



**Alzheimer's Disease  
International**

*The global voice on dementia*

**DEMENTIA: THE GLOBAL PERSPECTIVE**

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There could not be a better time to give a global perspective on dementia and how we should all be planning our advocacy for 2017 and beyond.

We are at a tipping point in tackling dementia and have the opportunities that ADI and its members have been working for over many decades.

We are within reach of making significant progress on the international stage in the World Health Assembly, acting on human rights and implementing dementia friendly communities and prioritising work in low and middle income countries.

The time to act to take advantage of these opportunities is now.

So, I would like to use the time I have to outline some of the things I believe ADI and country members should be thinking about now in planning for 2017 and beyond.

It has been a long journey to get to where we are today. And while we can be proud of what we have achieved a moments reflection suggests how far we have to travel in respect of the 60 per cent of people with dementia in low and middle countries with no dementia services, the stigma that continues to attach to dementia and the denial of human rights to people with dementia.

Today we are just starting to understand the importance of bringing together human rights with practical action if people with dementia are to live with dignity. This can only be achieved if we are working in true partnership with people who have dementia.

Alzheimer's Disease International (ADI) in its annual World Alzheimer Report on Stigma in September 2012 found in their survey work that about 75 percent of the participants thought that there was a stigma around people with Alzheimer's disease. In finding that stigma and social exclusion are major barriers for people with dementia and their carers the report found that worldwide:

- One quarter of people with dementia and one in ten carers admitted to hiding the diagnosis from others because of the stigma attached to the condition.
- Furthermore, 40% of people with dementia report not being included in everyday life.

In the time I have I will focus on:

- The draft resolution for the World Health Assembly in May 2017.
- Monitoring the human rights of people with dementia within the framework of the Convention on the Rights of Persons with Disabilities and implementing dementia friendly communities

## **The draft resolution**

One of the dreams of ADI has been to achieve a resolution of the World Health Assembly. This may become a reality next May. There is a draft resolution on the WHO website which has been the subject of consultation and will go to the WHO Executive early in 2017.

ADI has welcomed the work done by the WHO to progress the document this far. This plan is an important step forward in tackling dementia all over the world and in providing a framework for action within which governments and other partners can improve the lives of millions of people who currently receive little if any support.

It defines seven priority areas and sets targets and defines action for Member States, WHO and civic society. There is a welcome focus on the human rights of people with dementia in the draft.

Taking the global targets in turn

**GLOBAL TARGET 1:** 75% of countries will have developed or updated national strategies, policies, plans, or frameworks for dementia, either stand-alone or integrated into other policies/plans, by 2025

ADI agrees that this target is a strong and appropriate action but we believe it should be set higher at 100% of countries having a national plan by 2025 so that nobody is left behind.

**GLOBAL TARGET 2:** 75% of countries will have at least one functioning public awareness campaign on dementia and/or dementia-friendly initiatives to foster a dementia inclusive society by 2025

ADI agrees this is an important target but as the key to making progress is awareness, have suggested these campaigns should be in place by 2021 at the latest and in 100% of the countries. Further ADI believes Alzheimer's organisations should work with governments to make this happen.

**GLOBAL TARGET 3:** The global targets defined in the Global Action Plan for Prevention and Control of Non-communicable Diseases are achieved for risk reduction by 2025

The target is to achieve the targets from the NCD action plan by 2025. This will certainly help to reduce people's risk of getting dementia. But we need to make the public aware

about the link between physical health and brain health. ADI has suggested adding dementia to the Global Action Plan on NCDs by the time of the mid-term review in 2018.

**GLOBAL TARGET 4:** In at least half of countries, as a minimum, 50% of people with dementia are diagnosed and receive health and social care services.

ADI has supported this target. However, we feel strongly there should be a commitment to measure quality of care. Further we have suggested that after diagnosis, everyone should receive at least one year post-diagnostic support coordinated by a keyworker, which would include access to rehabilitation. We have pressed for action on palliative care and dementia.

ADI has proposed that each country should have a help-line, run by the national Alzheimer association and supported financially by their government).

**GLOBAL TARGET 5:** 75% of countries provide national support and training programmes for carers and families of people with dementia by 2025

This is a good target, but we should aim for 100%. Respite care is in the text but should in the view of ADI be included in the target as it is often identified as a top priority by family carers.

**GLOBAL TARGET 6:** 50% of countries routinely collect a core set of dementia indicators through their national health and social information systems on which they report every two years by 2025

ADI strongly supports the WHO Global Dementia Observatory to strengthen the evidence base for action on dementia. A stronger evidence base is needed even in high income countries like New Zealand. As I said previously we would like to see quality of care included in the dementia indicators, as well as the lived experience of people with dementia when measuring through indicators. This is important because it will enable service providers to continuously improve services and people with dementia and their care partners to make informed choices about the services that might best meet their needs.

**GLOBAL TARGET 7:** At least 50% of countries are allocating 1% of their dementia expenditure to dementia research

This has been the long-standing target of ADI.

These targets are not yet set in concrete. Some governments may argue for the draft to be weakened. Nor is it certain that the ADI comments will be acted upon.

Nonetheless, it is not too early though for ADI Members and other advocacy organisations to each ask themselves some hard questions about how they may be able to take advantage of the resolution.

- Should we seek discussions with our government to get their support for the resolution? This might be most useful where a country is on the Executive Board of the WHO, like New Zealand.
- How can we take advantage of the resolution in terms of our priorities?
- What evidence or support is needed to support those priorities in our country?
- What can be achieved by systemic change and better coordination within the health care system?
- What role is your organisation positioned to play in working with government? For example, in respect of helplines, training, support for family carers and awareness?
- What role can people with dementia and family carers play in supporting your advocacy?
- Is there scope for a national alliance or partnerships to support advocacy by your organisation?
- How can ADI help to support your advocacy? For example, should we better resource regional approaches to advocacy on the model of APRO and now Latin America/Central America and the Caribbean?

ADI for its part will need to consult members on how we can best give support to their work. For example, we have in mind a document to set out national indicators for national plans and a publication on existing dementia plans. Another will be an update of the publication capturing the different approaches to dementia friends and dementia friendly communities around the world. It might be helpful too to set out different approaches to home based care and support.

Some governments may suggest that dementia care is a core part of mainstream health and aged care services and that there is no need for a plan. While all services should be able to respond to the needs of people with dementia we have special dementia services that cater for those with special needs.

It is not too early for a few thoughts.

First, it is important to look for innovative ways to link different elements of the resolution. For example, to promote awareness through dementia friendly communities and friends and dementia risk reduction programs.

Second, to identify strategies that support the family carer given that in all countries it is the carer who provides most support. To varying degrees across the world home care

programs including respite have received a low priority. As the draft resolution suggests there is a need to move the priority away from institutional care.

Lastly, the 2016 World Alzheimer's report ***Improving healthcare for people living with dementia*** has suggested one important direction for reflection.

It recommends that ways must be found of scaling up the healthcare system while reducing the growth in costs. It suggests better balancing tasks between primary and specialist care could increase capacity and reduce costs; that evidence-based dementia care pathways should be established for dementia as they are for other chronic diseases and that the lack of research on the effectiveness of key components of dementia healthcare is striking, and should be considered an urgent priority.

## **Human rights**

There has been a welcome recognition by many countries of the need to better protect the human rights of people with dementia. To improve the quality of life of people with dementia will require a change in attitudes and culture of the kind that people with disabilities and their advocates have fought for over many decades and are founded in the Convention on the Rights of Persons with Disabilities (CRPD).

We must get ready to fight the same battle.

Many of the concerns and frustrations that people with dementia express about the consequences of their diagnosis on their daily lives are addressed in the wide –ranging provisions of the CRPD which 167 states and the European Union have ratified. For example:

- The preamble which recognises that “disability results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others,”
- Article 2 on equal recognition before the law and supported decision making that respects the person's capacity
- Article 19 on living independently and being included in the community and,
- Articles 24, 27, 28 and 30 which include comprehensive access to services including education, work, participation in recreational and sporting activities

ADI in partnership with Dementia Alliance International - an organisation of people with dementia – has provided a briefing to the United Nations Committee on the CRPD and requested that the full resources of the UN family be used to monitor the extent to which persons living with dementia are included in the implementation of the Convention by Member States.

We received a positive hearing and there is no doubt that dementia is included within the terms of the Convention. But no country to my knowledge has monitored the rights of people with dementia in their country reporting processes under the Convention. Perhaps even more importantly- most people with dementia and their families are unaware that their rights are protected under this Convention.

There is a lack of understanding amongst service providers, health professionals and the community that dementia is a disability and how it manifests is very much dependent on the social and physical environment. Perhaps the most obvious example of this is the inappropriate use of antipsychotic medications within aged care to “control” behavioural symptoms. Often these symptoms are a result of poor environment, boredom or pain. Yet too often the first line of approach is chemical restraint through the use of medication.

It is important that Alzheimer’s organisations seek partnerships with disabilities organisations in monitoring the application of the provisions of the CRPD in respect of the rights of people with dementia. In this work, it will be important to look at how to give practical expression to the rights of people with dementia.

For most people with dementia it seems unlikely that they will be treated with dignity and respect in their day to day lives unless our communities are more inclusive of people with dementia.

So, while it is critical we get better access to health care for people with dementia it is equally important to ensure social support and in doing so to give practical expression to human rights of people with dementia. That is why I am a strong advocate for creating dementia friendly communities.

The concept of dementia friends and dementia friendly communities has the power to change the way we think about living with dementia. It has two different but complimentary objectives

First, to reduce stigma and promote awareness – the lived experience

Second, to empower the person with dementia to take decisions about their lives – the rights approach.

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.

In summary, 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

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.

### **Conclusion**

I look forward at this conference and in the coming months to learning

- How ADI can work with Alzheimer's organisations in their advocacy
- How countries including New Zealand build on the resolution in the dementia policy
- How Alzheimer's organisations partner with disabilities organisations to monitor the rights of people with dementia

I hope to see you in Kyoto

Thank you.