



London, 15 October 2016

Re: Alzheimer's Disease International (ADI) – Dementia Alliance International (DAI), Alzheimer Europe and Global Alzheimer's and Dementia Action Alliance(GADAA) joint response to WHO Zero Draft:

Draft global action plan on the public health response to dementia 2017-2025

ADI has held meetings with members in Africa (8) on 21 September and the Caribbean (13) on 28 September and with Latin American members (15) on 12 October. Two teleconferences were held on 5 and 6 October.

DAI received feedback via email and online consultations from members in the USA, Canada, Japan, England, Scotland, Nigeria, Czech Republic, Hungary, Singapore, Mexico, Germany, Australia, New Zealand and Italy.

The GADAA network brings together a broad spectrum of civil society including international development organisations, health-focused NGOs, disability rights champions, human rights organisations, faith based groups and women's organisations, aiming to champion global action on dementia and to support NGOs in responding to the global challenge of dementia. The GADAA secretariat invited comments on the Global Plan from member organisations and held a webinar to discuss this submission.

We have been asked to send the following comments to the World Health Organization (WHO).

The Zero Draft addresses the main issues in dementia policy. It takes a whole of government approach and links to other key work streams of WHO activity including the plans for NCDs, Mental Health and Ageing. It also recognises that improving the lives of people with dementia and their families is a human rights issue and the framework provided by the UN Convention of the Rights of Persons with Disabilities (CRPD) which ADI and DAI regard as critical to monitoring the rights of people with dementia. 10/66 research has clearly shown that dementia is the main cause of disability and dependency among elderly.

ADI, DAI, Alzheimer Europe and GADAA recognise this plan as an important step forward in tackling dementia all over the world and in providing a framework for action within which governments and other partners will be able to improve the lives of millions of people who currently receive little if any support.

Furthermore we believe that spending on dementia will increase with or without a plan – so restraining growth by a well implemented plan involving more efficient use of existing healthcare resources is critical. The World Alzheimer Report 2016 makes valuable recommendations about this efficient use.

Please consider the following comments to make the plan even stronger. Our members have focused on sharpening some of the actions that can be done relatively easily and at low cost, because programmes and materials already have been developed, but not comprehensively rolled out in different countries. In addition, we want to strengthen the action on Human Rights and the CRPD.

With regards to the vision and goals, we think that the vision (par. 16) could be made stronger by deleting *'or without'* to express that living well with dementia is what we would like to see happening when this plan is implemented. Please note that 'living well' requires that the quality of care should be measured. The goal (par. 17) is to decrease the impact of dementia; consider turning that into a more positive goal would be: to improve the quality of life of people living with dementia and their families (or relatives).

We agree with the underlying principles (par. 18).

We are pleased that in paragraph 19 civil society organisations are mentioned as stakeholders and you might want to be more explicit in mentioning that Alzheimer's Disease International and its national member associations, Dementia Alliance International, Alzheimer Europe and Global Alzheimer's and Dementia Action Alliance are willing to contribute to the implementation of the plan.

Area 1: Dementia as a Public Health Priority. We think this is a strong and appropriate action but we believe the global target 1 (par. 26) should be set higher at 100% of countries having a national plan by 2025 so that nobody is left behind.

Area 2: Dementia Awareness and Friendliness. Again a very important area and we fully agree. Comment on the global target 2 (par. 39): as awareness is recognised as the key to making progress we suggest aiming for these campaigns to be in place by 2021 at the latest and in 100% of the countries. Awareness is the critical point of departure to tackle dementia. Governments should work with Alzheimer associations to make this happen.

The target says '...awareness campaign **and/or** dementia friendly initiatives..' We would prefer '**and**' only.

Area 3: Risk reduction. The target (par. 50) 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. We suggest adding dementia to the Global Action Plan on NCDs by the time of the midterm review in 2018. An indicator could be: at least a 10% reduction in the prevalence of dementia compared to the expected increase by 2025. Also note that the description of risk factors is not consistent between par. 48 and 52 with those in 48 being more accurate for dementia.

Area 4: Dementia Diagnosis, Treatment and Care. We support this target. However, this area should be made stronger by proposing in para 61 that member states should also measure quality of care outcomes. After diagnosis, everyone should receive at least one year post-diagnostic support coordinated by a keyworker, which would include access to rehabilitation. After Para 64 there could be a paragraph on palliative care and dementia. Palliative care should also be included in a number of other paragraphs. Para 68: Training tools to include the value of peer to peer support groups.

WHO could include people living with dementia and their families in the existing community-based rehabilitation programme, especially in LMIC (par. 67).

Each country should have a help-line, run by the national Alzheimer association and supported financially by their government (par. 68).

Area 5: Support for Dementia Carers and Families. Again we think this is a good target, but we should aim for 100% (par. 74). There is enough knowledge and experience with these programmes. Respite care is in the text but not in the target. We recommend adding it to the target given it is the often identified as a top priority by family carers. It would read: "...national support, training and respite services..."

The section should set the objective of enabling people with dementia to live for as long in the community as possible by giving priority to community based programs including home care, food services, transport and respite care and a dementia friendly community environment

In para 77 we recommend adding support in regional and rural areas as well.

Area 6: Information Systems for Dementia. A good target. We strongly support the Global Dementia Observatory. 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 carers to make informed choices about the services that might best meet their needs

Area 7: Dementia Research and Innovation. We agree with the target, as we asked for this at the First Ministerial Conference on Dementia in March 2015.

From the lower and middle-income countries (LMIC) it was suggested that dementia drug availability could be addressed through international aid development work streams similar to HIV in the past and that some of the research expenditure should go to LMIC.

On human rights we are delighted to see the action proposed by WHO in par. 31. But national governments who have ratified the Convention also have a responsibility to take action. We propose a new para in proposed actions for member states in area 1 to read along the following lines:

"Dementia is included within the Convention on the Rights of Persons with Disabilities. For the 166 countries that have ratified the Convention there is therefore an obligation to monitor the implementation of the Convention in respect of people with dementia along with other people with disabilities."

This is important because a number of rights issues are not included in the text. The framework provided by the Convention is critical to achieving the rights and respect for people with dementia in many respects including:

- Supporting people with dementia to remain independent
- Providing opportunities for people with dementia to remain employed or have voluntary work opportunities
- A greater priority for developing strategies to achieve greater independence and full inclusion in civil society for people with dementia –56 and 57 do not cover it adequately
- Steps to reduce stigma and discrimination against people with dementia and their families