
DEMENTIA ALLIANCE INTERNATIONAL RESPONSE TO

WHO Global Action Plan on the Public Health Response to Dementia “DRAFT ZERO”

GENERAL COMMENTS

Following the OECD conclusion in 2015 that *“Dementia receives the worst care in the developed world*, Dementia Alliance International welcomes this opportunity to respond to this draft of the WHO Global Action Plan.

Action Area 5 fails to address this conclusion, which is supported in books, numerous articles and discussions online and through other mediums such as conferences and events by people living with dementia, care partners and sometimes by the care couple themselvesⁱ.

We welcome the commitment to the human rights of people with dementia and in particular to the UN Convention on the Rights of Persons with Disabilities.

This also reflects the joint ADI-DAI commitment to a human rights-based policy, which includes full access to the Convention on the Rights of Persons with Disabilities (CRPD) and other relevant Conventions, including a future Convention on the Rights of Older Persons.

In principle, we agree with all feedback given on Day 1 of the mhGAP Forum about Draft Zero, and provide further elaboration of the feedback from our own members from 15 countriesⁱⁱ, to inform and advise the final draft. We especially support more in the draft on risk reduction of dementia.

Please consider the following comments and suggestions to make the plan even stronger. Our members have focused on some of the action areas, and in addition, on issues we feel are omissions or oversights in the preparation of the draft. We also see it as very constructive to strengthen the action on Human Rights and the CRPD.

AREAS OF CONCERN, OMISSIONS AND RECOMMENDATIONS:

1. Dementia as a neurological disability or disorder

It is of some concern to persons with dementia, as it was to Autism Minority International) that we are 'planned' within Mental health and Psychosocial disabilities.

Dementia is not a mental illness, or specifically a psychosocial disability, and this increases the stigma and myths of dementia. Dementia is one of more than 100 types of neurological disorders, causing cognitive disabilities.

We also acknowledge it will be unlikely for WHO to change this but we must insist that our distinctive needs are respected and taken into account.

2. Younger onset dementia

The draft does not represent people with younger onset dementia; this group also experience ageism due to the common belief that dementia is an older persons condition. They also require support to remain employed. Their more specific age appropriate needs should be taken into account.

3. The Strategic Plan

We believe that informal family carers and people with dementia need to be more clearly distinguished separated, as the needs of each are very different.

4. Diversity

It would be preferable to also reflect in the plan the diverse lives people are living, rather than assuming a nuclear family is common for most people, and where support for persons with dementia will be provided. For example 30% of people with dementia in the community live alone.

The draft also does not reflect issues faced by more marginalised groups such as LGBTIQ, ethnic and Indigenous minorities

5. Palliative Care

We recommend Palliative Care begins with post diagnosis support in the same way people with other terminal illnesses are supported.

Feedback has also been received from Palliative Care Australia; we also strongly support this statement from Palliative Care International;

'We believe there has been an oversight in omitting an explicit reference to palliative care in this plan. In particular this should be referred to in the need section and in Action Area 4 - paragraphs 56, 58, and 61 should include a reference to palliative care. Paragraph 66 could also be improved with the insertion of 'from early in the course of illness to the end-of-life' at the end of the paragraph. In addition, as the area requires significantly more research it must be included in paragraph 93''

6. Residential care for people with dementia

Following the Quality Rights session on 11 October led by Michelle Funk and Natalie Drew, there needs to be a recommendation that residential accommodation for people with dementia moves away from secure locked units within institutions, to community based care or accommodation.

We also recommend they are built to dementia enabling standards.

Michelle Funk indicated in the QR session that Quality Rights has been misused in the residential care sector, and that modernizing a dementia specific unit is not sufficient, but that transforming away from institutional to community care is necessary. It is not about modernizing or upgrading the accommodation, but about compliance with human rights and the CRPD.

On Day 1 of the mhGAP Forum, Julian Eaton noted that people with mental illness living in institutions may only get outside once a day; there is good evidence many with dementia living in locked institutions never get outside for the duration of their care period and up to their death. In some care homes, residents are not even allowed to walk in their care home gardens.

Locked accommodation is clearly a breach of human rights in the same way it is for those with mental illness.

Although still uncommon, there are excellent examples of alternative human rights based approaches to residential accommodationⁱⁱⁱ.

RECOMMENDATION: Residential care is transformed into community-based care (residential or in home care), and locked dementia units are phased out.

7. Para 13

Our concerns and recommendations are outlined in detail on pages 6-8 on Action Area 4 for a proactive rehabilitative approach to post diagnostic support, and include disability support for all people with dementia at the point of diagnosis.

We believe this innovative approach is not only more ethical for people diagnosed with dementia, in particular when diagnosed much earlier in the disease process when the value of rehabilitation but has more of a chance to be realised, and based on a human rights based approach.

We also believe it would also lead to decreased “long-term care costs for governments, communities, families and individuals, and to losses in productivity for economies”.

8. Para 16 - Vision Statement

In response to this Vision statement, we believe it would be preferable to delete “or without”, and to include “equal and full inclusion in civil society”.

9. Para 18. b)

DAI is in a unique position to support the proposed Cross-Cutting Principles; with current membership of more than 2500 people representing 38 countries. This can be strengthened by other advocacy organisations working with us. By further empowering people with dementia to be involved in advocacy, policy and planning, in all matters that are about them.

This is a human rights based approach with the potential to support governments, health care professionals, service providers and family carers to better support our unique needs.

DAI is also in a unique position to support LMIC’s in this work as we develop services, materials and resources in languages other than English, which will also support all Member States (paras 40, 41, 42).

10. Para 18. c)

Along with risk reduction and healthy lifestyle factors, outstanding emerging evidence^{ivv} indicates a rehabilitative disability pathway of support will slow down the progression of dementia, or even reverse dementia.

Draft Zero, the Version 2.0 of the mhGAP Intervention Guide, and even the iSupport intervention released at the forum all appear to promote continued prescribed disengagement and dependence and are too strongly focused on a medical model of care.

This post diagnostic pathway is disabling and disempowering, resulting in further disablement and the development of people taking on the “sick role” and learned helplessness. See more on rehabilitation and disability support on pages 6, 7 and 8.

11. CRPD

Our concerns and recommendations regarding the CRPD;

- 1) There is no evidence in the 63 reports submitted to the CRPD Committee so far of any Member State fully including persons with dementia in their implementation of the Convention.
- 2) With the exception of Scotland, there is no evidence that the Convention has been used to design two regional (EC and PAHO) and 29 national dementia plans.

The UN Human Rights Bodies could see this^{vi} as examples of systemic discrimination, even though unintentional, as it reflects the widespread but mistaken assumption that the symptoms of all dementias are not viewed as disabilities.

RECOMMENDATIONS FOR AMENDMENTS IN THIS AREA

- 1) Include a clear statement that the 168 Member States who have ratified the Convention are already committed in international law under CRPD Article 1 to include persons with dementia in its implementation.
- 2) Include an explicit commitment to the Global Action Plan being compliant with CRPD Principles and Articles, comparable to that expressed in Para 39 of the WHO *2013-2020 Mental Health Action Plan*, the *2014-2021 Global Disability Action Plan* and in the *Revised CBR Guidelines and Toolkits*.
- 3) Indicators listed in the Appendix should include WHO’s on-going work on *Mental Health Quality Rights Indicators* which have been designed to assess the impact of five CRPD Articles equally relevant to persons with dementia.

12. Action Area 2: Dementia Awareness and Friendliness

DAI members believe this must also include full and **equal access** to community, with the equivalent disability support all others with other disabilities receive, and have a right to demand under CRPD Article `19.

13. Action Area 4: Dementia Diagnosis, Treatment and Care

The current Prescribed Disengagement^{®vii} from a pre diagnosis life, is a breach of human rights. Support immediately after diagnosis must change to one that includes enablement, disability support and rehabilitation, as someone after a stroke would receive.

The sector continues to promote dependence on the health system, the burden of care is placed on family carers and health professionals, and the economic burden on families and governments.

RECOMMENDATION: the immediate post diagnostic support changes from late stage disease management to earlier stage diagnosis management and a rehabilitative approach that includes proactive disability support.

This will reduce dependence and with proper disability support increase independence and a person's capacity to live in their own homes for longer. It will also reduce the economic and human cost of care, and is a basic human right for all people with any type of brain injury or deficit, including dementia.

POSSIBLE INNOVATIVE INTERVENTION FOR LIVING WELL WITH DEMENTIA: THE IPT depression intervention

In better supporting people with dementia to live well with dementia, following the presentation and launch of the IPT depression intervention by Myrna Weissman, we suggest that if this was adapted to support people newly with dementia to live well with dementia it could prove to be a very innovative way of supporting independence and reducing the emotional and economic costs of dementia.

DAI is already in contact with her about this, and would support WHO's involvement. Our online support groups have already proven to re-empower and re-able people to live well with dementia and to become self-advocates or strong public advocates.

13. Action Area 5: Support for dementia carers and families

Firstly, we strongly recommend action areas for people with dementia are distinguished from those of family carers due to their very different needs.

A diagnosis of dementia can be a traumatic experience, resulting in symptoms associated with Post-Traumatic Stress Disorder. It frequently leads to social isolation because friends and relatives stop visiting. This isolation is compounded by the newly-diagnosed person not going out because of fear of failure.

Loss and grief counseling for the person with dementia must be included, as they experience deep feelings of loss and grief, and this untreated and usually unresolved grief becomes more complicated, making symptoms appear worse, and for many are the root of many of the behavioural changes.

RECOMMENDATION: A POST-DIAGNOSTIC REHABILITATION AND DISABILITY PATHWAY (FOR PEOPLE WITH DEMENTIA)

In our recent submission to the CRPD Committee, we proposed a 'Rehabilitation Pathway' comparable to that provided after a severe brain injury, a major stroke, traffic accident, penetrating gunshot wound or brain infection.

A rehabilitation pathway for dementia would begin at the point of diagnosis with an introduction to a rehabilitation specialist in the same way a person would be referred after a recoverable stroke or other brain injury.

A trained Key Worker should also be available to the individual or the care couple to discuss their needs and priorities and to provide links to a wide range of professional and community supports and services.

A rehabilitation pathway would include, but not limited to:

- 1) An occupational therapist to discuss possible adaptations to the home, domestic appliances, personal computers, adaptive programmes and phone apps to support people to live well in their own homes and continue to participate fully in life of their own community.
- 2) A disability advisor to support them to set up strategies for the person with dementia to implement disability strategies specific to their individual disabilities.
- 3) A physiotherapist to improve and maintain mobility, range-of-motion, strength, balance and co-ordination.
- 4) A speech and language therapist to facilitate language production, comprehension and communication upon diagnosis, not only to and to advise on swallowing difficulties when the disease progresses nearer to end of life.

- 5) A clinical psychologist to provide appropriate loss and grief counselling, and to counsel on adjusting to the diagnosis, monitor changes in cognition and social-emotional responses to dementia and to consider the need for appropriate psychosocial interventions to support quality of life^{viii}.
- 6) A social worker to consider family issues and provide access to community resources, including rehabilitative education, the re-learning of knowledge and skills needed for keeping a job, or simply to fulfil our right to lifelong learning, as stated in Article 24 of the CRPD.

12. Para 70 - COMMUNITY-BASED REHABILITATION

Community-based rehabilitation programmes were launched by WHO following the Alma Ata Declaration on Primary Health Care in 1978. They are now used in around 100 Low and Middle Income Countries and provide a home-based, first line of support for persons with disabilities and their families by local health and community workers and family members.

In 2010 WHO, UNESCO, ILO and the International Development and Disability Consortium (IDDC) published Revised CBR Guidelines and Toolkits fully based on CRPD.

In order to reach people with dementia in Low and Middle Income Countries and to reduce the risk of their exclusion from the implementation of SDGs, we propose that CBR should be extended to Older Persons, which would naturally include people at risk of dementia. DAI presented a video poster to the recent CBR World Congress held in Kuala Lumpur to support this policy and to suggest ways in which it could be promoted at local as well as national level.^{ix}

CONCLUSION

In conclusion, we are hopeful our recommendations will be carefully considered and included in the final draft, and there is a much stronger focus on human rights and the CRPD.

DAI believes it will be the full and equal inclusion of people with dementia in civil society including in their care, and the assignment of equal power between the service users, the service providers and the health care professionals and other experts that will have the greatest potential to create change and improve the quality of life of all people with dementia and their families or carers.

ⁱ Bryden, C. (2015) *Nothing About Us Without Us*; Swaffer, K. (2016) *What the Hell Happened to my Brain?*; Rohra, H. (2016). *Dementia Activist: Fighting for Our Rights* (English translation from German original); Whitman, L. (ed.) (2015) *People with Dementia Speak Out* (all published by Jessica Kingsley Publishers, London); Taylor, R. (2007, 5th printing 2015) *Alzheimer's From the Inside Out*. Baltimore, Md.: Health Professionals Press.

ⁱⁱ Australia, Scotland, England, Wales, USA, Canada, Nigeria, Japan, New Zealand, Indonesia, Singapore, Czech Republic, Germany, Italy and Mexico.

ⁱⁱⁱ Group Homes Australia; De Hogeweyk, Amsterdam, Weesp – NL; Dementia Village, Rome, Italy; Schlegel Villages, Ontario, Canada.

^{iv} Bredesen, D 2014, 'Reversal of cognitive decline: a novel therapeutic program', *Aging*, 6, 9, pp. 707-717

^v Bredesen, D, et al, (2016), Reversal of Cognitive Decline, *Aging*, Vol 8, No 6.

^{vi} www.unohrc.org

^{vii} Swaffer, K. (2013) "Prescribed Dis-engagement: what is it?." *Dementia*, Vol. 4, 3-6.

^{viii} British Psychological Society (2014) *A Guide to Psychosocial Interventions in Early Stages of Dementia*. www.bps.org.uk

^{ix} <https://www.youtube.com/watch?v=Qzcui3mLOUQ>;