Dementia Friendly Communities

19th Asia Pacific Conference of Alzheimer’s Disease International (ADI)

New Zealand

Glenn Rees AM

Chair, ADI
Yesterday I suggested that the concept of dementia friendly has captured the imagination of people around the world.

The dementia friends program was pioneered in Japan in 2005 and most recently adopted in the UK. Both governments provide some funding. There are currently 6.3 million dementia friends with a target of 8 million by 2018 and over 1 million in the United Kingdom.

The program’s aim is to transform people’s perception of dementia by creating dementia friends who commit to learn what it is like to live with dementia though basic training. They then turn that understanding into social actions that lead to the development of dementia-friendly communities.

These social actions can take many forms, for example, by helping out in a dementia café or by raising awareness about dementia among work colleagues, family and friends.

Dementia friends in turn recruit and create more dementia friends.

Business organisations including banks have recognised that it is in their business interests to train staff and make their services more dementia friendly.

There are excellent resources to help Alzheimer’s organisations develop their own approaches on the websites of ADI, the UK Alzheimer’s society and Alzheimer’s Australia.

The concept of dementia friendly communities and the different ways in which it has been implemented around the world is described in two Alzheimer’s disease International publications on dementia friendly-communities.

The concept of dementia friends and dementia friendly communities is important because it marks a fundamental shift from a focus on meeting the physical and health needs of the person with dementia to an approach that recognises the need to support the person to achieve the best quality of life possible.

There are two very different underlying objectives of dementia friendly communities which have as their end goal a better life for people with dementia.

First, the objective of reducing stigma and understanding of dementia by greater awareness and meaningful engagement for persons with dementia of all ages - that is the lived experience approach.

Second, the objective of empowering people with dementia in their own communities by recognising their rights and capabilities so that they feel respected empowered to take decisions about their lives – the rights approach.

The focus on dementia is needed because:
We are only just emerging from centuries of the belief that dementia is an inevitable part of ageing. A positive approach is needed which is direct and moves away from the stereotypes of senile dementia.

Social action that brings together people with dementia and the wider community is perhaps the best form of awareness, if you believe as I do, that social isolation is the consequence for many of a diagnosis of dementia.

It has already proven to have appeal across different cultures and geography.

It has often proved hard to get dementia included within other policies – e.g. ageing cities movement and healthy ageing.

It is important to emphasise the point that dementia is both a social and a medical condition.

Across the world the concept of dementia friendly communities is being given practical expression in four different ways by:

1. Being inclusive and supporting and protecting the rights of a person with dementia.
2. Tackling stigma and lack of community understanding of dementia.
3. Increasing the capability of the health and care workforce and availability of key services.
4. Improving the physical environment – a topic that is central to the ageing cities movement.

There is no one size fits all in designing dementia friendly communities. But to be successful there are some key steps.

First, to involve people with dementia as equal partners.

Second, to determine what action is needed.

Third, to ask people with dementia and other stakeholders if they consider their community to be dementia friendly. And if not, why not.

Fourth, to form local dementia alliances involving businesses, local government, service agencies, medical services and hospitals. This may help attract funds for the project and a project officer.

The model looks like this:

People with disabilities fought hard to achieve their full participation in society on an equal basis with others. We have opportunities to learn from and partner with disabilities organisations.

First as I said yesterday to work with disabilities organisations in monitoring the rights of people with dementia under the Convention on the Rights of Persons with Disabilities (CRPD). ADI for its part has a commitment at the international and national levels to
work within the framework of the Convention on the Rights of Persons with Disabilities to better protect the human rights of people with disabilities.

Second to learn from the Community Based Rehabilitation movement that was founded 40 years ago on the principle of a community based approach to deliver rehabilitation in many low-income countries that were not positioned to deliver rehabilitation services. It has evolved to address the realities of everyday life for people with disabilities and the need to service a strategy involving sectors beyond health for all people with disabilities.

It maybe that CBR has learnt some important lessons that dementia advocates can learn from in thinking about dementia friendly communities in terms of:

- The need for workers able to support the implementation of social action through CBR programmes.
- The need for care in the way the term rehabilitation is interpreted if it is not to be misunderstood and lose the support of Health ministries – because it extends to education, employment or social services.
- Despite the success of CBR the fact that it may only reach 10 per cent of individuals who could benefit from these services.
- The difficulties of gaining inter agency co-operation and co-ordination between the work of non-government agencies, UN agencies and governmental agencies

Thirdly, there is a new training resource, the BRIDGE, to develop the capacities of advocates in disabilities organisations in low and middle income countries to engage and take action in the promotion of an inclusive (all persons with disabilities) and comprehensive (all human rights) CRPD perspective on development. It has been trialled in a number of LMIC countries including in the Asia Pacific. You can read more here.

I am not about to set myself up as an expert on human rights or disabilities – I am reliant on Professor Peter Mittler and Kate Swaffer from Dementia Alliance International (DAI) for advice. But I do want to make the point that we can and should learn from the disabilities movement.

The conclusion is that Alzheimer’s organisations should;

1. Promote the lived experience of people through dementia friendly communities
2. Monitor the rights of people with dementia within the Convention on the Rights of People with Disabilities in partnership with disabilities organisations
3. Learn from the CBR and the BRIDGE

Thank you.