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To cite this article: Suzanne Cahill (2020) WHO's global action plan on the public health response to dementia: some challenges and opportunities, *Aging & Mental Health*, 24:2, 197-199, DOI: [10.1080/13607863.2018.1544213](https://doi.org/10.1080/13607863.2018.1544213)

To link to this article: <https://doi.org/10.1080/13607863.2018.1544213>



Published online: 02 Jan 2019.



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WHO's global action plan on the public health response to dementia: some challenges and opportunities

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ABSTRACT

WHO's global action plan on the public health response to dementia (GAPD) approved by the World Health Assembly in May 2017 when fully implemented should make a tangible difference to the lives of people affected by dementia since it identifies seven priority actions areas, sets out parallel targets for countries to achieve and provides governments with the required framework to develop their own national dementia plans. The Plan reflects global solidarity on the world dementia stage: it is heavily embedded in rights-based principles and augurs much hope for people living with dementia and their family members. But what practical steps will be required of countries committed to ensuring that their policy plans comply with the GAPD? What are some of the tensions and contradictions embedded in the Plan? Who are the winners and losers in this Plan and what action will be required of civic society to ensure that countries step up to the challenge of dementia and develop and implement their own policy plans? How likely is that all of the targets set out in the Plan will be achieved by 2025? This paper discusses the relevance of the GAPD for policy makers and civic society and critically reviews aspects of the Plan highlighting some of the key challenges and opportunities the Plan is likely to pose.

ARTICLE HISTORY

Received 15 June 2018
Accepted 18 October 2018

KEYWORDS

Global Action Plan on dementia; human rights; challenges; opportunities; dementia strategies

Introduction

Alzheimer's Disease International define Dementia Plans as government led actions in which the government holds itself accountable to measurable objectives, whilst Dementia Strategies are collaborative partnerships usually between governments, non- government organizations and health and social care sectors (Batsch, 2016). Today some thirty-two nations around the world have developed their own National Dementia Strategies¹ of which only four belong to low and middle-income countries (LMICs) and twenty-eight new Strategies are at various stages of development (ADI, 2018). Despite some cross-national diversity, common across these Strategies is a commitment to the values of personhood and social citizenship (O'Shea & Carney, 2016), to a timely diagnosis, community awareness and to improving quality of care (Fortinsky & Downs, 2014) and quality of life.

Whilst the earlier Strategies/Plans like the first French National Plan for Alzheimer and related diseases (FNPAD, 2001–2005) and the English Dementia Strategy (DOHE, 2009) were strongly bio-medically driven, more recent Strategies {see for example Finland's National Memory Programme (MSAH, 2013), and the Dementia Action Plan for Wales, (LCWG, 2018)} have framed dementia as a public health issue emphasizing the importance of brain health, risk reduction and primary prevention. This makes sense according as more empirical evidence comes on stream, highlighting the important role cardiovascular risk factors play in heightening risk. A rights-based approach, with an emphasis on autonomy, self-determination, independence, participation, equity and choice is also beginning to

penetrate some countries' new dementia policy plans as for example in Belgium and Luxembourg and other countries' updated plans as for example in Scotland, Norway, the US and Australia (Cahill, 2018).

National Dementia Strategies are important and hugely needed as every new Plan creates opportunities for heightening awareness (ADI, 2018) reducing risk, challenging prejudicial attitudes, generating new knowledge and potentially improving the lives of all those affected by dementia. Although country specific Strategies are needed (Pot & Petrea, 2013), recent years have also witnessed a call for a European Strategy (see <https://www.alzheimer-europe.org/Policy-in-Practice2/Glasgow-Declaration-2014>) and a Global dementia Strategy (Rees, 2017). Possibly in response to these calls, along with improvements in scientific knowledge on the epidemiology of dementia, WHO has recently published its first Global Action Plan on Dementia (WHO, 2017). Now some eighteen months after its formal adoption by the World Health Assembly it seems timely to critically review aspects of this important Global Action Plan and highlight some of the key challenges and opportunities the Global Plan poses.

Global Action Plan on Dementia

The GAPD's vision is to create ... 'a world in which dementia is prevented and people with dementia and their carers live well and receive the care and support they need to fulfill their potential with dignity, respect autonomy and equality' (WHO, 2017, p. 6). This authoritative public health

response, builds on WHO's earlier dementia-specific policy documents {see for example 'Dementia a Public Health Priority', (WHO, 2012)} and on its inaugural 2015 Ministerial Conference on Global Action Against Dementia attended by representatives from close to 90 countries around the world. It has involved consultation with Member States, along with UN organizations and non-state actors. A powerful platform likely to have informed the GAPD was a joint response to the draft plan produced by the Alzheimer Disease International (ADI), Alzheimer Europe, (AE) the Dementia Alliance International (DAI) and Global Alzheimer's and Dementia Action Alliance (GADAA) (Rees, 2017).

The Plan outlines seven key action areas and in relation to each sets down targets for countries to achieve over the period 2017–2025. The priority actions are dementia:

- Action 1: as a public health priority,
- Action 2: awareness and friendliness,
- Action 3: risk reduction,
- Action 4: diagnosis, treatment care and support
- Action 5: support for dementia carers
- Action 6: information systems
- Action 7: research and innovation.

Regarding Action 1 and 5, targets set out are that by 2025, 75% of countries will have developed or updated national policies on dementia as either stand alone or integrated and will have provided support and training programs to carers and families of people affected by dementia. Targets set out for Action 2, are that by 2025, all countries will have at least one functioning public awareness campaign established and half of all countries will have at least one dementia friendly initiative. Regarding Action 3, targets set out relating to modifiable risk factors are multiple and include an overarching target of a 25% relative reduction in premature mortality from dementia by 2025. Targets set out for Action 4 and 6 are that by 2025, in at least 50% of countries, half of the estimated numbers of people with dementia will be diagnosed and that by 2025, 50% of countries will have collected core data on dementia every two years. Finally the target set out for Action 7 is the doubling of global research on dementia by 2025.

Relevance of GAPD to policy makers

The GAPD provides an authoritative blueprint for governments committed to improving quality of life for those affected by dementia and is considered a powerful agent for change (Rees, 2017). Countries are expected to establish focal points within government ministries to ensure sustainable funding for dementia. Although the Plan is not legally binding and WHO cannot compel Member States to commit, Ministries in all member states are obliged to provide regular progress reports (three times over the seven years) to WHO (Rees, 2017). Civic society including the ADI and its Members States must also hold countries and Members to account and intervene when governments do not deliver (Marc Wortmann, personal communication, 2017).

Relevance of GAPD for people living with dementia and their family members

The Plan generates new hope for people living with dementia and their family members because of WHO and

the ADI's leadership role in the area; InterDem and Alzheimer Europe's endorsement albeit unofficial of the Plan (personal communication with Myrra Vernooij Dassen and Jean George, 2018) and because of the potential the Plan has to change how dementia is experienced and understood by current and future generations. In the past, policy makers tended to frame dementia negatively and the legacy of this type of deficit-thinking is reflected in the design and ethos of many health and social care services which have been generic rather than personalized, clinical and custodial rather than empowering and restrictive rather than person-centred (O'Shea et al., 2015; Cahill, 2018). The human rights ideology underpinning the Plan challenges such nihilism. It calls governments to account and demands sustainable funding for dementia. But it also requires civic society including people living with dementia, their family members and representative organizations to monitor the way in which countries comply with the Plan. Human rights look good on paper but how exactly they become operationalized ultimately depends on resources and on the education, empowerment, energy and commitment of those most acutely affected by dementia, i.e. the individual living with the condition, their family members and advocacy groups.

Some challenges

Whilst some action areas and the corresponding targets set out by WHO may be achievable in the foreseeable future, like Action 2, with a target set that all member countries will have at least one functioning public awareness programme by 2025; others, like Action 7, with its target set of doubling the output from global research by 2025, is more highly ambitious, particularly in LMICs and in the absence of ring fenced funding set aside for dementia research. Already in a review of 23 member states' Plans reported on recently (ADI, 2018), research activities, when compared with other targeted activities in the Plan, have not been a key priority for many countries. Action 4, with its target set of ensuring that by 2025 at least 50% of the estimated numbers of people with dementia are diagnosed in half of all member countries, fails to consider the significant variation currently evident in diagnostic rates between LMICs and HICs. Also, the fact that to date only three out of twenty one countries (14%) have provided data on diagnostic rates for the Global Dementia Observatory (ADI, 2018) does not augur well for the more long-term achievement of this target. Action 1 with a target set that 75% of all member countries have a dementia plan in place by 2025 is highly ambitious. For the target to be reached it would mean on average 15 new plans per year, a target which is somewhat unrealistic particularly given how only one new plan has been adopted since the GAPD was first launched in May 2017 (ADI, 2018).

Whilst the Global Action Plan appears to place an equal emphasis on cause, cure, care and prevention the merger of a rights-based approach (with a focus on choice, autonomy and self-determination), with a public health paradigm (with its focus on risk factor control/compliance and lifestyle modification), will undoubtedly create its own tensions and contradictions. The rights-based approach also means that countries must ensure that their policies,

legislation and programmes are sensitive to the human rights of people with dementia as set out in the UN Convention on the Rights of Persons with Disabilities (CRPD, 2006) and other human rights instruments.

This requirement will prove difficult for some Western countries where outdated legislation exists on legal capacity; where substitute rather than supportive models of decision-making are in evidence and where policies and programmes fail to comply with Article 12 of the UN Convention (CRPD, 2006). Article 12 refers to the right to legal capacity. This means that every person has the right to be both the holder and executor of legal rights and must be treated equally before the law. It means that in cases where people can no longer exercise their legal capacity, such as in the case of a person with a more moderate to severe dementia, assistance must be provided to that person to support their decision-making. The principle of 'universal health and social care coverage' wherein countries are required to provide a broad range of services, including palliative, rehabilitation and social support (WHO, 2017, p. 6), is also likely to pose challenges. Although only a principle and not a prioritized action, if linked to Article 19 –'the right to choose one's place of residence and have the personal assistance needed to support living in the community', the principle could open up new zones of freedom for many people living with dementia.

Some opportunities

A challenge in developing any new policy initiative is how proposed actions will affect both future and current generations. In this context, the GAPD with its public health and primary prevention focus, yet its emphasis on diagnosis treatment and care has been most successful in targeting both generations. A further strength of the Plan rests in the important emphasis it places on research, data collection and monitoring since the latter is critical for evidence-based clinical practice and service planning. Another laudable aspect of the Plan is the fact that WHO has agreed to provide technical advice to countries developing or reframing their national plans and WHO is already engaged in a number of activities directly related to the GAPD. Examples here include the development of support for carers (iSupport with online training for carers) and designing a framework for a Global Dementia Observatory. The establishment of this Global Dementia Observatory is important as it means that countries are obliged to report progress and showcase activities against targets set down. The Global Dementia Observatory also plays a key role in supporting countries to measure progress on the Actions outlined in the Plan and assists countries in strengthening their policies, service planning and health and social care responses to dementia. These top down approaches are desirable but what is also needed is concerted action on the part of all stakeholders to create a society truly inclusive of all people living with dementia and their family members.

Summary and future directions

As a policy document, the GAPD is comprehensive, business like and reflects much solidarity on the world dementia stage. However these are early days yet and what remains unclear is how certain countries will step up to the

challenge this Plan poses: how leadership in dementia will develop especially in LMICs, how effective advocacy groups will be in lobbying for change and how influential the ADI, AE and civic society will be in holding countries to account who fail to deliver on this Plan. The best case-scenario is that by 2025 the Global Action Plan will have played a lead role in helping to prevent most dementias and for those who do develop dementia, in promoting, respecting and fulfilling the individual's human rights so that people and their families can live well and enjoy a good quality of life. The worse case-scenario is that awareness campaigns and risk reduction programmes will yield no dividends, prevalence rates especially in LMICs will continue to soar, the public health approach will generate a culture of blame and shame thereby reinforcing stigma and many countries will produce glossy policy plans but fail abysmally in terms of their implementation and evaluation.

Note

1. Although ADI differentiate between the terms Dementia Strategy and Dementia Plan, for the purpose of this editorial these terms are used interchangeably.

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