Statement to the 22nd Session of the OECD Health Commission, Directorate for Employment, Labour and Social Affairs

Item 6. Dementia report: Key Findings and Recommendations

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My name is Paola Barbarino and I am the Chief Executive Officer of Alzheimer's Disease International, better known as ADI. ADI is the global umbrella organisation of dementia and Alzheimer associations, it represents 90 organisations and has been in official relations with the UN and WHO since 1996. Our ethos is “prevention, care and inclusion today, and cure tomorrow” and it is in this spirit that we strongly welcome this paper, which builds on the excellent OECD report of 2015.

ADI has a long history of representing the voices of people with dementia, of their families and care partners and of the professionals in the field of dementia. Overall, we praise the report’s emphasis on the importance of people-centred and rights-based approaches and on the involvement of people and communities throughout the stages of this terrible disease. In particular, we welcome the emphasis on Dementia Friendly initiatives and on the role business and the community can play in these. We also praise the call for adoption of new models of residential long-term care.

ADI has spent more than a decade warning policymakers globally about the impending scale of the dementia crisis, providing figures on the global socioeconomic impact and creating a framework for solutions and for disseminating best practice globally.

Every 3 seconds someone in the world develops dementia and this is the scale of the problem. From that point onward the cost to society, families and people with dementia is huge. Dementia will be a trillion dollar disease by 2018. So, it makes economic sense to bolster our communities and economies to be ready for this growing issue. Our World Alzheimer Reports contain key recommendations and examples of how this can be achieved.

I thank OECD for giving me an opportunity to attend this session with a call to action. I would like to draw your attention to the following priority areas highlighted in the report which in our opinion need urgently addressing.
1. Governments should develop clear strategies to increase and improve timely diagnosis rates. Perhaps the most intriguing challenge is how to fit together the pieces of the mosaic flagged in the report. This includes the role of primary care with access to specialist care and memory clinics and the location of post diagnostic support services. The individual right to diagnosis and post diagnostic support is essential to start the journey with dementia well.

2. Equally important is the balance of coordination and integration of care pathways in a way that both serve the needs of the person with dementia and the need of achieving greater efficiency in the health and care systems.

3. Training and education is important at all levels of society and Governments should look at it holistically. In schools, to help us break the stigma of dementia at an early stage. In higher education where early integration in education curricula can make a huge difference in future medical and paramedical personnel approaches to dementia.

4. Availability of diagnostic tools is essential and this includes access to scanning equipment.

5. We welcome the mention of the role that pharmacists can play in diagnosis and would like to see this developed further as we think it has much promise.

6. Government policies are founded on enabling older people to stay at home for as long as possible This may sound good but in actual fact it can become a problem if there is no availability of good long-term care systems and in particular access to community-based care systems and carer support.

7. There is also a big role that assistive technology and better environment design can play. Governments can build incentives around the study, development and implementation of those.

8. As well as incentives for the medical staff we would welcome a closer look at strategies to empower the consumer and at the potential of stronger market mechanisms.

9. Flexibility in service delivery is key especially in relation to supporting family carers, for example through access to well-designed dementia respite care for those in the workforce.

10. The report mentions the importance of introducing flexibility in the workplace for carers, we would welcome a closer look at how policy could be developed in this direction and for people with dementia at earlier stages.

11. The evidence base for concern about care for those with cognitive impairment in acute care is overwhelming and evidently there are strategies which should be adopted to improve care and efficiency in hospitals, notably in relation to hospital avoidance and end of life care.
12. On the complex issue of data we welcome the report’s realistic views on the availability and accessibility of national data. Only by being transparent about the scale of the challenge can we start doing something about it. We strongly support the recommendation that hospital coding standards that promote recording a dementia diagnosis should be developed.

13. At the macro level, only 22 OECD countries have developed national plans so far however data remains extremely limited. The launch of the Global Dementia Observatory at the WHO this same week will certainly start challenging the data currently held by governments pretty soon, so it is clear that urgent action is needed to ensure that the baselines we will be working from in the next 7 years are more accurate than thus far.

14. As I am in the presence of so many government representatives this is also my chance to make a plea to those OECD nations who are yet to develop a national action plan to do so and to reflect on how care and support for people with dementia can be better delivered through their health and care systems. As ever, ADI would be delighted to help and support through our national members.

15. Finally, we also suggest future reports look at other promising areas of development where the lives of people with dementia and their families can be improved. Physical rehabilitation is one of those areas which is not explicitly mentioned in the report.

Thank you for the opportunity to address this timely report.