



Australian Government

NHMRC National Institute for Dementia Research

Roundtable: World Dementia Council: The meaningful dementia friendly initiatives review

12:30pm – 2:00pm AEST, 26 September 2019, Hyatt Regency Sydney

Communiqué

Invited representatives from the dementia research sector, dementia advocates, Department of Health, Dementia Australia and local Councils engaged in dementia friendly community (DFC) initiatives participated in a two-hour Roundtable to discuss, and provide input to, the World Dementia Council's 'Meaningful dementia friendly initiatives review'.

Lenny Shallcross, Executive Director World Dementia Council, provided background to the review, and the history of the DFC commitment undertaken by the G8 London Dementia Summit in 2013. There has been substantial growth since 2013 in 'dementia friendly' and 'age friendly' initiatives, often with overlap between the two. However, there is considerable diversity associated with these initiatives: in their design, provision, delivery and assessment; in their geographical reach; and in the impact they intend to have. In addition, there is an increasing recognition of the need to establish what evidence of impact there is for these initiatives. Based on this, the World Dementia Council is conducting a review throughout 2019 to identify the key evidence that exists and evidence gaps, with the aim of developing a toolkit to provide support to member nations – for communities and policy makers – looking to develop dementia friendly communities.

Dr Lyn Phillipson presented on her community-based participatory action research on establishing a dementia friendly community in Kiama, a coastal town of 22,000 residents on the south coast of New South Wales. Dr Phillipson's project was developed as a model to inform future action in Australia, and incorporated a key research and evaluation function from the project's inception. Dr Phillipson described how the Dementia Friendly Kiama project was built on an initial Dementia Australia model, with people living with dementia at the core, and with civic participation at the heart of governance structures. Project activities were developed around World Health Organization (WHO) Age Friendly domains, with the project designed to evolve on a constant knowledge translation cycle; incorporating consultation, knowledge products, and their dissemination and application. Evaluation of the project to date has determined that its impact includes increasing inclusion of people living with dementia, and reduction of dementia stigma in the community through a progressive process of awareness, acceptance, and attitude change.

Following the two opening presentations, participants discussed several key themes emerging from DFC implementation:

Nature of 'community'

Participants discussed whether the size and location (including non-geographic) of the community was a determining factor in a DFC project's success. Participants agreed that having an existing 'sense of community' (i.e. meaningful connections) was an important element in getting a project started and embedded. For example, size of the community was felt to be less important than the existing functions, networks, investments, and assets (social capital) of a community, be it geographic or self-identified. Participants also noted organisations could be considered separately from communities when introducing dementia-friendly initiatives, as they had different and unique organisational structures that could be used to effect change. On the question of the size of communities, it was noted that the international experience suggests that smaller and more cohesive communities provided potentially stronger and more enduring implementation platforms.

Leadership

Discussion centred on whether volunteer-led models could be successful in delivering lasting change. Participants noted that local community-led initiatives often relied on a passionate advocate or 'champion' and, without that person, the initiative's sustainability was vulnerable.

Further discussion focused on the role of local Councils, and the use of formal structures to implement a DFC initiative. Participants agreed that engaged Councils and local Members of Parliament were important for an initiative to gain and retain traction. Dementia Australia can also play a valuable role in ensuring those driving the dementia friendly initiative locally receive appropriate support, guidance and encouragement. Participants also agreed that more effective project models involved a large scale consultation process; that alliances often formed at community engagement events; and that implementation by a diverse group of people, according to their individual capacities, was an effective way to mobilise a strategy.

Difficulty of evaluation

The Dementia Friendly Kiama project took a developmental approach to evaluation, with emergent and continual outcomes feeding back into the project. Generally participants noted that DFC projects relied on a small amount of funding, which limited communities' ability to evaluate. Participants also noted that evaluation or assessment of a project's effectiveness was difficult because it sits between practice, research and community. Participants discussed the need to learn how to do social evaluation; and whether outcomes should be measured on a community-level, national/systematic-level, or both. It was noted that incorporating individual outcomes as well as identifying common indicators of success for DFCs would be helpful.

Language: Dementia or Age Friendly?

Finally, participants talked about the nomenclature of 'dementia friendly' in relation to the success of these initiatives. Participants agreed that using the word 'dementia' was essential to galvanise support for DFC initiatives, and identifying people living with dementia at the centre of the DFC movement. It was noted that Dementia Friendly design and activities were automatically age-friendly. Under a human rights framework, it was also noted that 'friendly' was not conceptually the same as 'inclusive'. While the word 'friendly' appeared to resonate with many community members, it was not explicit in describing the need for inclusiveness at all levels, from the national to the community level. For example, public transport, often found to be a major barrier for people living with dementia, is managed at the state and/or national level, and remains outside the scope of a DFC initiative.

In summary, the main challenges for DFC initiatives going forward were identified as:

1. Projects' reliance on a small number of influential individuals – this is a problem across all social change models.
2. Measuring a project's impact and success - funding and capacity of the project remain key barriers.
3. Defining the purpose and value of evaluation – on a national level, to what extent is measuring change about how people live in a particular community important? Should evaluation be performed on a national or regional level, rather than on the community level?
4. Language: often things that impact a community lie beyond what a project can provide, e.g. public transport. From a broader public policy perspective, both state and national infrastructure need to be inclusive, as this extends to community inclusion. As such, a top down change program that contributes to grassroots movements is required.

Participants

Name	Organisation
Lenny Shallcross (Co-Chair)	Executive Director, World Dementia Council
Maree McCabe (Co-Chair)	CEO, Dementia Australia
Lyn Phillipson (Presenter)	University of Wollongong
Stephanie Ellis (Scribe)	NHMRC National Institute for Dementia Research (NNIDR)
Meagan Ang (Zoom)	Hawkesbury City Council
Janice Besch	NHMRC National Institute for Dementia Research (NNIDR)
Robin Bilston	Department of Health
Adam Chapman (Zoom)	National Health and Medical Research Council
Shane Hardiman	Department of Health
Danijela Hlis (Zoom)	Buderim Dementia Alliance
Susan McCarthy	Dementia Australia
Jade Maloney	ARTD Consultants
Victoria Marshall-Cerins	Dementia Australia
Jo Mond	Department of Health
Maria O'Reilly (Zoom)	CQUniversity
Bobby Redman (Zoom)	Dementia Australia Advisory Committee
Ann Reilly	Dementia Australia
Theresa Scott	University of Queensland
Kaele Stokes (Zoom)	Dementia Australia

Apologies: Phil Hazel, Chair Dementia Australia Advisory Committee, Dennis Frost, Dementia Australia Advocate