Alzheimer's Disease International

Input to WHO Global Mental Health Action Plan 2013-2020 Zero Draft

10 October 2012

Summary:

1. Alzheimer's disease and dementia are a target action area for WHO and Member States.
2. There is a lack of awareness about Alzheimer's disease and other dementias worldwide.
3. Stigma is a barrier to find solutions.
4. Like with other mental and neurological disorders, there is a huge treatment gap for dementia. We estimate that in high income countries 20-50% of people with dementia are diagnosed, in lower and middle-income countries only 10%.
5. There are practical actions that are ready for adoption now to support persons with dementia and their families, including some validated in lower and middle income countries.

i) Introduction and Reference Points

Dementia as a major NCD was recognised in the UN High Level Political Declaration on NCD's, in September 2011.

And further noting resolution **EB130.R6 "**Noting that the Political Declaration of the High-level Meeting of the United Nations General Assembly on the Prevention and Control of Non-communicable Diseases recognizes that mental and neurological disorders, including Alzheimer's disease, are an important cause of morbidity and contribute to the global burden of noncommunicable diseases, and therefore it is necessary to provide equitable access to effective health programmes and interventions including for the whole population, from an early age; Recognizing the importance of gender-based approaches, solidarity and mutual support for social development, of the realization of the human rights of older persons, of promoting quality of life, health equity and the prevention of age discrimination, and of promoting social integration of aged citizens;"

And further noting **WHA65.4 resolution "**Noting the High-level Meeting of the United Nations General Assembly on the Prevention and Control of Non-communicable Diseases (New York, 19 and 20 September 2011), at which it was recognized that mental and neurological disorders, including Alzheimer's disease, are an important cause of morbidity and contribute to the global non communicable disease burden, necessitating provision of equitable access to effective programmers and health-care interventions"

And further noting "Countries must include dementia on their public health agendas. Sustained action and coordination is required across multiple levels and with all stakeholders at international, national, regional and local levels." *Dementia: a public health priority*, WHO, 2011, p. 94

Alzheimer Disease International offers these comments on the zero draft of the Global Mental Health Action Plan 2013-2020.

ii) Background

Alzheimer's Disease International (ADI) is the international federation of 78 Alzheimer associations around the world (www.alz.co.uk). Each member is the Alzheimer association in their country who support people with dementia and their families. ADI was founded in 1984 as a network for Alzheimer associations around the world to share and exchange information, resources and skills. ADI is based in London and is registered as a non-profit organisation in Illinois, USA. ADI has been in Official Relations with the World Health Organization since 1996 and the United Nations since 2012. ADI's vision is an improved quality of life for people with dementia and their

families throughout the world. 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.

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 Working Relations with since 1996. ADI has just been granted ECOSOC Consultative status.

Since 2000, ADI has been a leader in research into dementia in lower and middle income countries by financially supporting the 10/66 Dementia Research Group. This group gets its name from the fact that, when it was formed in 1998, less than 10% of all population based research into dementia was directed towards the 66% or more of all people with dementia who lived in developing countries. 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. They also develop practical tools for medical and social care of persons with dementia specifically in the context of LMIC countries that are now ready for dissemination.

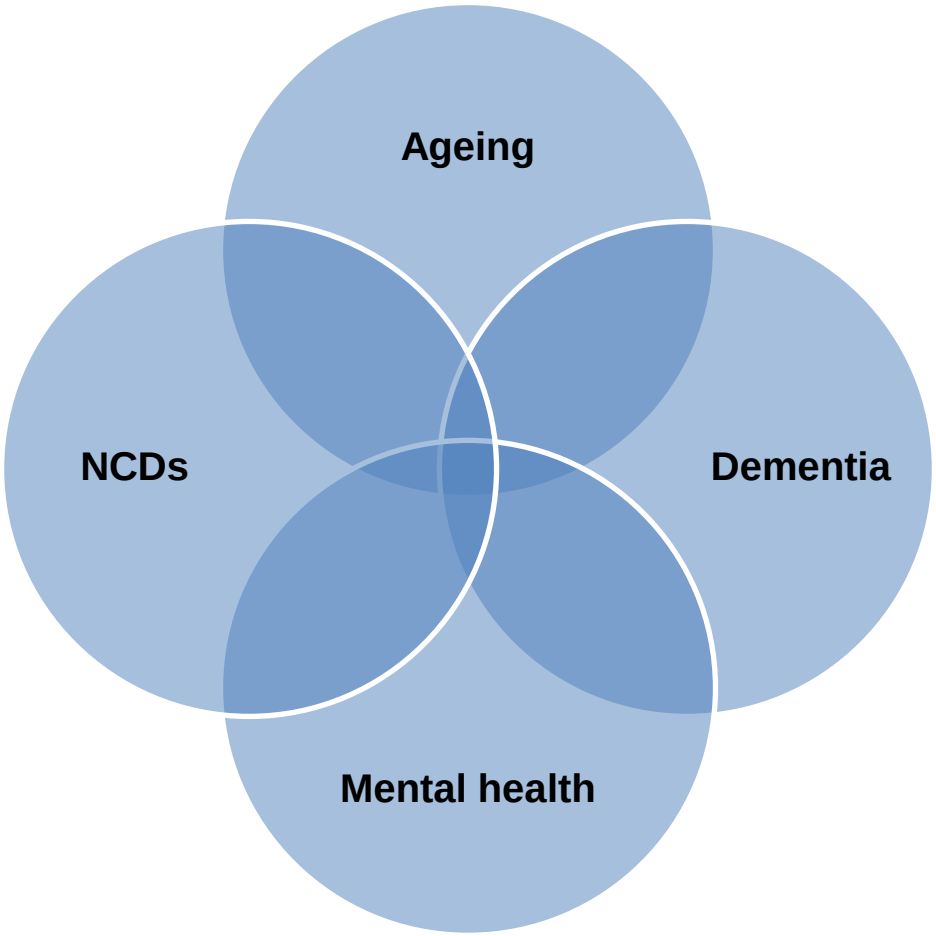
The size of the dementia problem is enormous and growing. 36 million people worldwide had dementia by 2010. Due to global ageing, this number will go up to 66 million by 2030 and 115 million by 2050. The main increase will take place in lower and middle-income countries especially in Asia Pacific, Latin America and the Middle East. There are 7.7 million new cases every year, one every four seconds. Dementia is a very expensive disease, not so much for the health budgets, but mainly because of the social care costs and the costs of informal care. We calculated these costs in 2010 at US$604 billion, or 1% of global GDP. At the moment, there is no cure, there is only medication that can slow down the progression of the disease. Dementia shares most risk factors, like smoking, hypertension, obesity and lack of physical activity with the other main NCDs.

iii) Intersection between dementia and Mental health Plans and Resources

ADI maintains that mental health actions can play an important role in the dementia crisis, though we are in accord with the finding on page 2 of the zero draft that, “Although dementia and psychoactive substance abuse are included under the ICD-10 classification, strategies over and above those considered here may be required for the prevention and management of these disorders (as, for example, described in a 2012 WHO report on dementia and the Global Strategy to Reduce the Harmful Use of

Alcohol).” Below are key points of intersection based on today’s knowledge and available treatments.

- Dementia (of which Alzheimer’s disease is the major cause) is a complex, long term chronic illness that requires, at different points, social, medical, family support or mental health interventions. Mental health resources are a vital but minor player in the overall life scheme of a person with dementia, though in many countries may be the only formal resource available. The graphic below demonstrates this complexity.



- In the early stages of the disease, mental health resources may play an important role in the detection of cognitive impairment and diagnosing dementia in the individual. In some cases, people with early stage dementia may seek counselling or other support for depression associated with the diagnosis and adjustment to life with a terminal progressive illness and to loss of work or other roles.

- In the middle and later stages of the disease, families are the principal caregivers for people with dementia, and many evidence based carer supports are delivered through mental health channels and many, in fact, have mental health outcomes for the family career. Further, issues of capacity and decision-making may engage mental health practitioners.

- Our brain is the physical hub of our psycho-social life, and as the damage to the brain from progressive dementia intensifies, many people with dementia suffer behavioral symptoms and syndromes quite like people with mental illness. Mental health interventions, including the thoughtful evidence based use of psychoactive medications, may be another intersection point with mental health services.

- In more developed countries, mental health professionals are involved in multi-disciplinary teams that support people with dementia in long term care or community care settings or are part of hospice counselling teams providing palliative care and support to the bereaved.

iv) Solutions

ADI proposes:

1) That the Global Mental Health Action Plan must support the WHO report *Dementia: a global health priority* (WHO, 2012) and the report's recommendations 1 and 2, (public awareness and stigma reduction) especially as mental health has the experience base and authority on stigma issues. Mental health authorities should use their influence and channels of communication to assist in basic awareness campaigns and activities through providing up to date and accurate information about Alzheimer's disease and dementia to its constituencies and, where possible, lend technical assistance on anti-stigma messaging.

2) The WHO report *Dementia: a global health priority* (WHO, 2012) found that "the large majority of people with dementia and their family caregivers do not benefit from the positive intervention and support that can promote independence and maintain quality of life. Timely diagnosis and early intervention can help people with dementia and their families to steer a course through the 7-12 years they may be living with dementia, and will assist them to avoid crises and promote their well-being." ADI proposes that the Action Plan should direct that MhGAP

disseminate practical tools to increase access to diagnosis, especially those validated for use in lower and middle income countries.

3) As noted earlier in this commentary, carers often seek coping assistance from mental health resources. ADI proposes working collaboratively to disseminate practical tools to support caregivers such as the *Helping Carers to Care* (*Ayudando al Cuidador a Cuidar*) programme developed and validated through trials in lower and middle income countries as well as novel ideas such as providing online carer support.

4) Public health surveillance on dementia is lacking and we propose WHO could begin by tracking national Alzheimer and dementia plans, with more inclusion of prevalence and incidence data in the WHO Mental Health Atlas. We would be delighted to partner on developing these systems and data.

5) The Action plan should call for mental health authorities to support national dementia plans and their implementation, with technical assistance from both WHO and ADI.

6) We suggest that the Action Plan call for increasing NGO and private sector engagement in collaboration around the WHO Quality Rights Initiative, and link in with efforts through ALCOVE in the European Union and similar opportunities in North America to champion patient's rights to be free of unneeded and harmful psychoactive medications.