



**Alzheimer's Disease
International**

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Statement of Ms Jan Killeen, representing Alzheimer's Disease International

**Open Ended Working Group for the Purpose of Strengthening the Protection of
the Human Rights of Older Persons
(General Assembly resolution 65/182)**

**August 2, 2011
New York, New York**

My name is Jan Killeen. I head up the policy development and research team at the Alzheimer Society of Scotland and far from being remote from reality I deal with complex cases which come through our 24hr freephone Dementia Helpline – very often these focus on rights issues in relation to care, treatment, abuse and access to justice. On a personal level I am very sensitive to these issues too, being a post war baby boomer makes me a member of a protected class.

I am here on behalf of Alzheimer's Disease International (which I will hereafter refer to as ADI) to provide a perspective on the right to health of older persons and to represent the interests of the millions of older people with ADRD and their families who, by the very nature of this devastating condition, struggle to have their voice heard.

The talk is divided into five sections

- A brief discussion of what ADI is and the current scope of its activities,
- A discussion of Alzheimer's disease and related dementias (ADRD) and why they are so connected to age
- Information about how persons with Alzheimer's Disease and related disorders are an example of real and potential age discrimination
- Fourth, an example of our work with rights issues in our community.
- And last I will highlight some areas of policy which show promise.

What is ADI?

Alzheimer's Disease International (www.alz.co.uk) is the umbrella organization for Alzheimer's Associations around the world. It was founded in 1984 and has a small secretariat of 4 in a London office. The founding member organizations were the UK, Australia, Canada and the US.

Its aims are to empower national Alzheimer associations to promote and offer care and support for people with dementia and their carers, whilst working globally to focus attention on the epidemic and campaign for policy change from governments and the World Health Organization with who it has been in official status since 1996.

In late 2010 we added a US based policy adviser to our team who has represented us here in New York with the NGO Committee on Ageing. We have recently submitted our application for ECOSOC consultative status with the United Nations and have been very active in the NGO activities leading up to the fall summit on Non Communicable Disease.

ADI has members across the world, though growth in Africa and the Middle East has been slower than in the European region and the Americas.

Each September ADI releases one major global report in several languages. (<http://www.alz.co.uk/research/world-report>) In 2009, a report was published on global prevalence of dementia and in 2010 a report on the worldwide cost of ADRD. We believe these reports are useful in measuring progress in implementation of several national and international activities.

Since 2000 ADI financially supports the 10/66 Dementia Research Group. This group gets its name from the fact that less than 10% of all population based research into dementia is directed towards the 66% or more of all people with dementia who live in developing countries—and this group is committed to changing that fact! The network is made up of over 100 active researchers from more than 30 developing countries who are studying the prevalence and impact of dementia in communities where it has not been studied before.

The group encourages active collaboration between research groups in different developing countries and between developed and developing countries.

This work has resulted in several major journal articles and the development and validating of instruments for detection of dementia in individuals and improved ways to support them and their carers. Examples of the types of studies are listed on this slide.

We believe 10/66 studies (<http://www.alz.co.uk/1066>) are relevant to monitor progress on implementation on several international agreements, conventions

and reports are relevant, including. **The Madrid International Plan for Action on Ageing (2002), the UN Convention on the Rights of People with Disabilities (2006), The World Health Organization - Improving the quality of health care for chronic conditions – WHOCC (2004) and World Health Organization - Towards an International Consensus on Policy for Long-Term Care of the Ageing. (2000).**

What is Alzheimer's disease and why is it so connected to age?

To date, age is the most proven and best known non modifiable risk factor for ADRD. About 1 person in 9 over age 65 has Alzheimer's disease, with the curve rising sharply above age 74 and over age 85. And our world is ageing. There are over 450 million ageing boomers world wide — and without effective interventions or treatments, the number of persons affected worldwide will double in the next 20 years . ADRD is not just a problem in the developed world. The largest anticipated growth in the next ten years is in the developing world, especially in Asia.

The global cost of ADRD is estimated at US\$ 604 billion 1% of total global GDP

Put another way, if ADRD was an economy it would be the 17th largest economy.

This report does not include any estimate of the economic impact of family carers for example, leaving the workforce, especially in LAMIC countries.

ADRD as an example of discrimination against older persons

People with ADRD have the same human rights as every other citizen but unfortunately and for a number of reasons which I will set out here, they can face discrimination in every aspect of their lives.

First there is the disabling impact of the illness on the mental, emotional and physical well being on the person and their family and in addition they face cultural, social and economic barriers to accessing their rights. Most people with ADRD are old and social perceptions of ageing are complicated by the disability of ADRD which in many countries, particularly developing countries, is not recognized as an illness, but wrongly as a 'normal part of ageing' about which nothing can be done.

These factors are interrelated and reinforced in our negative cultures of aging and because they live longer, the majority of people with ADRD are women who also face gender discrimination, plus the stigma of being considered 'bad' or 'mad' and are some of the poorest in society.

The general public believes that Alzheimer's disease is a problem with memory, which is in fact just the tip of the iceberg of the impairment. Short term memory is most affected, and short term memory is the key to all new learning by any of us. In addition cognitive problems mean the loss of ability to articulate our views and wishes and make reasoned decisions, to concentrate, to organize simple tasks, recognize objects — all add up to a cluster of difficulties for the person that OVER TIME make it impossible for them to navigate the ordinary bits of life, including their own care.

Person's with ADRD lose their capacity to act or make decisions in their own interests. They eventually lose the legal capacity to act or make important decisions about their own lives, including management of their finances. The loss of mental capacity severely compromises the ability of the person to protect their own rights and for this reason people with ADRD are often at greater risk of violence, injury or mental abuse, neglect or negligent treatment, maltreatment or financial exploitation. They become open to undue pressures and easily suggestible – for example, easily persuaded to allow strangers into their homes and to give away their possessions and money. .

The psychological and behavioral symptoms of dementia sometimes exacerbated by the social and physical environment, but can be caused by certain types of dementias, are distressing for the person and particularly challenging for family members, also for many professionals, to understand and know how best to respond— such behavior is also subject to misinterpretation by society and can lead to further marginalization and discrimination.

Let me pause and highlight the good work of HelpAge International, Age UK and the ILC who have collected and put in evidence at the previous session of this working group several examples of actual discrimination from around the world.

The potential for discrimination is not just individual cases; there are systems issues.

On a systems basis, ageing and dementia issues have not **yet** been that well represented or mainstream in national and international public health planning.

For example, only 7 nations have a published national government ADRD plan, and nearly all have tobacco control plans which have been supported broadly by international public health authorities.

THIS IS A RAPIDLY CHANGING AREA OF POLICY, AND ADI IS VERY PLEASED TO BE WORKING WITH THE WHO AND ITS REGIONS TO BRING MORE AWARENESS OF THE PROBLEMS OF DEMENTIA TO LIGHT ESPECIALLY THE WHO MHGAP PROGRAMME AND WORKING TOGETHER ON A NEW WHO REPORT TO BE RELEASED IN 2012.

That being said, despite much work by key NGO's and governments, it appears at this moment that ageing and Alzheimer issues may not been well represented in the current drafts of UN documents for the fall Non Communicable Disease summit.

Lack of inclusion in health planning for ageing and dementia can lead to discrimination by default.

Let me offer an example of a rights approach in the Alzheimer community.

The experience of rights as an organizing principle in our community is relatively recent, and we are still uncertain of its impact. Alzheimer Scotland has concluded that a human rights approach is the central to the empowerment of people with ADRD and their families – and that this is one of the keys to the elimination of discrimination, both institutional discrimination and discrimination in society. As an NGO we view it as one of our major objectives to facilitate people to have their own voice – that early diagnosis and support is essential if people are to have the opportunity to remain in control of their lives for as long as possible – independence being a fundamental right.

In Scotland we support a campaigning group of over 100 people with a diagnosis of ADRD.

Taking a human rights approach has proved to be very effective in Scotland and I can say this after 30 years of campaigning. Together, with the All Party Group on Alzheimer's we produced a charter of rights for people with dementia and their families which has been adopted by the Scottish Government, and the Charter's principles underpin the National Dementia Strategy for Scotland which was launched this summer. The Charter brings together key rights statements drawn from existing international conventions and treaties - and follows the rights that people with ADRD have throughout the journey of the illness, from early diagnosis to end of life care

To accompany the Scottish Government's Standards of Care for Dementia in Scotland Alzheimer Scotland has produced a short guide for people with ADRD and their carers which provides a rights check list.

Older people with ADRD and their families need to know what their rights are and how to use them. They should not have to wade through a plethora of international treaties and conventions in order to point out to the authorities which of their rights are being disregarded.

Promising policies that support rights

I would like to highlight several promising policies were highlighted in the advance unedited version of the Secretary General's report on the Follow Up to the International year of Older Persons and Second World Assembly on Ageing

<http://social.un.org/ageing-working-group/documents/2011%20SG%20Report%20on%20Ageing,%2022%20July%202011.pdf>

These include "age" as a forbidden ground of discrimination and several laws as containing specific provisions for older person's rights. The report's discussion on the link between older persons and disabilities (sec 47) calls out the unique nature of age based discrimination that may not be sufficiently covered as age is not generally seen as and should not be seen as a disability in itself.

Initiatives to protect the exercise of older person's legal capacity (sec 57) are fundamental to protecting the right to health.

In the domain of health, we are greatly encouraged by national policies documented that adjust the increasing level of chronic diseases that to a large extent affect older persons (sec 59-60) despite our belief that older persons in general are still de prioritized and health policies and resource allocations.

To conclude, a journalist once asked me what I would like my epitaph to be, and at that time I told her: say 'Jan Killeen kept her head above the parapet until the end' - I would like to think that the outcome of these deliberations here mean that I won't have to do that!!

Thank you for the opportunity and privilege to address these important issues.