Dementia Friendly, Dementia Capable, and Dementia Positive: Concepts to Prepare for the Future

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With an aging global population, the number of dementia cases is growing exponentially. To address the upcoming dementia crisis, the World Health Organization and Alzheimer’s Disease International (2012) collaborated on an extensive report, Dementia: A Public Health Priority. In the United Kingdom, Prime Minister David Cameron initiated a national challenge on dementia, forming 3 dementia challenge champion groups aimed at improving health and care, creating dementia-friendly communities, and promoting dementia research. In the U.S., President Obama signed the National Alzheimer’s Project Act, which led to the formation of the Advisory Council on Alzheimer’s Research, Care, and Services and the launch of the first National Plan to Address Alzheimer’s Disease. The term “dementia capable” was introduced in the 2012 Recommendations of the Public Members of the Advisory Council and has since been adopted in both the recommendations and annual updates of the national plan. This paper will first compare and contrast government usage of the concepts dementia friendly and dementia capable, along with another valuable concept, dementia positive, that was added after reviewing the literature. Finally, a new vision statement for the U.S.’ national plan will be proposed and recommendations incorporating these 3 concepts in policy, research, and practice will be made.

Key words: Dementia policy, Alzheimer’s disease, Essential dementia-related concepts, Social inclusion
In 2013, estimates suggested that more than 44 million people worldwide were living with dementia. As the world’s population ages, this number will surpass 135 million by 2050 (Alzheimer’s Disease International [ADI], 2013). The growing number of dementia cases has extensive economic and societal impacts. Economically, dementia cost the world approximately $604 billion in 2010 (Wimo & Prince, 2010). Societally, in the United States alone, more than 15 million Americans provided unpaid care to those with dementia in 2013 (Alzheimer’s Association, 2014). As pointed out by the World Health Organization (WHO) and ADI (2012), “There is little doubt that dementia poses one of the greatest societal challenges for the 21st century that must be addressed internationally, nationally and locally, as well as at family and personal levels” (p. 90).

In order to better prepare the United States for this upcoming crisis, President Obama signed into law the National Alzheimer’s Project Act in 2011. The same year, the Advisory Council on Alzheimer’s Research, Care, and Services was formed. The duties of the Council included reviewing the draft of the national plan, making priority recommendations, evaluating the implementation, and updating the national plan annually. In 2012, the original National Plan to Address Alzheimer’s Disease was released, followed by its 2013 and 2014 annual updates (U.S. Department of Health and Human Services [HHS], 2012b, 2013b, 2014b). The national plan vision statement says:

For millions of Americans, the heartbreak of watching a loved one struggle with Alzheimer’s disease is a pain they know all too well. Alzheimer’s disease burdens an increasing number of our Nation’s elders and their families, and it is essential that we confront the challenge it poses to our public health. (HHS, 2012b, p. 8)

Guided by this vision, much has been improved. Now is the time to further alleviate the heartbreak, pain, and burden, as well as better prepare the nation for this upcoming public health challenge by incorporating dementia-friendly, dementia-capable, and dementia-positive elements into policy.

In this paper, we review the national dementia plans of the following countries, comparing and contrasting how they incorporate the concepts of dementia friendly and dementia capable: Australia, Canada (subnational plan), England, Finland, France, Northern Ireland, Israel, Malta, the Netherlands, Norway, Scotland, the United States, and Wales. Due to a lack of English-translated versions, we are unable to review national plans of several countries, including Denmark, Japan, Luxembourg, the Republic of Korea, and Switzerland. As various terms such as plan, policy, strategy, or framework are used by different countries, we use the term “plan” to include all the varieties, except when we refer to the specific title of a document. Additionally, we consider a third concept, dementia positive. Although it has not yet been promoted through government programs, the concept of dementia positive brings new insights that complement the concepts of dementia friendly and dementia capable, thus demanding further examination. Finally, we propose a new vision statement for the U.S. national dementia plan that incorporates the concepts of dementia capable, dementia friendly, and dementia positive, with recommendations for policy, practice, and research.

### Dementia Friendly

In 2012, with an intent to “raise awareness of dementia as a public health priority, to articulate a public health approach and to advocate for action at international and national levels based on the principles of inclusion, integration, equity, and evidence” (WHO & ADI, 2012, p. 2), WHO and ADI jointly released an extensive seven-chapter report, Dementia: A Public Health Priority. In Chapter 6, “Public Understanding of Dementia: From Awareness to Acceptance,” WHO and ADI presented a six-stage “Acceptance of Dementia” model, including: Stage 1: Ignoring the problem; Stage 2: Some awareness; Stage 3: Building dementia infrastructure; Stage 4: Advocacy efforts; Stage 5: Policies and dementia plans or strategies; and Stage 6: Normalization (see Figure 1). Even though the
report acknowledged that the normalization of dementia has yet to occur anywhere in the world, WHO and ADI (2012) believed that “a promising approach towards this stage is the concept of ‘dementia-friendly communities,’ which are emerging in some places” (p. 88). As of 2014, many countries worldwide have achieved Stage 5 status of dementia acceptance through the development of their national dementia plans. With the premise that building dementia-friendly communities is key to the final stage of dementia acceptance (Stage 6: Normalization), an examination of the governmental usage of the concept of dementia-friendly in their national dementia plans is timely.

Dementia Friendly in National Dementia Plans

Among the 13 countries we reviewed, some used the term “dementia friendly,” whereas others did not. It is noteworthy that Finland presented a special case by using a broader concept of memory-friendly and that the Scottish government proposed dementia-supportive communities instead of dementia-friendly communities. Among the countries that used the term “dementia friendly,” some applied it to physical environments only, whereas others applied it to a broader context, such as communities. The term was not specifically defined in the government documents we reviewed, but a shared concern for the user experience/living experience of persons with dementia (PWDs) could be inferred through the contexts.

National Dementia Plans that Applied the Concept of Dementia Friendly Explicitly

The concept of dementia friendly was applied to the physical environments in both Scotland’s first national dementia plan (Scottish Government, 2010) and the Northern Irish national dementia plan (Department of Health, Social Services and Public Safety [DHSSPS], 2011). In its first national plan, the Scottish Government (2010) suggested that “the hospital environment and the care and treatment the person experiences need to meet the standard expected for any patient and to be appropriate for somebody with dementia. This includes making the physical environment of the hospital more dementia-friendly” (section 65, para. 1). Similarly, in the Northern Irish national plan (DHSSPS, 2011), the term “dementia friendly” was applied to standards of care for the physical environment by requiring an “environmental audit . . . to make [care] homes more dementia friendly” (section 10.8, para. 1).

Even though the term “dementia friendly” did not appear in England’s national plan, Living Well With Dementia: A National Dementia Strategy (Department of Health [DH], 2009), this plan provided a solid foundation for the dementia-friendly movement set forth by the government of the United Kingdom 3 years later. In 2012, building on Living Well With Dementia, Prime Minister David Cameron initiated a national dementia challenge to mobilize both government and society to address the anticipated impact of future PWDs on their National Health Service and social care. In the document Prime Minister’s Challenge on Dementia (DH, 2012), three key areas for action were proposed: (a) driving improvements in health and care, (b) creating dementia-friendly communities that understand how to help, and (c) better research. Notably, according to the document, the notion of “dementia-friendly communities that understand how to help” should be apprehended from the standpoint of PWDs:

We would like people living with dementia to be able to say that they know what they can do to help themselves and who else can help them, and that their community is working to help them to live well with dementia. (DH, 2012, p. 12)

In a similar fashion, the Scottish Government (2013) applied the term “dementia friendly” to the context of communities in its second national plan, Scotland’s National Dementia Strategy 2013–2016, and listed “dementia-enabled and dementia-friendly local communities, that contribute to greater awareness of dementia and reduce stigma” (p. 5) as one of the seven strategy outcomes.

In 2014, the Maltese Parliamentary Secretariat for Rights of Persons with Disability and Active Ageing published the National Dementia Strategy: Malta 2015–2023. Unlike the first Scottish plan and the Northern Irish plan that applied the concept of dementia friendly only to physical environments, the Maltese government applied this concept both to physical and social environments (e.g., dementia-friendly attitudes). Moreover, instead of applying the concept to a broad context such as communities, as seen in the U.K.’s Prime Minister’s Challenge on Dementia (DH, 2012) and the second Scottish plan (Scottish Government, 2013), the dementia-friendly terms mentioned in the Maltese national plan were more specific, with narrower contexts such as “dementia-friendly wards” and “dementia-friendly measures” (for monitoring community care homes; Maltese Parliamentary Secretariat for Rights of Persons with Disability and Active Ageing, 2014).

Special Cases: Memory Friendly and Dementia Supportive

In 2013, the Finnish Ministry of Social Affairs and Health published its national plan, National Memory Programme 2012–2020: Creating a “Memory-Friendly” Finland, which addressed both dementia and brain health.
As defined by the Finnish Ministry of Social Affairs and Health (2013), “A ‘Memory-Friendly’ Finland is a society that takes the promotion of brain health and the early detection of cognitive symptoms seriously” (p. 8); it is a society in which “anyone diagnosed with a cognitive problem or dementia has access to appropriate treatment, care and rehabilitation” (p. 8), and it ensures that “patients can lead their lives with dignity, and they will not be left without support” (p. 8). Finland’s emphasis on brain health and cognitive functioning is similar to that of the Healthy Brain Initiative established by the U.S. Centers for Disease Control and Prevention (2014), but with an additional emphasis on dignity.

The Welsh national plan, National Dementia Vision for Wales: Dementia Supportive Communities, was released in 2011 (Llywodraeth Cynulliad Cymru Welsh Assembly Government [WAG], 2011). Rather than promoting dementia-friendly communities, the plan advocated for the creation of dementia-supportive communities. As explained in the document, creating dementia-supportive communities “requires a change in attitudes and behaviors towards dementia at all levels of society, which reflect the challenge of demographic change and the impact of dementia” (WAG, 2011, p. 4). Also, “It requires a society in which people with dementia, and those who care for them, are treated with the dignity and respect they deserve, along with the help and support they need” (WAG, 2011, p. 4). In another section of the document, dementia-supportive communities were referred to as “communities which have the capacity to support people affected by dementia so they can enjoy the best possible quality of life” (WAG, 2011, p. 5).

National Dementia Plans without Mention of the Term “Dementia Friendly”

The term “dementia friendly” was not found in the national plans of the following countries: Australia, Canada, France, Israel, the Netherlands, Norway, and the United States.

Dementia Capable

According to ADI (n.d.), the worldwide federation of Alzheimer associations, the creation of national governmental plans to address dementia is imperative in that “unlike international initiatives, these plans are capable of addressing the problem using a system tailored to the unique culture and demographics of each country” (para. 1) and that “government dementia plans can promote the creation of infrastructure and accountability necessary to build dementia-capable programmes for the growing number of people with the disease” (para. 2). In other words, in addition to its flexibility in creating a system that fits each nation’s unique cultural and demographic backgrounds, a national dementia plan is in the position to mobilize national resources to establish dementia-capable programs. Interestingly, we found that dementia capable is a concept unique to the U.S. documents and that there is no mention of this term in any other country’s documents that we reviewed. Regardless, this concept has developed into one of the greatest fortes of the U.S. national plan, guiding the creation of nationwide dementia-capable workforces, services, and programs.

What Is Dementia Capable?

There are at least two meanings to the term “dementia capable.” It can refer to something that PWDs are able to do/enjoy (similar to “dementia friendly”). It can also be interpreted as an ability (a combination of staff knowledge, skills, and competency as well as available programs and services) to fulfill the needs of PWDs and their caregivers. In the U.S. national dementia plan and relevant documents, the term “dementia capable” refers to the latter (HHS, 2012a, 2013b).

The exact term “dementia capable” first appeared in the Recommendations of the Public Members of the Advisory Council on Alzheimer’s Research, Care, and Services (HHS, 2012a) before it was officially adopted in the update of the national plan (HHS, 2013b). The concept of dementia capable was in fact present in the original national plan as well, but was represented under a similar term, AD-capable or Alzheimer’s disease-capable. Since the adoption of the exact term “dementia capable” in the 2013 update, it remains the preferred term.

Dementia Capable in the U.S. National Plan and Related Documents

The U.S. national plan utilized five fundamental goals to organize all of the underlying strategies and action plans: (a) prevent and effectively treat Alzheimer’s disease by 2025; (b) enhance care quality and efficiency, (c) expand support for people with Alzheimer’s disease and their families; (d) enhance public awareness and engagement; and (e) improve data to track progress. In the original national plan, the concept of dementia capable was applied to strategies and actions under Goals 2 and 3. In the 2013 and 2014 updates of the national plan, the usage of dementia capable was expanded to apply to strategies and actions under Goal 4 as well (HHS, 2013b, 2014b).

Through tracking the concept of dementia capable (including AD-capable) across the original plan (HHS, 2012b), updates (HHS, 2013b, 2014b), and
Dementia Friendly Versus Dementia Capable

According to the “Acceptance of Dementia” model proposed by WHO and ADI (2012), the ultimate solution to the approaching dementia challenge is to create a society where dementia is normalized and accepted as a disability. Both the dementia-friendly approach led by the European Union countries and the dementia-capable approach carried out in the United States can be promising in reaching this goal, regardless of the differences in their focuses. Despite the fact that both approaches can be interpreted as efforts to create better support for PWDs and their families, the dementia-friendly approach focuses on the living experience/user experience, whereas the dementia-capable approach focuses on special needs. With a focus on the living experience/user experience, the dementia-friendly normalization process requires modifications of the living environment (involving people, resources, places, activities, cultures, technologies, and so on) to ensure that PWDs and their families can enjoy a normal life in their communities for as long as possible. With a focus on special needs, the dementia-capable approach adapts the U.S. language and philosophy of care for persons with disabilities to serve PWDs and their families and ensure their needs are met. Both approaches encourage inclusion and acceptance, but an interesting difference is that the dementia-friendly approach attempts to include PWDs and their families in the community directly, whereas the dementia-capable approach uses a two-step approach, where Step 1 involves inclusion into the disability community and Step 2 promotes inclusion into the society at large through being a member of the disability community.

Would Dementia Friendly Be a Good Addition to Dementia Capable?

The concept of dementia capable represents a unique strength in the U.S. national dementia plan. Through adopting the concept of dementia capable, U.S. dementia care, workforces, services, programs, and systems are all organized under a central theme. Unlike other national plans, fragmented efforts to tackle dementia-related issues separately, the U.S. dementia capability is an integrated force consisting of both the person/workforce issues (knowledge, skills, competency) and the structure/system resources (programs and services), designated to address all special needs (the ultimate goal) of PWDs and their families. The following description of dementia-capable systems illustrates this unique integrated force:

In model dementia-capable systems information and assistance services identify those with dementia who contact them, options counseling staff have specialized communication skills they use with PWDs and their families, and public and private services programs offer services tailored to the unique needs of this population. To promote optimum quality of services, self-direction is a viable option for those with dementia and their family caregivers, workers at all levels have dementia training, and the quality assurance system incorporates some measures of progress toward dementia capability. (U.S. Administration on Aging & Alzheimer’s Association, 2011, p. 11)

This is a description of a potent system that utilizes the concept of dementia capable; however, does it speak to “a meaningful life”? According to Kitwood (1997),

A man or woman could be given the most accurate diagnosis, subjected to the most thorough assessment, provided with a highly detailed care plan and given a place in the most pleasant surroundings—without any meeting of the I-Thou [person to person; the whole being] kind ever having taken place. (p. 12)

Comparably, a dementia-capable system may demonstrate excellence in addressing all of the needs, but the living experience of the person may be overlooked. Without the addition of the concept of dementia friendly, which focuses on the living experience, we run the risk of reducing the person-to-person interaction to an impersonal “service-need” relationship. In another light, the living environment influences the manifestation of abilities and disabilities (or special needs). Through the creation of a dementia-friendly
living environment that supports and sustains the lifestyles of PWDs and their families, some of their needs may be naturally nurtured, which in turn may reduce the pressure of boosting workforces and services quickly enough to keep up with the rapidly increasing number of individuals and families affected by dementia. Finally, the addition of dementia-friendly components to the dementia-capable approach will help accelerate the social inclusion process for individuals with dementia and their families. Although efforts are being made to include dementia into the disability culture, parallel efforts can be made to help PWDs and their families integrate into the society at large.

Dementia Positive

The first two concepts, dementia friendly and dementia capable, address the living experience and needs of PWDs and their caregivers. However, in order to achieve a true normalization stage—or real social inclusion of PWDs and their families—we need to bring in a third concept, dementia positive. In this paper, dementia positive is defined as positivity towards dementia with an intentional emphasis on strength finding, manifesting through attitudes, beliefs, communication, and behaviors. This concept is similar to the concept of dementia supportive in the Welsh national plan (WAG, 2011). However, dementia positive demands not only changes in attitudes and behaviors, but also changes in beliefs and communication, and that dementia positive has a strong emphasis on strength-finding. The addition of positive beliefs is essential because positive attitudes alone only represent changes in value. With positive attitudes, people may agree PWDs deserve to live a meaningful life, but without positive beliefs, they may not believe PWDs can actually live a meaningful life. The addition of positive communication (e.g., sounds, words, body language, images) is imperative because it conveys meanings and influences society’s attitudes and beliefs towards dementia. These positive behaviors are essential because they lead to practical changes in the life of PWDs and their families. Finally, the underlying principle of strength-finding affirms that just as everyone else in the world has strengths and weaknesses, so do PWDs.

In order to better illustrate the necessity of dementia positivity, let us first picture what a society that is dementia capable and dementia friendly, but not dementia positive would be like. This hypothetical society would have the following: (a) a sufficient number of highly trained staff and providers (e.g., health care, social services, private sectors) equipped with dementia-specific knowledge, skills, and competencies, paired with diverse programs and services tailored to address the special needs of PWDs and their families; (b) communities consisting of people who are aware of dementia, knowing how to help and to interact respectfully with PWDs; (c) opportunities for PWDs and their families to remain engaged with society; (d) environmental modifications to ensure safety and accessibility; and (e) activities and places PWDs and their families would enjoy. At first glance, this society seems to have everything to ensure a good life for PWDs and their families. However, without dementia positivity, it is merely a society that tolerates and respects differences. It is merely a society that supports or takes care of its members. It is not a society that truly sees PWDs as equal contributors.

The desires of PWDs to make contributions to society and be seen as persons with strengths and abilities have been documented in books written by PWDs and their advocates alike, such as Christine Bryden’s (2012) Who Will I Be When I Die, John Zeisel’s (2010) I’m Still Here, and Anne Davis Basting’s (2009) Forget Memory, to name a few. PWDs want society to accept their disabilities. They also want society to see their strengths and abilities. Without dementia positivity, regardless of how well the society provides resources, accommodations, services, activities, and opportunities for PWDs and their families to stay engaged, it is merely a pseudo social inclusion.

Recommendations

In this paper, we reviewed the usage of the concepts of dementia friendly and dementia capable in the dementia plans of 13 different countries. We also discussed how a third concept, dementia positive, would be an essential complement to these two concepts. Although “dementia friendly” has gained increasing popularity internationally, “dementia capable” represents an integrated force of dementia resources in the United States, whereas “dementia positive” leads to a truly inclusive society for PWDs and their families. In order to be better prepared for the upcoming dementia crisis and to enter the normalization stage of the WHO and ADI’s (2012) dementia acceptance model, we recommend that the U.S. government (a) expand the existing concept of dementia capable from health care, social, and legal services to include research, education, urban planning, and community living, which will serve to create a comprehensive dementia-capable alliance and (b) complement this comprehensive dementia-capable alliance with the concepts of dementia friendly and dementia positive. We recommend the addition of modules on dementia friendliness and dementia positivity into the existing curriculum for health care providers and as part of staff training for all dementia-related services. We recommend the establishment of a dementia-friendly, dementia-capable, and dementia-positive research system, where (a) sufficient funding is granted not only to biomedical research,
but also to social science research; (b) the priority areas include effective dementia treatment and prevention, as well as interventions to promote social inclusion and daily living for PWDs and their families; and (c) all scientists and staff are considerate of the user experience of PWDs from recruitment to follow up (e.g., dementia-friendly consent progress) and possess positivity toward dementia. For health care professionals and services providers, we recommend the practice of (a) an open, positive attitude toward PWDs and their families; (b) positive beliefs that you are making a difference regardless of the severity of the person’s dementia and beliefs that PWDs are capable of living a more normal, meaningful life with your help; (c) positive communication with PWDs and their families conveying confidence and hope; (d) positive behaviors, such as collaborating with PWDs and their families to identify strengths and abilities; and (e) an understanding of the living experience of PWDs and their families. In the end, we would like to propose a new vision statement for the U.S. national dementia plan: For millions of Americans, the heartbreak of watching a loved one struggle with Alzheimer’s disease is coming to an end. The vision of this national plan should propose that the United States is a dementia-friendly community whereby all individuals with dementia and their families are empowered to live a meaningful life, inspired by dementia positivity, and well taken care of by a comprehensive, integrated dementia-capable alliance.

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References

