

Presentation to UN Committee On The Rights Of Persons With Disabilities

Alzheimer's Disease International and Dementia Alliance International

16th Session: Side Event: August 25th, 2016 12.45-13.45 Geneva

Glenn Rees, Chairman, Alzheimer's Disease International

On behalf of Alzheimer's Disease International and the Dementia Alliance International, I thank you for this opportunity to speak to you about the necessity for action on the human rights of people with dementia. In the brief time I have, I wish to make three points.

First, that the time is right for action.

Second, that the social and economic impact of dementia is established beyond doubt.

Third, that people with dementia are positioned to self-advocate and to set their priorities in respect of human rights.

The time is right for action because

- i. People with dementia, through DAI, have expressed a determination to ensure their human rights through the CRPD;
- ii. It is now understood that dementia is not a natural part of ageing and that dementia is both a medical and social condition;
- iii. There is evidence to support the view that the risk of getting dementia can be reduced.

There is a huge body of evidence and personal experience to support the concern that dementia attracts stigma and social isolation. The first consequence of a diagnosis of dementia is to lose friends and family and opportunities to access to participate in the community and access services.

It is only since the turn of this century that people with dementia have been empowered through Alzheimer's Disease International to speak out and more recently in establishing their own self advocacy organisation. And while ADI are willing partners, it is because of DAI that human rights are now a priority on the advocacy agenda for the 85 country members of ADI.

To get dementia on the agenda of international bodies such as the World Health Organisation it has been necessary over the last five years to generate international information on the social and economic impact of dementia on society and health systems.

In summary, there are 47 million people today with dementia, a number that will rise to 131 million by 2050. About 60 per cent of these people are in low and middle income countries where health and care systems are not equipped to respond to the needs of people with dementia. The total cost of dementia by 2018 is projected to rise to US\$1 trillion.

The policy requirement is to have a clear vision that links the human rights of people with dementia to practical action.

ADI is tackling this in four main ways:

First, through a partnership with the World Health Organisation to achieve a Resolution on Dementia in May 2017 that will commit countries to national action;

Second, to advocate at the country level for national dementia plans – there are currently 26 plans of varying degrees of comprehensiveness and funding;

Thirdly, by encouraging ADI country members to seek involvement in country reports within the framework of the CRPD;

Lastly, through social action and the establishment of dementia friendly communities.

We are excited and passionate about these opportunities. There is some optimism that the World Health Assembly will act in 2017. There is an increasing acknowledgement that for an issue as significant as this, long term planning is a fundamental requirement. A few members of ADI have started at the national level to be engaged on CRPD reporting.

As an organisation ADI is pleased with the way dementia friendly communities have been embraced worldwide. We believe it is important to develop these communities organically and to be inclusive of people with dementia. ADI has produced two seminal documents on dementia friendly communities: one to set out the principles that should drive them and another to report on activity across the world. We have some copies of these publications today and they can of course be accessed on the ADI website.

Making the link between human rights and practical action is critical. Scotland has led the way by implementing a Charter on the Rights of People with Dementia and has then gone on to ensure that policy drives a right to diagnosis and post diagnostic support.

My colleague from DAI, Professor Peter Mittler, will say more about how the provisions of the CRPD link to the priorities of people with dementia. In listening to Peter, keep in mind that fewer than 10 per cent of people with dementia receive a diagnosis in low and middle income countries and less than 50 per cent in most higher income countries.

And, while we can be pleased with progress in recent years to increase awareness and understanding of dementia, we have a long way to go even in higher income countries in respect of community based support and care and stopping medical and physical restraint of people with dementia.

Note

Materials on Dementia Friendly Communities can be found on the ADI website at www.alz.co.uk/DFC