



**Alzheimer's Disease
International**

The global voice on dementia

National Dementia Plans: Engagement of People with Dementia

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May 2017

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The purpose of this review is to study the involvement of people living with dementia in policy and decision making. This report is divided into two main sections:

- A review of the involvement of people living with dementia in the development of national and sub-national dementia plans.
- A more general review of qualitative information gathered from experts in the field about how and how often people with dementia and care partners are involved in decision making and approached for their views on what is important to them.

Involvement of People with Dementia in National Dementia Plans

An increasing number of countries are developing national, as well as sub-national, plans to address dementia. These plans are developed in various ways, and a review of 20 national plans and 51 sub-national plans (six regional plans, 44 state plans from the USA, and one state regional plan from the USA) was conducted in order to study how people with dementia were included in the development process.

First, plans were reviewed to see if people with dementia were included as members of a task force, working group, or committee set up to directly input into the content of the plan. If there was no mention of this, then we looked to see if people with dementia were involved in another capacity (*see appendix for detailed review findings*).

From the review, it is evident that people with dementia fall into three categories in terms of involvement in the development of dementia plans:

- People with dementia were included as members on a task force, working group, or committee
- People with dementia were involved in a public comment period or consultation process
- There was no mention of involvement by people with dementia

Of the 20 national plans reviewed, the following was found:

- One plan stated that people with dementia were included in their working groups
- One plan requires two Alzheimer's Patient Advocates to be on the Advisory Council on Alzheimer's Research, Care, and Services, which helped create - and now update - the national plan annually
- Five plans involved people with dementia in workshops or consultation/dialogue/questionnaire processes, or mention that the plan was informed by the views of people with dementia
- The remaining 14 plans do not specifically mention the involvement of people with dementia in the development of their national plans, but that does not necessarily correlate with no involvement of persons with dementia.

For sub-national plans:

- One regional plan held consultation workshops that included people with dementia
- One regional plan describes people with dementia as key stakeholders in the development of the plan

For the state plans from the USA:

- 20 state plans included people with dementia on their task force, commission, committee or working group
- 10 state plans described engaging people living with dementia in advising, listening sessions, or public comment periods
- Several other state plans used public comment sessions or surveys for public input during the development, but they did not declare that they expressly engaged people with dementia.

Limitations

It should be noted that analyses of seven of the 20 national plans is based on unofficial Google translations of national plans into English. Two of the six sub-national plans are also based on unofficial Google translations.

Also, where this review states that plans do not mention the involvement of people with dementia in their development, this does not necessarily mean that there was no involvement of people with dementia. The search terms used for this review were “dementia”, “Alzheimer’s” and “consumer” and it is recognised that other words or terms may have been used. In addition, some plans simply listed names of the individuals involved, and do not describe who they were or why they were involved.

What people with dementia want in their lives

The purpose of this second part of the review was to gather qualitative information from experts in the field about how and how often people with dementia are being approached to share their thoughts on what they want in their lives and how they expect and hope their lives will change with a disease modifying treatment. We asked experts three common questions to get a better sense of how the field is approaching this topic. These questions were:

1. What are you hearing about this topic?
2. Do you know of anyone trying to gather this information on an empirical basis?
3. What are your thoughts on this topic, i.e. is enough attention being placed on it?

Lisa Loiselle, Associate Director of Research at the Murray Alzheimer Research and Education Program (MAREP)

- Often hears people have conversations about what people living with dementia want.
- Feels that people say that they are doing things in the best interest of the person living with dementia, but they are not actually asking the person.
- Assumptions are often made about treatment and there is not a lot of input from the person with dementia. Care partners are asked for their opinion, and then just circle around the individual living with dementia in the conversation, rather than actively involving them. Does not think people realise that this is a gap in the field.
- Professionals talk about the importance of including people living with dementia. However, a number of professionals say that people with dementia are being included, but inclusion to them means thinking of them as participants not as designers or decision makers.
- Believes that programmes will fail if we do not know about the hopes and expectations of people living with dementia.
- In the production of MAREP's "By Us For Us" guides, they talked to hundreds of people living with dementia.
- People living with dementia place more emphasis on living than the medical aspects of their diagnosis.
- Recommended and described "Living and Celebrating Life through Leisure" as MAREP's most comprehensive research piece on information gathered from people living with dementia.

Mary Schulz, Director of Information, Support Services and Education at the Alzheimer Society of Canada

- Believes that there is a good portion of research that looks at expectations of families versus residents within long-term care. Within this, families often focus on the physical care, whereas residents focused more on relationships and engagement.
- Described a hypothesis that she has concerning family care partners: that they may think more about a cure than the person with dementia does because they are thinking about their own risk in the future.

- There is a lot of work on the rights of people with dementia, but with little heard from the average person with dementia. Those with younger onset dementia, under the age of 65, are more willing to speak out, but it is a challenge to reach others, such as those who are less educated.
- There has been a history of not talking to the person with dementia. For example, prior to medication for the disease, professionals did not talk to people with dementia because they were often diagnosed so late. The profession has shifted and there is more focus now on including the person with dementia.
- In terms of studies of what people with dementia want, hope, and expect, outside of long-term care, Mary rarely encounters research in this area, while she regularly sees research on most other topics.
- Recognises how challenging and time consuming it can be to engage people with dementia.
- After recognising that they were not involving people with dementia effectively, the Alzheimer's Society of Canada created a resources on this topic.
- People with dementia want to help build projects from the ground up, creating a partnership model, and this can be a learning curve for professionals in the field.

Laura Bowley, Mindset Centre for Living with Dementia

- There is not enough attention being placed on understanding what people with dementia want in their lives.
- Hopes that someone is gathering input from people with dementia on what they want in their lives, but would not be surprised if no one was.
- In its own way, To Whom I May Concern (TWIMC) gathers evidence. It is a performance tool for asking people with dementia, "What is it like? What do you need? What are your hopes, your dreams?" TWIMC gets people talking, breaks down barriers between those who have dementia and those who seek to understand dementia, and humanises the experience of dementia. A "Sharing Group" of people with dementia get together with a trained facilitator for a series of meetings, usually weekly for six weeks. Within the group, they share (with each other and the facilitator) their stories of living with dementia, which are then incorporated into a script by the facilitator. The script is based on a general letter addressed "To Whom I May Concern". The "I" highlights the fact that they are people, not objects, not "its" with a disease. The script tackles issues such as the diagnosis experience, how people adapt to cognitive changes, how they would like others to adapt, their challenges and their hopes for the future. The script is reviewed and approved by the group. The group rehearses the script, helps make the arrangements for the performance and design the invitations and announcements, sends out invitations to family, friends, and community members. On the big day, group members perform the script in front of a live audience. All of the performers have dementia. The performance is followed by a Talk Back session, where the audience can speak directly to the performers, ask questions, comment, and give feedback.

TWIMC is also piloting a new approach of reaching out to people individually in their homes at a retirement community to recruit people. They have found that this is the first time some people are being told of their dementia diagnosis because their families did not want them to know. They are going door-to-door as putting up a poster to attract people was not enough, and they realised that nobody is going door-to-door to reach out to the average person with dementia. Most of the time, once people receive a diagnosis "they just go home".

- Facilitated an online video conferencing support group of people with dementia for two years, meeting every week. This gave a good sense of what people with dementia want in their lives.
- Senses that there are few support groups both online and in-person, and believes that those with younger onset dementia may be more likely to seek out online support groups.
- A person's expectations of a disease modifying treatment may differ depending on what they are told the outcome of their treatment may be. Experiences with doctors vary greatly. Doctors don't seem to always fully explain the treatment and people are often told, "here's a prescription, come back in six months".
- The Ontario Advisory Group, which helps advise the government, is comprised of only people with dementia.
- There are still issues with involving people with dementia. For example, Health Quality Ontario in Canada recently released a document on what a person with dementia should expect when visiting a doctor. Health Quality Canada did not ask people with dementia for their input when putting this document together.

Monica Moreno, National Director of Early-Stage Initiatives & E-Services at the Alzheimer's Association National Office, and Emily Shubeck, Early-Stage Initiative at the Association's National Office

- The Alzheimer's Association Early Stage Advisory Group started in 2006, following concern about the lack of involvement of people in the early stages of dementia. Prior to this, the Association was more geared towards caregivers. They held four events to hear about the lived experience of people with dementia, such as: what prompted them to go to the doctor; what the diagnostic process was like; what challenges they experience; and how they deal with stigma. The Alzheimer's Association brings on board a new advisory group every year. They have rolling nominations year round, and nominations can come from chapters or self-nominations. Each year, the number of nominations has been increasing, and there are 10 places on the Advisory Group. Advisors must have a diagnosis of MCI or of dementia/Alzheimer's. The Association has a one-hour phone call with each nominee, during which they look at the ability of the individual to articulate their story. The Advisory Group does the following: raises awareness of the disease; provides input on the development of support programmes; and, leverages voices for public policy. They have two in-person meetings, where they fly the person living with dementia and their companion to one meeting in Chicago and one meeting in Washington, D.C. The Advisory Group also has monthly conference calls, during which they may talk about projects, have guest speakers, or give input on a project or something that has been written. Members of the Advisory Group may also receive email surveys throughout their term asking for their input. There is also an active alumni group. Some chapters have local Advisory Groups, but the structure of those programmes may be different. Monica and Emily do not know of any other organisation that has an Advisory Group that consistently engages as much as they do, and the Association has dedicated staff for this initiative. The impact of the group was described as phenomenal. They have garnered media coverage, received training, and are prepared to participate in governmental groups that have decision making power.

Both Monica and Emily recognise that the Advisory Group is representative of only a small percentage of people with dementia, and that millions of others may feel the stigma, or want to hide or ignore their diagnosis. There is difficulty with engaging diverse groups in the Advisory Group as well.

- The desire for people in the early stage of dementia appears to be to live a meaningful life and stay engaged, which was evident from the initial Advisory Group events and has since been reinforced and solidified. It was pointed out that nowhere on their website did it mention how to live with the disease, which prompted the Association to start running surveys, gathering feedback, and talking with advisors about this topic. Based on these findings, the Association created a webpage written to the person with the disease, and tip sheets for living with the disease.
- The Association are currently working on interactive micro-learning modules on living well with dementia (six dimensions of wellness). They had no empirical information, so they engaged Boston Consulting to survey people with dementia about living well (these results are in an internal report), and they found that people want to live well with dementia, but aren't sure how.
- Often people who participate in clinical trials know that they won't see a treatment in their lifetime, but they express that they are doing it for future generations.
- Currently, the majority of people with a diagnosis are not fully educated on what a "disease modifying treatment" is and some may think this means cure. A study into how people with dementia would define a disease modifying treatment could produce interesting results.

Themes and conclusion

- One theme that is of importance to note, is that almost every interviewee suggested that we interview people living with dementia.
- Many interviewees also explained how it is difficult to reach out to the average person living with dementia, and that there do not seem to be many initiatives actively pursuing this.
- Most of the interviewees said that they did not know of many people or resources that are gathering empirical information on what people with dementia want in their lives, or what they hope and expect from a disease modifying treatment. However, most of them did talk about a few resources that they have been involved with or know of that gather evidence related to this topic.
- It would be interesting to learn how people with dementia became involved in the development of national dementia plans and how they were recruited, as well as who decided the level of involvement or decision-making capacity.

Overall, based on this review, there appears to be a grey area where professionals are trying to establish the best way to effectively involve people with dementia, but there are discrepancies in how people think this should be done. While some may feel participation is enough, others stress the importance of decision-making opportunities for people with dementia. There is also evidence of this in the development of national and sub-national dementia plans.

Appendix

Below are the detailed findings from the review of the development of each national and sub-national dementia plan, and the involvement of people with dementia in this process. Details highlighted in bold denote areas of direct involvement of people with dementia.

Links to the plans included here can be found online at www.alz.co.uk/dementia-plans/national-plans

Nation	Details of plan development
Australia	<p>“This National Framework for Action on Dementia 2015 - 2019 (the Framework) has been developed under the auspices of the Australian Health Ministers Advisory Council (AHMAC) following an extensive national consultation process involving people with dementia, their carers, families, peak bodies that represent them, clinicians and service providers.” (p. 1)</p>
Cuba (<i>based on unofficial translation</i>)	<ul style="list-style-type: none"> • Participating Institutions: Department of care of the elderly, welfare and mental health of the Ministry of Public Health, Section of Biomedicine of the Academy of Sciences of Cuba, Section Cuban Alzheimer Society of Neurosciences of Cuba, University of Medical Sciences of Havana, Center studies Alzheimer Research Center "Aging, Longevity and Health" (CITED), National School of Public Health, Service Geriatric Hospital Salvador Allende, Hermanos Ameijeiras Hospital, National Institute of Neurology Dr. Rafael Estrada, Neuroscience Center Cuba, National Center of Medical Genetics, Primary Health Care, Legal Department of the Ministry of Public Health. Social Security Department of the Ministry of Labor and Social Security Research Group Dementias 10/66. • P. 44-45 lists authors who participated in the preparation of the document; does not state if any of the authors have dementia.
England	<ul style="list-style-type: none"> • “I am also grateful to Neil Hunt from the Alzheimer’s Society for leading the work of the External Reference Group. The close co-operation with the Alzheimer’s Society has been a key feature in undertaking an informed and expert analysis of all the issues involved.” (p. 3) • “During the last few months, I have met many people living with dementia, both those who have the illness and their family carers. I have been hugely impressed with the contribution they have made to the debate on the Strategy. They were also represented on the project’s External Reference Group, and their role in developing the Strategy has been crucial.” (p. 6) • “We would first like to thank all the people who have worked with us to produce this Strategy. In particular, we must thank the people with dementia and their carers whose testimony has truly shaped this plan.” (p. 7)

	<ul style="list-style-type: none"> • Core External Reference Group - Dr Daphne Wallace, member of the Alzheimer’s Society and a person with dementia. (p. 98) • ERG Raising Awareness Working Group - Keith Turner, member of the Alzheimer’s Society and a person with dementia. (p. 98) • ERG Early Diagnosis and Working Group - Ken Clasper, member of the Alzheimer’s Society and a person with dementia. (p. 99) • ERG Improving the Quality of Care Working Group - Peter Ashley, member of the Alzheimer’s Society and a person with dementia. (p. 99)
Finland	<ul style="list-style-type: none"> • The European Parliament adopted a written declaration in 2008 which highlighted the increasing importance of memory disorders from the perspective of public health and the national economy and the need for national dementia strategies as one means of preparedness. Finland’s national programme was produced by a committee set up by the Finnish Ministry of Social Affairs and Health (p. 2). • Development of the National Memory Programme was the responsibility a committee set up by the Finnish Ministry of Social Affairs and Health. The committee was tasked with preparing a national dementia strategy for Finland, including objectives for: promoting brain health; ensuring the early detection and treatment of memory disorders; establishing a system to ensure the availability of timely support and services for people with dementia and their families; and formulating an action plan for implementing the necessary measures (including details about coordination and timescale). (p. 5) • Members of the committee are listed on p. 5 and 6 - none are stated to be a person with dementia.
Greece <i>(based on unofficial translation)</i>	<ul style="list-style-type: none"> • A National Committee Working Group drafted the plan. “The Working Group attempted to record deficits and problem areas, actions and practices that form the basis for developing an integrated Action Plan for dementia and Alzheimer’s disease”. Members of the Working Group are not listed. (p. 3)
Indonesia <i>(based on unofficial translation)</i>	<ul style="list-style-type: none"> • “Gratitude and high appreciation are due to all those who have contributed to the preparation of the National Strategy for Alzheimer’s Disease and Other Dementias [...], the Institute of Education, Research, Organization of Public Social Care for the elderly, in particular dementia, and related private sector.” (p. 2) • Drafting team listed on p. 36 - does not state if anyone is a person with dementia.
Ireland	<ul style="list-style-type: none"> • A commitment to develop a Dementia Strategy is included in the Programme for Government 2011-2016. The Strategy was prepared with the assistance of an expert Working Group which included clinicians and other healthcare professionals, researchers, and representatives of the Department of Health and the Health Service Executive. (p. 6)

	<ul style="list-style-type: none"> • The members of the Working Group are listed on p. 6 and no one is listed as a person with dementia. • Workshops (2) for People with Dementia, Carers and Former Carers - Workshops were convened by the Alzheimer Society of Ireland to allow people with dementia and their carers, along with former carers, to meet with the Strategy Working Group. (p. 9) • The Minister for Health has decided to establish an Advisory Group to assist in the drafting of a National Dementia Strategy for his consideration. (p. 36)
Israel	<ul style="list-style-type: none"> • Includes a page listing “Group of Experts Involved in the Preparation of the Israeli National Strategic Plan for Alzheimer’s and other Types of Dementia,” but does not specifically state if anybody on this list is a person with dementia. • “The plan was formulated by an interdisciplinary group composed of experts from government ministries (health, social affairs and services, national insurance, and senior citizens), health plans, hospitals, JDC-Eshel, non-profit organizations (Emda and Melabev), and leading academics. The process was headed by the Center for Research on Aging at the Myers-JDC Brookdale Institute (MJB) and the National Geriatric Council, with the support of the Helen Bader Foundation.”
Italy <i>(based on unofficial translation)</i>	Details of how the plan was developed are not included.
Luxembourg <i>(based on unofficial translation)</i>	<ul style="list-style-type: none"> • The Ministry of Family and Integration is assigned the establishment of an action plan "dementia" in consultation with the Ministry of Health. (p. 9) • Four working groups were set up: “They incorporate stakeholders, family members, field professionals, government officials and institutional delegates from many associations and political actors and civil society. Each working group consists of 15-19 people. Groups meet on the period from December 2010 to January 2012 in plenary 6-8, plus intermittent preparation meetings.” (p. 9)
Malta	<ul style="list-style-type: none"> • This strategy is a continuation of previous work carried out by the Malta Dementia Strategy Group on recommendations for a dementia strategy in the Maltese Islands presented to the authorities of health in January 2010 (Executive Summary). • "The strategy highlighted in this document adds on previous work conducted by the Malta Dementia Strategy Group launched in May of 2009 by the Parliamentary Secretariat for the Elderly and Community Care. Preparatory work undertaken by this multidisciplinary group included a field analysis of dementia services available in the Maltese Islands, a consultative exercise involving stakeholders providing local dementia services, training and support, and feedback from the general public through a specifically designed questionnaire that was available online (www.dementia.gov.mt) together with its dissemination in printed form to all government elderly homes and members of the Malta Dementia Society. A total of 613 completed

	<p>questionnaires were received from different categories of respondents including caregivers, individuals with dementia, healthcare professionals, relatives and other interested parties (Figure 2.1). The majority of the respondents were females (71.5 per cent) and above the age of 50 years (55.3 per cent). The complete results were collated, analysed and presented in the document <i>Inspiring New Frontiers: Recommendations for a Dementia Strategy in the Maltese Islands</i> in January 2010 (Scerri, 2010, 2012)." (p. 40)</p> <ul style="list-style-type: none"> • For the implementation of the strategy - ensure that individuals living with dementia and their caregivers and family members are directly involved during the various stages of the implementation process. (p. 131)
Mexico (based on unofficial translation)	<ul style="list-style-type: none"> • List of Workgroup Members does not indicate if anyone involved is a person with dementia. (p. 4) • "Continuing these efforts and under which has among its powers support the Ministry of Health in the development and implementation of sectoral programs, the National Institute of Geriatrics along with the Academy convened the consultation forum <i>Ageing and health: research for a plan of action</i>, held on April 10, 2013. Hence the date on aging information was submitted, aging and health in Mexico, obtained from different sources of information, highlighting the National Health and Nutrition Examination Survey - ENSANUT- 2012 and state surveys Health and Welfare in Aging - SABE-, in order to contribute to the formulation of the new National Development Plan and the National Health Program 2012-2018.1." (p. 41) • "The proposal to create the Plan of Action on Alzheimer and Other Dementias - driven by the National Institute of Geriatrics and organized civil society interested in improving the comprehensive care of Mexicans suffering from some form of dementia - is the culmination of a series of initiatives originating in 1986 and are in effect because of the increasing incidence of this disease." (p. 43) • List of organizations on the working group that developed the plan. (p. 53)
Netherlands	<p>"To achieve these aims the Ministry of Health, Welfare and Sport, Zorgverzekeraars Nederland (the Health Insurers' Association), Alzheimer Nederland (the Dutch Alzheimer Association) and ActiZ (the Employers' Association for Care Providers) joined hands and initiated the Programme on Integrated Dementia Care. They made this guideline as an aid for the development of integrated dementia care. In 2008 16 so called 'spearhead regions' made their first action plans. As from 2009 these regions offer integrated dementia care to their clients. In June 2009 a second group of regions joined the programme" (p. 2).</p>
Norway	<p>Details of how the plan was developed are not included.</p>
Northern Ireland	<ul style="list-style-type: none"> • "The strategy and the values and principles which underpin it have been informed by the views of people with dementia and their families." (Executive Summary) • Overarching strategic context for this work is the Executive's Programme for Government priority of promoting tolerance, inclusion, health and well-being. Ageing in an Inclusive Society aims to promote

	<p>the social inclusion of older people and create an enabling environment, which gives older people choice and control over the services that influence their lives. A Commissioner for Older People has been established in law to provide a 'strong independent voice' for older people. A Commissioner has been appointed in 2011.</p> <ul style="list-style-type: none"> List of steering group and project team members does not specify if anyone is a person with dementia. (Appendix 5)
Puerto Rico (<i>based on English summary</i>)	Does not state who was on the Task Force.
Scotland	<ul style="list-style-type: none"> "I greatly value the significant role and expertise of Alzheimer Scotland and others in this process. People with dementia and their carers are continuing to take a full role in helping to improve services, both nationally and locally, and their participation and the wealth of experience they bring is hugely important. I would also like to give recognition to all of you who contributed to this strategy as part of the Dementia Dialogue process." (p. 1-2) "This Strategy has been produced on the basis of participation and dialogue. Last October we produced a paper setting out our assessment of progress to date in taking forward Scotland's Dementia Strategy and of the continuing challenges. Following that we took forward our National Dementia Dialogue in conjunction with Alzheimer Scotland. This included a series of events which also allowed discussion of Alzheimer Scotland's new policy paper on integrated community-based support for dementia, based on their "8 Pillars" model and the Big Lottery's Life Changes Trust. At the conclusion of that process in February we published an initial Proposition Paper. This paper reported a strong consensus on the actions that should form the basis of our second dementia strategy. That paper was also the starting point for the work undertaken by an expert group which met between March and May to support the production of this document." (p. 2)
Switzerland (<i>based on unofficial translation</i>)	<ul style="list-style-type: none"> Had a Parliamentary mandate for the "National Strategy for Dementia". (p. 6) "To clarify the need for priority action, workshops following the path of a person with dementia pathology were organized. The model developed in five phases (see chap. on clinical tables). The project leaders have visited and met different people in charge of projects implemented as well as those directly involved. 66 representatives from different backgrounds: people's organizations concerned, service providers in the areas of patient care, long term and hospital, trainers and researchers, professional groups and professional associations at the national level participated in thematic workshops: "Primary prevention and early stage of the dementia pathology "/" secondary prevention, diagnosis and treatment "/" care and treatment in outpatient care (at home "/" treatment at the hospital "/" care and treatment in care long term (EMS). "representatives of organizations of

	<p>persons concerned and primary care medicine were invited to all workshops. CDS has made an inventory of the implementation of the support offerings from pathologies of dementia. The aim of this survey was to take stock of the current situation in Switzerland (CDS, 2013). The results of the expertise and state of the current situation in the townships were supplemented with further data on the need for action (see FOPH CDS, 2011; National Ethics Commission in the field of human medicine (NEK-CNE), 2011) and assembled in a comprehensive synthesis." (p. 7)</p>
Taiwan	<ul style="list-style-type: none"> • "Since 2007, Taiwan government has adapted many policies and projects, including cooperated with non-government organizations (NGO) to establish national dementia social supporting centers, dementia helpline service, dementia information websites and on-line counseling, and community early intervention services for people with dementia." (p. 3) • "The composition of the National policy strategy has referred to many other sources including the Dementia: a public health priority by WHO in 2012, the Kyoto Declaration by the Alzheimer Disease International ADI in 2004, dementia policies and plans developed in other countries, and considered the development and present practice of the Taiwan healthcare system." (p. 4)
USA	<ul style="list-style-type: none"> • "The first step in developing the National Plan was to set up a federal interagency working group and conduct an inventory of all federal activities involving AD (Appendix 3). In creating the plan, HHS and its partners sought to leverage these resources and activities, improve coordination, and reduce duplication of efforts to better meet the challenges of Alzheimer's disease." • "The law also establishes the Advisory Council on Alzheimer's Research, Care, and Services and requires the Secretary of HHS, in collaboration with the Advisory Council, to create and maintain a national plan to overcome Alzheimer's disease (AD)." NAPA legislation states that 2 Alzheimer's patient advocates shall be included on the advisory council. • "In consultation with stakeholders both inside and outside of the Federal Government, this National Plan represents the initial blueprint for achieving the vision of a Nation free of AD." • The National Plan to address Alzheimer's Disease does not discuss in detail how the plan was developed
Wales	<ul style="list-style-type: none"> • "There has been a significant amount of work undertaken in Wales, including a full public consultation, to identify the actions that are required to deliver better quality of life for people with dementia in Wales immediately." • "The Minister for Health and Social Services established the Mental Health Programme Board to ensure that mental health services are high quality and provide the best value for money. It is this Group that has been tasked with ensuring that NHS Wales, local government and the voluntary sector work together in an efficient and effective way to deliver coordinated services. The Welsh Assembly Government will continue to provide leadership to support this work and implement the

	vision. This work will be regularly reviewed and reported to Ministers to make sure improvements are being made.”
Sub-nation	Details of plan development
Australia - New South Wales	<ul style="list-style-type: none"> • Through input of an expert advisory group, consultation with NSW dementia services networks and Alzheimer’s NSW regional consumer committees and through a review of relevant reports and research articles, the NSW Dementia Policy Team has identified current issues and challenges along the service pathway from dementia awareness to palliative care, outcomes for people with dementia, carers and families into the future and the service elements required along the service pathway to achieve these outcomes. (p. 2) • Members on the Advisory Group (p. 87) - do not appear to be any people with dementia. • Held workshop consultations (p. 89) - Consultation workshops for the Framework have involved the participation of near 350 service providers and 50 consumers/carers from across NSW for which a presentation was provided on development of the Framework and through which information was collated.
Australia - Queensland	“Implementation of the Queensland Health Dementia Framework 2010-2014 will enable the delivery of Queensland Health’s vision of ‘a better quality of life for people living with dementia and their carers and families’. It has been endorsed by the Statewide Dementia Clinical Network and the integrated Policy And Planning Executive Committee (IPPEC).”
Australia - South Australia	Key Stakeholders (p. 28) - list “people with dementia, their carers and families” as key stakeholders.
Australia - Victoria	Does not appear to include information about the development of the action plan or the involvement of people with dementia.
Germany - Bavaria <i>(based on unofficial translation)</i>	<ul style="list-style-type: none"> • "The Bavarian government wants, with the dementia strategy and interagency and concerted effort in the context of the available sites and resources, to meet the challenges ahead early and to make, in all areas of life, innovative approaches and solutions to the topic of dementia." (p. 5) • “The object of the inter-ministerial steering group is to bundle the existing and future measures necessary to improve the quality of life of people with dementia and their families together and, in particular, to ensure that the information arrives in society and reaches citizens. In terms of monitoring results, until 2020 there will be regular review and monitoring of the implementation of the key objectives.” (p. 99) • The Federal Government sees the need for a common, coordinated action to meet the challenge of dementia effectively. An expert group, "Alliance for People with Dementia", is drawing up a catalogue of measures with the aim of improving the quality of life and, in particular, the sustainable participation in society for people with dementia. (p. 99)

<p>Germany - Saarland (<i>based on unofficial translation</i>)</p>	<ul style="list-style-type: none"> • "Saarland's dementia plan was, on behalf of the Ministry, developed in close cooperation with the national specialized dementia body for Social Affairs, Health, Women and Family Institute for Social Research and Social Economy (iso). The iso-Institute was responsible for the scientific support of the process, the moderation of the measures adopted [...]. The organizational work for the implementation of events and workshops was carried out by the Consulting Centre Dementia. All steps on the way to the dementia plan were in close consultation, and in a professional dialogue, with the Ministry of Social Affairs, Health, Women and Family." (p. 9-10) • "The creation of the Saarland dementia plan builds on previously present scientific work. Decisive here was the expertise of the iso-Institute for National dementia strategies from 2012, [...] a working basis for the Alliance for people with dementia under the auspices of the Federal Ministry of Health. The expertise was based primarily on an evaluation of national dementia strategies and expert interviews with key players in the "dementia scene" from different fields of work." (p. 10) • "Between March and July 2015, five workshops were held, two events to discuss "optimizing supply structures" because of the variety of topics. The discussions in the various workshops included partially overlapping issues, such as the need for better integration of medical, counselling and care services." (p. 11)
<p>USA - Alabama</p>	<p>"The membership of the task force included clinical and administrative professionals from public and private health care organizations, representatives from state agencies, and individuals and family members directly affected by Alzheimer's disease and other related dementias." (p. 3)</p>
<p>USA - Alaska</p>	<ul style="list-style-type: none"> • "The Alaska Commission on Aging (ACoA) initiated this effort with support from the Alaska Mental Health Trust Authority (The Trust) and Alzheimer's Resource of Alaska. The core team expanded to include a representative from AARP, the Alaska Department of Health and Social Services, Divisions of Senior and Disabilities Services, Public Health, Behavioral Health and the Alaska Pioneer Homes and the Office of Long Term Care Ombudsman. Using previous planning documents for guidance, including results from a series of ACoA community forums, a caregiver survey and other states' ADRD plans, the core team drafted six goals each with a set of recommendations and strategies. The core team invited a broader group of stakeholders to review the draft document, identify priorities, and highlight opportunities for further collaboration. With stakeholder guidance, the core team selected seven strategies to work on in the near future; these are outlined in the Implementation Plan chapter at the end of the Roadmap." (p. 1-2) • Core team members and stakeholders - does not specifically list anyone as a person with dementia. (p. 6-8)
<p>USA - Arizona</p>	<ul style="list-style-type: none"> • "The Arizona Alzheimer's Task Force was formed to bring together a wide range of public and private stakeholders throughout the state to address the growing human and financial cost of dementia in

	<p>Arizona. Over 100 community members throughout Arizona have been engaged in the Task Force and its Work Teams to develop the Arizona Alzheimer’s State Plan, including professionals from multi-disciplinary fields, government and non-profit agencies, the research community, aging services providers, individuals in the early stage of Alzheimer’s disease, and family caregivers. The initial Task Force Planning Group has been a collaboration of the Governor’s Office on Aging, the Arizona Department of Economic Security Division of Aging and Adult Services, the Arizona Alzheimer’s Consortium, and the Alzheimer’s Association Desert Southwest Chapter.” (p. 5)</p> <ul style="list-style-type: none"> • Task Force organizations, members, and volunteers - do not specifically list anyone as a person with dementia. (p. 31-33)
USA - Arkansas	<p>Under Task Force Members - Cheryl LaRue - Younger-Onset Patient, Ft. Smith, AR, Appointed by Speaker of the House Robbie Wills. (p. 3)</p>
USA - California	<ul style="list-style-type: none"> • “Under the leadership of the State Alzheimer’s Disease and Related Disorders Advisory Committee, a broad-based task force was appointed. Working with the Alzheimer’s Association and the California Health and Human Services Agency, the task force engaged more than 2,500 individuals in plan development, including people living with the disease, underrepresented communities, providers, family caregivers, researchers and educators.” (p. 7) • Committee, Task Force Members, and Contributors - does not specifically state that anyone is a person with dementia. (p. 42-43)
USA - California, San Francisco	<ul style="list-style-type: none"> • “The Department of Aging and Adult Services (DAAS) led and managed this initiative. In September 2008, DAAS retained the services of a research team consisting of Gibson & Associates, Resource Development Associates, and the Mental Health Association of San Francisco. This research team worked with the Expert Panel and DAAS staff to undertake an evaluation of San Francisco’s current dementia care services, project the need for additional services, and with guidance from the Expert Panel, prepare a plan and recommendations to address the needed services during the next 10 years (2010 to 2020). The work of the Expert Panel took place between December 2008 and May 2009. There were six Expert Panel meetings. Four sub-committees researched specific topics and reported back to the Expert Panel to assist in its deliberations. Each sub-committee met approximately five to seven times.” (p. 1) • “The Alzheimer’s/Dementia Expert Panel spent months deliberating on research, local data, and input from caregivers and other stakeholders.” (p. 7) • Expert panel members and subcommittee members - does not specifically state that anyone is a person with dementia. (p. 11-13) • "Following the completion of the Expert Panel’s deliberations in May 2009, the recommendations were presented at an Alzheimer’s/Dementia Summit, held in City Hall in July 2009. This offered an

	opportunity for the community to learn about the crisis in dementia care and to provide additional input into the recommendations prior to the completion of the initial draft Strategy." (p. 18)
USA - Connecticut	"The task force shall consist of the following members... (2) One appointed by the speaker of the House of Representatives, who shall be a person diagnosed with Alzheimer's disease. " (p. 42)
USA - Colorado	"Members of the Council were appointed by the legislature and the governor to represent a range of perspectives related to Alzheimer's disease from an individual diagnosed with early stage Alzheimer's disease to state agency representatives and publicly elected officials. The Colorado Health Institute (CHI) served as the convener and facilitator for the Council, providing analytical, research and report drafting support under the Council's direction." (p. 13)
USA - Delaware	<ul style="list-style-type: none"> • "The Delaware State Plan to Address Alzheimer's Disease and Related Disorders is a joint project of the Alzheimer's Association Delaware Valley Chapter and the Division of Services for Aging and Adults with Physical Disabilities (DSAAPD)" (p. 2) • "The Alzheimer's Association and DSAAPD established a task force, comprised of caregivers, advocates, and professionals representing a broad range of organizations. (A list of task force members is included in Appendix A)." (p. 6) • "Following the December 2012 meeting of the task force, five working groups were formed, each of which was co-chaired by two members of the task force and included additional persons recommended by the chairs (See Appendix B)." (p. 6) • "Three town hall meetings were scheduled in June 2013 to provide the general public the opportunity to offer input into the plan. The town hall meetings were advertised via a statewide press release as well as an announcement on DSAAPD's website. The goals, objectives and strategies document was made available in advance of the town hall meetings via web download. (Individuals who needed or preferred the document in another format were encouraged to contact DSAAPD for assistance.) In addition, individuals who were not able to attend the town hall meetings or who preferred to make comments outside of the meetings were informed that comments would be accepted by phone, mail, e-mail or fax until mid-July 2013." (p. 6-7) • Task Force members and Working Group Members - nobody specifically listed as a person with dementia. (p. 17-19)
USA - District of Columbia	<ul style="list-style-type: none"> • Under "Acknowledgements" no individuals are identified as a person with dementia. (p. 3-4) • "Although this plan was prepared by a government agency, the execution requires collaboration from the community as a whole so that all the available stakeholders are aligned in their thinking. Including all stakeholders in the process is necessary to eliminate or at least reduce conflicts of interest and contradictory information." (p. 7)
USA - Florida	Purple Ribbon Task Force Members: "Albert Johnson, Representative of persons having Alzheimer's

	disease or related form of dementia.” (p. 80)
USA - Georgia	<ul style="list-style-type: none"> • “The Georgia Alzheimer’s and Related Dementias State Plan Task Force shall be composed of six members and shall include the director of the Division of Aging Services within the Department of Human Services, the commissioner of community health or his or her designee, the state health officer or his or her designee, the chairperson of the House Committee on the Health and Human Services, the chairperson of the Senate Health and Human Services Committee, and the chairperson of the House Committee on Human Relations and Aging.” (p. 2) • (c) “The task force shall invite other advisory members to assist the committee and may consider the following in making its selection: a person with Alzheimer’s disease; a person with Alzheimer’s related dementia; such person’s caregiver; a representative of the nursing facility industry; a representative from the adult day care services industry; a representative of the home health industry; a representative of the personal care home industry; a physician; a consultant pharmacist; an Alzheimer’s disease and related dementias researcher; law enforcement personnel; and other stakeholders from the public, private, and nonprofit sectors, voluntary health organizations, and the faith-based community.” (p. 2) • “Acknowledgements” - describe some people as “Community Representatives”. (p. 3-5)
USA - Idaho	<ul style="list-style-type: none"> • “A year before the publication of the AP article, the push for a plan had already begun. In the fall of 2010, a group of dedicated individuals formed a grass roots organization called the Idaho Alzheimer’s Planning Group, known as IAPG. Comprised of educators, researchers, administrators, advocates and lay people, the IAPG became a project of Boise State University’s Center for the Study of Aging. Its steering committee grew to incorporate a wide range of stakeholders, including representatives from the Idaho Commission on Aging (ICOA), Idaho AARP and the Alzheimer’s Association (see Appendix). Its stated mission is “to improve the spectrum of prevention, diagnosis, treatment and caregiver support services for people with Alzheimer’s disease and other dementias.” From the beginning, IAPG members have been dedicated to making Alzheimer’s and other dementias a public policy priority for our state.” (p. 19) • “The majority of states that have developed plans for a specific health issue have worked from the top down – that is, the legislature passes a bill (usually with funding) that empowers a panel of experts (often appointed by the governor) to study a problem and create a plan to address it. The Idaho Alzheimer’s Planning Group chose a different path. With the help of respected professional stakeholders and lay people willing to donate their time and expertise, IAPG developed a fact-based presentation for appropriate members of the state legislature.” (p. 20) • “The needs assessment used several research methodologies involving a total of 444 individuals representing all regions of the state (see Appendix). Participants included individuals with ADRD,

	<p>their family members, community-based health care and social service professionals, and administrators of assisted living (ALF) and skilled nursing (SNF) facilities. Information was gathered through the use of surveys, focus groups, and telephone and in-person interviews." (p. 23)</p> <ul style="list-style-type: none"> • “We would like to offer a special thanks to all the people across the state of Idaho who are affected by Alzheimer’s disease and related dementias, who provided input into this plan.” (p. 40)
USA - Illinois	<ul style="list-style-type: none"> • “The alliance was instrumental in coordinating three public hearings to gain broad input into the content of this plan. The public hearings were held in southern, central and northern areas of Illinois. Community members and staff of agencies providing programs and services to persons with Alzheimer’s disease and related dementias, their families and caregivers offered suggestions for the plan.” (p. 2 & 3) • "The Illinois Alzheimer’s Disease State Plan was prepared by the Alzheimer’s Disease Advisory Committee and partners from public health and aging service organizations and academic institutions." (p. 31) • List of members of the Advisory Committee - but do not specifically state if they are people with dementia. (p. 31)
USA - Indiana	<ul style="list-style-type: none"> • “The Task Force that developed this plan includes state legislators, non-profit organizations, state government agencies, academic researchers, issue experts, physicians, care providers, and family caregivers.” (p. 6) • Members of task force - does not specifically state that any of the members were people with dementia. (p. 7) • "Input sessions were held in Fort Wayne, Indianapolis and Bloomington in August and September 2011. More than 150 participants provided input." (p. 9) • "An electronic survey was posted online throughout summer and fall 2011 and was distributed widely to the mailing lists of task force members and the organizations they represent. A total of 946 usable responses gauging satisfaction with services were collected. Hundreds of respondents also provided open-ended comments/suggestions. Respondents included people with Alzheimer’s disease (1%), family caregivers (62%), non-family caregivers (2%), professional caregivers/providers (33%), and public employees/officials (2%) from 84 of Indiana’s 92 counties." (p. 9)
USA - Iowa	<ul style="list-style-type: none"> • Alzheimer’s Disease Task Force - Senate File 489 - “b. The following members appointed by the governor: (1) One person with Alzheimer’s disease.” (Appendix B) • Appendix C - lists members of the task force, including the person with Alzheimer’s disease.
USA - Kentucky	<ul style="list-style-type: none"> • "Senate Joint Resolution 6 (SJR 6) (Appendix B) directed the Office on Alzheimer’s Disease and Related Disorders and the Alzheimer’s Disease and Related Disorders Advisory Council to assess

	<p>the current and future impact of Alzheimer’s disease on Kentuckians and State systems, programs, and services.” (p. xii)</p> <ul style="list-style-type: none"> • Kentucky Advisory Council on Alzheimer’s Disease Workgroups - members listed at the beginning of the document; do not specifically state if anyone is a person with dementia. • "The membership of the Council was delineated in the statute to include representation from three (3) agencies of state government, three (3) from local health departments, one (1) from the University of Kentucky Alzheimer’s Disease Research Center at Sanders-Brown Center on Aging, one from each of the chapters of the Alzheimer’s Association serving the Commonwealth with the remainder of the fifteen (15) representing consumers, health care providers, and the medical research community.” (p. 9)
USA - Louisiana	<ul style="list-style-type: none"> • SCR 80 says that one person with Alzheimer’s must be on the task force. • They describe two people as “consumers” under task force members.
USA - Maine	<ul style="list-style-type: none"> • "The Maine Department of Health and Human Services and the Alzheimer’s Association Maine Chapter would like to thank the more than 75 individuals who helped inform the development of this plan. Stakeholders included family caregivers, individuals living with the disease, representatives from the Maine Center for Disease Control and Prevention, medical providers, health and social service organizations, professional caregivers, and representatives of the Maine Association of Area Agencies on Aging, home care, long-term care facilities, assisted living, the Long-term Care Ombudsman, public health, hospitals, health care focused nonprofits, elder law and finance organizations, higher education and businesses.” (p. 3) • “Conducting community forums to hear comments allowed caregivers, family members, health and social service providers, and other community members, to share stories and experiences about caring for and providing services to individuals with Alzheimer’s disease and other dementias and further inform the plan. Individuals with Alzheimer’s disease and other dementias were also encouraged to share their experiences at the forum.” (p. 10) • Does not list any members as people with dementia on p. 3 and 4.
USA - Maryland	Commission members listed - describe one member as a “Consumer” . (p. ii)
USA - Massachusetts	<ul style="list-style-type: none"> • "It was developed at the request of Governor Deval Patrick by the Massachusetts Executive Office of Elder Affairs (“Elder Affairs”), in partnership with the Alzheimer’s Association, Massachusetts/New Hampshire Chapter (“Alzheimer’s Association”) with a statewide Advisory Committee over the last two years.” (p. 2) • “The recommendations, goals and strategies are the result of research and deliberation by the statewide Advisory Committee convened by Elder Affairs/the Alzheimer’s Association of Massachusetts/New Hampshire and consisting of people with Alzheimer’s, family members, and

	<p>representatives from state and local health and human service agencies, councils on aging, universities, hospitals, public safety agencies, and professional caregiver associations. The Advisory Committee’s work reflects the concerns and priorities conveyed to the Committee during four listening sessions and seven focus groups held at locations throughout the state, involving more than four hundred (400) individuals with Alzheimer’s, family members, professional caregivers, and representatives of state and local government.” (p. 1)</p> <ul style="list-style-type: none"> • "In response, these two agencies have convened a statewide Advisory Committee, consisting of people with Alzheimer’s, family members, and representatives from state and local health and human service agencies, councils on aging, universities, hospitals, public safety agencies, and professional caregiver associations." (p. 3) • List of members on the work groups convened by the Advisory Committee - does not specifically state that anyone is a person with dementia. (p. 19-21)
USA - Michigan	<ul style="list-style-type: none"> • “The Michigan Dementia Coalition serves a vital role as the coordinating body for the group of professionals and organizations addressing dementia in Michigan. Comprised of consumer representatives, community groups, university partners, and government, the Coalition implements selected priority initiatives to reduce the burden of dementia in Michigan. The Michigan Dementia Coalition is guided by a Leadership Team (see Appendix A) and support staff from the Michigan Department of Community Health, Public Health Administration.” (p. 2) • Leadership Team of the coalition - do not specifically list anyone as a person with dementia. (p. 20)
USA - Minnesota	Members of Alzheimer’s Disease Working Group - two individuals listed as people with Alzheimer’s disease. (p. 6)
USA - Mississippi	<ul style="list-style-type: none"> • "The Mississippi State Strategic Plan to address Alzheimer’s Disease and Related Dementias is a collaborative project led by the Department of Mental Health, Division of Alzheimer’s Disease and Other Dementias; the Alzheimer’s Association Mississippi Chapter; and The MIND Center at the University of Mississippi Medical Center; in partnership with stakeholders from across the state including the Department of Human Services, Division of Aging and Adult Services; and the Department of Health, Office of Preventive Services; and other organizational stakeholder industries and occupations including long term care, hospice, clinical research, social work, nursing, public safety and pharmacy." (p. 2) • Does not list any “Plan Contributors and Partners” as a person with dementia. (p. 30-32)
USA - Missouri	One member on the task force has early stage Alzheimer’s or related dementia. (p. 7)
USA - Nebraska	“To create the most comprehensive state plan for Alzheimer’s Disease and Related Dementias (ADRD) it was crucial to work with a variety of key stakeholders. This included, the Department of Health and Human Services, the Office of the Public Guardian, the Area Agencies on Aging, organizations advocating for

	patients with ADRD and their caregivers, the law enforcement community, people living with ADRD and their informal caregivers, client advocacy organizations, health care provider organizations, private health care providers and community-based professionals.” (p. 11)
USA - New Mexico	<ul style="list-style-type: none"> • “This Task Force worked diligently throughout 2012 and 2013 to create the plan that is now before you. Comprised of more than 60 participants, the Task Force had broad representation from state government, providers, caregivers, tribal organizations, individuals with Alzheimer’s disease, educators, and researchers.” (p. 2) • A person with Alzheimer’s disease acknowledged. (p. 32)
USA - New York	Member list - does not specifically state if any members are people with dementia. (p. 35 and 36)
USA - Nevada	None of the members are listed as people with dementia. (p. 38 and 39)
USA - North Carolina	<ul style="list-style-type: none"> • Gives thanks to individuals who shared their experiences and expertise with the task force - lists one person as a person living with Alzheimer’s. (p. 1 and 2) • Task Force Members - no members with dementia. (p. 4)
USA - Oklahoma	Members of the state plan workgroup are listed at the beginning of the document - does not state if any members are people with dementia.
USA - Oregon	<ul style="list-style-type: none"> • Task Force Members - listed at the beginning of the document; does not list any member as a person with dementia. • “In late 2010, the Alzheimer’s Association Oregon Chapter brought together numerous community partners in Oregon who share a concern about the impact of the disease on our communities. The State Plan for Alzheimer’s Disease in Oregon (SPADO) Task Force was formed and includes non-profit organizations, state government agencies, academic researchers, issue experts, physicians, family caregivers, care providers, and state legislators. The Alzheimer’s Association Oregon Chapter provided staffing for the SPADO Task Force. Each of the workgroups focused on different aspects of the impact of ADRD – Education and Public Awareness, Public Safety, Continuum of Care, Legal/Financial, and Medical/Research. The workgroups helped craft questions for an online survey, participated in public input sessions, and drafted recommendations to address the most critical needs of people impacted by ADRD.” (p. 15)
USA - Pennsylvania	<ul style="list-style-type: none"> • Introductory letter talks about how the committee included an individual living with Alzheimer’s. • Michael Ellenbogen mentioned. (p. 44)
USA - Rhode Island	“RESOLVED, That the Long Term Care Coordinating Council, as established in R.I.G.L. 23b17.3, shall convene an Alzheimer’s Disease and Related Disorders working group (hereinafter “working group”), to be chaired by the Chair of the Long Term Care Coordinating Council, the Lieutenant Governor, or the Lieutenant Governor’s designee, and co-chaired by the director of the Division of Elderly Affairs, for the

	<p>purposes of developing such a state plan; and RESOLVED, The working group shall consist of a comprehensive array of community stakeholders, including but not limited to members of the Long Term Care Coordinating Council; and RESOLVED, The working group shall transmit to the Governor and to the General Assembly, a State Plan for Alzheimer’s Disease and Related Disorders on or before July 1, 2013.” (p. 82)</p>
USA - South Carolina	<ul style="list-style-type: none"> • Task Force Members - does not state that any members are people with dementia. (p. iv and v) • However, legislation states that the Task Force must have, “(3) one person with Alzheimer’s disease or a related disorder.” (p. 35)
USA - Tennessee	<ul style="list-style-type: none"> • Alzheimer’s Disease Task Force Members - describes one member as a person with Alzheimer’s disease. (Listed at the beginning of the document) • Legislation says that at least one person with Alzheimer’s disease must be on the task force. (p. 8)
USA - Texas	<ul style="list-style-type: none"> • Acknowledgements - does not specifically list anybody as a person with dementia. (p. 4) • Plan/Contributors/Partners - lists one person as someone diagnosed with early-onset Alzheimer’s disease. (p. 51- 56)
USA – Utah	<ul style="list-style-type: none"> • Acknowledgements - lists one person as an “Alzheimer’s Disease Recipient”. (p. 29)
USA - Vermont	<ul style="list-style-type: none"> • Acknowledgments - does not describe who the people are. (Listed at the beginning of the document) • “The Vermont Department of Disabilities, Aging and Independent Living (DAIL), in its efforts to design and develop the State Plan on Dementia, convened a subcommittee of the Governor’s Commission on Alzheimer’s Disease and Related Disorders and other aging network providers. This subcommittee was charged with providing guidance and oversight for the development of a plan to help the state policy makers and stakeholders better understand how the estimated increase in people with dementia will need to be met with a corresponding increase in resources; including caregivers, specialized care units, respite services and education.” (p. 1) • During 2007 and 2008, JSI Research and Training Institute Inc., under contract with the Department of Disabilities, Aging and Independent Living engaged in a planning process to develop a State Plan on Dementia. As part of this work JSI staff: <ul style="list-style-type: none"> ○ Project Task 1: Conducted a literature search, secondary source review and inventory of state dementia activities. ○ Project Task 2: Convened an advisory committee to oversee plan development. ○ Project Task 3: Interviewed 20 community stakeholders. ○ Project Task 4: Convened 4 focus groups with consumers or family members. ○ Project Task 5: Convened 4 focus groups with aging services network staff. ○ Project Task 6: Developed recommendations and prepared the final report.

USA - Virginia	<ul style="list-style-type: none"> • “The Commission has worked diligently to develop this plan through collaboration with researchers and clinicians and through a statewide series of public hearings providing valuable input from individuals with dementia and family caregivers.” (Introductory letter) • Does not state who is on Virginia’s Alzheimer’s Disease and Related Disorders Commission. (p. 20)
USA - Washington	<ul style="list-style-type: none"> • “As a result, we have formed a cross-sector Alzheimer’s Disease and Dementia Working Group – made up of consumers and public-private stakeholders – to identify major goals, strategies and recommendations as part of our state plan. This is a starting point to prepare Washington State for meeting this challenge.” (Introductory letter) • Members of Alzheimer’s Disease Working Group/Subcommittee Members - lists three people as consumers. (p. 71 - 73)
USA - West Virginia	<ul style="list-style-type: none"> • Working Group Contributors - does not list anyone as a person with dementia. (Listed on the first few pages)
USA - Wisconsin	<p>“This sobering prospect, together with a recent decision by the Wisconsin Supreme Court in the case of Helen E.F. and creation of a Special Legislative Committee on Legal Interventions for Persons with Alzheimer’s Disease and Related Dementias, prompted Department of Health Services Secretary Kitty Rhoades to call for a redesign of Wisconsin’s dementia care system in order to provide appropriate, safe and cost-effective care throughout the course of the disease. From the start, the Department recognized that redesigning the system of dementia care in Wisconsin would require cooperation and coordination with the many partners involved in providing dementia care services. To launch the initiative, the Department convened a Dementia Care Stakeholder Summit in October 2013. This brought together 33 key stakeholders with diverse perspectives to identify concrete ways the Department and its partners will work together to make Wisconsin more “dementia-capable” and to identify priorities. Summit participants identified six top priorities, which were then used to guide the Department’s development of a “Wisconsin Dementia Care System Redesign Plan.” Following the Summit, the Department developed a draft Dementia Care System Redesign Plan (the Plan). This Plan was initially released as a draft to provide an opportunity for review and input from partners throughout the dementia care network. Stakeholder feedback was collected through a web-based survey linked to the draft plan. In addition, some individuals and organizations submitted comments directly to Department leaders. These responses were analyzed and considered in the process of creating a final Plan. A summary of the stakeholder input, along with a description of the process for reviewing and incorporating stakeholder input into the Plan itself, is contained in an appendix to this revised Plan.” (p. 1)</p>