



Alzheimer's Disease International

64 Great Suffolk Street
London SE1 0BL
United Kingdom
Tel: +44 (0)20 7981 0880
Fax: +44 (0)20 7928 2357
Email: info@alz.co.uk
Web: www.alz.co.uk

From a global perspective, the NAPA law, Council and subsequent plan development have given a shot in the arm to the Alzheimer's community which has been pursuing many of the same aims of the act in countries on all five continents. Alzheimer's Disease International (ADI) would like to offer some brief comments to the NAPA planners about the broader context of your work. Though there are major differences in resources and the cost of care between developed and less developed nations, the similarities of challenges around diagnosis, family support, health system development and quality care are universal, as are the aspirations for improved treatment and prevention of Alzheimer's a disease and related dementias.

We offer our comments based primarily in response to draft strategies 1D and 1E, which recommend more international collaboration in the research and public health education sectors, a concept we heartily endorse.

ADI is the international federation of Alzheimer associations around the world, in official relations with the World Health Organization. Each member is the Alzheimer association in their country who support people with dementia and their families. ADI's vision is an improved quality of life for people with dementia and their families throughout the world.

Alzheimer's as a Global Public Health Issue

The global health community is waking up to the size and scope of the problem of Alzheimer's disease and related disorders. These comments review 3 global developments: information reports by our private organisation, Alzheimer's Disease International (of which the Alzheimer's Association is a member), United Nations and World Health Organization reports and actions, which have recently increased and in which the US has played and could continue to play a helpful role.

Since 2009, ADI has issued major data reports about Alzheimer disease and related dementias worldwide. Each report is the product of scientific collaboration, led by an epidemiologist and full research team. I would highlight the most recent report, which provides the latest evidence of the medical and social benefits of an early and accurate diagnosis as a tool on which to base further work to fight the gap between prevalence estimates of 36 million worldwide and actual numbers of people diagnosed. It is estimated that probably no more than 1 in 4 people with dementia have received a formal diagnosis, which has been identified as a significant issue in the US draft plan framework and *Healthy People 2020* objectives.

In September 2011 the United Nations held only its second high-level meeting on a health issue in its history. This consultation on non-communicable diseases was held to debate a policy document and the final political declaration urges that member countries: "18. Recognize that mental and neurological disorders, including Alzheimer's disease, are an important cause of morbidity and contribute to the global non-communicable disease burden, for which there is a need to provide equitable access to effective programmes and health-care interventions."

This UN session directed the WHO to develop a series of targets, measures and indicators for reducing non-communicable diseases to be adopted by the World Health Assembly in its May 2012 meeting.

The World Health Organization's involvement in Alzheimer's disease dates back to at least 1982, when it held an expert meeting on senile dementia. For many years most of the focus of the WHO has been through its mental health Programme (mhGap). The programme has produced a steady body of work for international professional and public health audiences about Alzheimer's and dementia. Our summary chart of all WHO publications is appended to these comments.

With WHO now deeply involved in follow-on planning from the NCD summit, efforts are underway to get Alzheimer's disease recognised as the fifth major non-communicable disease. ***However we need support from the US Government to make that happen and include Alzheimer's disease in the next NCD Strategy 2013-2020!*** Alzheimer's disease was used as an example of how ageing is a factor in the growing non-communicable disease challenge in a recent resolution passed at the Assembly's executive meeting in January, and it is certain to be debated at the assembly meeting in May.

WHO Global Report

On April 11 2012 the World Health Organization will release a major global report on Alzheimer's disease and dementia. This is the result of collaboration with over 100 experts around the world to produce a volume similar in size and style to the world report on disabilities. Basic themes of the report will include the need for improved and coordinated research, more professional development of medical and non-medical staff, family caregiver support, and better linkages between health and social services in order to support people with Alzheimer's. The report will also focus on population risk reduction for Alzheimer's disease and dementia, identifying what might be done in the public health sector to better define and reduce population risk of dementia. The prevalence/diagnosis gap is also a theme of the report and it has a section on small subpopulations of people with Alzheimer's disease, such as rural, minority language speaking, or people with Alzheimer's referred to as early or younger onset.

The WHO will signal that we are on the brink of a global health catastrophe. Across the world, 36 million people are living with dementia today. But unlike people with other serious conditions, their plight is very often not recognised. They will argue that their condition attracts only minimal research investment and a lack of awareness about adequate care and treatment mean their condition is often made needlessly worse than it needs to be. As the global population ages the problem will only get bigger.

Scientific Collaborations

Though there are many cross-national, scientific collaborations we suggest the following three that go beyond the bio-medical focus and highlight some of that work as suggestions for additional directions that international collaboration in research could foster.

JPND

The EU supports the European Union Joint Programme - Neurodegenerative Disease Research (JPND) to facilitate trans-European research. The idea was launched in 2008 during the French presidency of the European Union. It is a major effort to improve EU alignment of scientific strategy on Alzheimer's disease and make best use of available resources. It now numbers 24 countries.

JPND major effort to date has been to collaboratively create a strategic research agenda to guide activity and investments. Just released, this strategy is based on the most complete compendium of current country-by-country efforts ever created. It lays out five scientific priorities and a robust set of cross-cutting enabling activities to move the strategy forward, of which two are unique when compared to the draft NAPA framework.

The JPND healthcare and social care research goal identifies the major disconnect between health and social care systems and proposes research activities that may address the gap. Priority activities planned include coordinated studies to validate social care interventions, evaluation of pathways to treatment and support and their effectiveness, the effects of co-morbidity in dementia care and the study of assistive technologies.

The JPND treatments and prevention goal includes a set of activities to examine psychosocial interventions and some population health activities, with a significant public health element of the strategic research agenda is using the planned European Health Examination Study to provide new Europe-wide data on the prevalence of people with early cognitive difficulties. This could be cross-walked with the CDC work on surveillance and compared to the ongoing effort adding cognitive questions to other population health studies such as NHANES, which could lead to better understanding of population risk factors and the challenges of co-morbid chronic conditions existing with dementia.

Coordinated Prevention and Risk Reduction Studies

We would encourage the NAPA planners to begin to think about Alzheimer's disease as the fifth non-communicable disease, and to take advantage of growing evidence that demonstrates that some of the risk of Alzheimer's and dementia is modifiable, with many of the same risk factors as the other major NCDs.

We support additional careful study and our members are careful not to say "prevention of Alzheimer's" but there is sound science on risk reduction and several more large European dementia prevention studies are targeting cardio-vascular and lifestyle related risk factors which will report in 2012 and 2013. These are:

- The Finnish Geriatric Intervention Study to Prevent Cognitive Impairment and Disability (FINGER)
- The Prevention of Dementia by Intensive Vascular Care (PreDIVA)
- The Multidomain Alzheimer Preventive Trial (MAPT)

- The European Dementia Prevention Initiative is a new (2011) convening body of many of these collaborators. (www.edpi.org)

10/66 Dementia Research Group

The 10/66 Dementia Research Group is a collective of researchers carrying out population-based research on dementia, non-communicable diseases and ageing in low and middle income countries. 10/66 is a part of Alzheimer's Disease International, and is coordinated by the Institute of Psychiatry, King's College London. All protocols, survey instruments, and de-personalised 10/66 study datasets are available for secondary data analyses, subject to scientific and ethical review. The group has run carer intervention trials as well as validated measures for dementia identification in low resource countries, both of which might find application in the US with cultural or ethnic minorities.

Thank you for the opportunity to offer our comments and support for your efforts.

A handwritten signature in black ink, appearing to read 'Marc Wortmann', with a large, stylized initial 'M'.

Marc Wortmann
Executive director