 2012: Overcoming The Stigma Of Dementia*. Available at: www.alz.co.uk/research/WorldAlzheimerReport2012.pdf.

Argyle E, Dening T, Bartlett, P (2016) Space, The Final Frontier: Outdoor Access For People Living With Dementia. *Aging & Mental Health* 21(10) 1005-1006.

Banerjee S (2010) Living Well With Dementia – Development Of The National Dementia Strategy For England. *International Journal of Geriatric Psychiatry* 25(9) 917-922.

Bartlett R, O'Connor D (2010) *Broadening The Dementia Debate: Towards Social Citizenship*. Bristol, UK: Policy Press.

Biggs S, Haapala I, Carr A (2019) *Dementia In The Public Domain Voice And Age-Based Perspectives On Dementia, Social Disadvantage And Public Health Campaigning*. Melbourne: University of Melbourne.

Biglieri S (2018) Implementing Dementia-Friendly Land Use Planning: An Evaluation Of Current Literature And Financial Implications For Greenfield Development In Suburban Canada. *Planning Practice & Research* 33(3) 264-290.

Blackberry I, Wilding C, Perkins D *et al* (2019) Virtual Dementia-Friendly Rural Communities. *Australian Journal of Dementia Care* 7(6) 11-13 (December 2018/January 2019).

Blackman T, Mitchell L, Burton E, Jenks M, Parsons M, Raman S, Williams K (2003) The Accessibility Of Public Spaces For People With Dementia: A New Priority For The 'Open City'. *Disability & Society* 18(3) 357-371.

Buckner S, Mattocks C, Rimmer M, Lafortune L (2018) An Evaluation Tool For Age-Friendly And Dementia Friendly Communities. *Working With Older People* 22(1) 48-58.

Buckner S, Darlington N, Woodward M *et al* (2019) Dementia Friendly Communities In England: A Scoping Study. *International Journal of Geriatric Psychiatry* 1-9.

Cahill S (2018) *Dementia and Human Rights*. Bristol, UK: Policy Press.

Chadborn N, Van der Marck M (2019) Illuminating Community Services And Assets Towards Better Dementia Care. *Perspectives in Public Health* 139(3) 125.

Charras K (2020) Human Rights, Design And Dementia: Moving Towards An Inclusive Approach. In Fleming R, Zeisel, J, Bennett K (Eds) *World Alzheimer Report 2020: Design Dignity Dementia: Dementia-Related Design And The Built Environment* (1) 113-116. England: Alzheimer's Disease International.

Clark A (2009) From Neighbourhood To Network: A Review Of The Significance Of Neighbourhood In Studies Of Social Relations. *Geography Compass* 3(4) 1559-1578.

Downs M (2013) Putting People – And Compassion – First: The United Kingdom's Approach To Person-Centered Care For Individuals With Dementia. *Journal of the American Society on Aging* 37(3) 53-59.

Forbes D, Ward-Griffin C, Kloseck M, Mendelsohn M, St-Amant O, DeForge R, Clark K (2011) Her World Gets Smaller And Smaller With Nothing To Look Forward To: Dimensions Of Social Inclusion And Exclusion Among Rural Dementia Care Networks. *Online Journal of Rural Nursing & Health Care* 11(2) 27.

Greenwood N, Mezey G, Smith R (2018) Social Exclusion In Adult Informal Carers: A Systematic Narrative Review Of The Experiences Of Informal Carers Of People With Dementia And Mental Illness. *Maturitas* 112 39-45.

Griffiths F, Cave J, Boardman F, Ren J, Pawlikowska T, Ball R, Clarke A, Cohen A (2012) Social Networks – The Future For Health Care Delivery. *Social Science & Medicine* 75(12) 2233-2241.

Hebert DA, Scales K (2017) Dementia Friendly Initiatives: A State Of The Science Review. *Dementia* 0(0) 1-38.

Henwood C, Downs M (2014) Dementia-Friendly Communities. In: M Downs, B Bowers (Eds) *Excellence In Dementia Care: Research Into Practice* 20-25. Berkshire: Open University Press.

Keating N, Swindle J, Fletcher S (2011) Aging In Rural Canada: A Retrospective And Review. *Canadian Journal on Aging/La Revue Canadienne du Vieillissement* 30(3) 323-338.

Lin SY (2017) 'Dementia-Friendly Communities' And Being Dementia Friendly In Healthcare Settings. *Current Opinion In Psychiatry* 30(2) 145.

Miles S, Pritchard-Wilkes V (2018) Dementia-Friendly Housing Charter. *Working With Older People* 22(2) 76-82.

Milligan C, Thomas CJ (2016) Dementia And The Social Model Of Disability: Does Responsibility To Adjust Lie With Society Rather Than People With Dementia? *Signpost* 21(3) 5-16.

Mitchell L, Burton E, Raman S, Blackman T, Jenks M, Williams K (2003) Making The Outside World Dementia-Friendly: Design Issues And Considerations. *Environment and Planning B: Planning and Design* 30(4) 605-632.

Mitchell L, Burton E (2010) Designing Dementia-Friendly Neighbourhoods: Helping People With Dementia To Get Out And About. *Journal of Integrated Care* 18(6) 11-18.

Phillipson L, Hall D, Cridland E, Fleming R, Brennan-Horley C, Guggisberg N, Frost D, Hasan H (2018) Involvement Of People With Dementia In Raising Awareness And Changing Attitudes In A Dementia Friendly Community Pilot Project. *Dementia* 0(0) 1-16.

Rahman S, Swaffer K (2018) Assets-based Approaches And Dementia-Friendly Communities. *Dementia* 17(2) 131-137.

Shakespeare T, Zeilig H, Mittler P (2019) Rights In Mind: Thinking Differently About Dementia And Disability. *Dementia* 18(3) 1075-1088.

Steele L, Swaffer K, Phillipson L, Fleming R (2019) Questioning Segregation Of People Living With Dementia In Australia: An International Human Rights Approach To Care Homes. *Laws* 8(3) 18.

Swaffer K (2020) Disability Rights, Enabling Design And Dementia. In Fleming R, Zeisel, J, Bennett K (Eds) *World Alzheimer Report 2020: Design Dignity Dementia: Dementia-Related Design And The Built Environment* (1) 117-118. England: Alzheimer's Disease International.

Thomas C, Milligan C (2018) Dementia, Disability Rights And Disablism: Understanding The Social Position Of People Living With Dementia. *Disability & Society* 33(1) 115-131.

Wiersma EC, Denton A (2016) From Social Network To Safety Net: Dementia-Friendly Communities In Rural Northern Ontario. *Dementia* 15(1) 51-68.

Williamson T (2016) *Mapping Dementia-Friendly Communities Across Europe*. Available at: https://bit.ly/3mWecJN.

■ **'Dementia-friendly communities in practice', see Research News p42.**

■ From left: Carmela Leone is a PhD candidate with the Webster Rural and Regional Dementia Care Project, at the John Richards Centre for Rural Ageing Research, La Trobe University; Dr Rachel Winterton is a Senior Research Fellow at the John Richards Centre for Rural Ageing Research, La Trobe University; and Professor Irene Blackberry is the John Richards Chair of Rural Ageing and Aged Care Research and Director of the John Richards Centre for Rural Ageing Research, La Trobe University. If anyone is interested in learning more about this study, please contact Carmela at C.Leone@latrobe.edu.au