



February 8, 2012

RE: Comments on the Draft Framework for the National Plan to Address Alzheimer's Disease, submitted to the HHS Advisory Council on Alzheimer's Research, Care, and Services

The Pioneer Network is pleased to have this opportunity to submit comments relating to the *Draft Framework for the National Plan to Address Alzheimer's Disease*. The creation of this plan represents an important opportunity to outline and launch a national approach to curbing a disease that negatively impacts millions of elders as well their families and communities. We agree that this national effort is a critical step for securing a brighter and higher-quality future for those affected by the disease today, as well as those that will be affected in years to come. Pioneer Network commends the Department of Health and Human Services and the Advisory Council on their action to move this agenda forward.

Pioneer Network is a national non-profit that serves as the leading national voice for culture change in long-term care and the promotion of person-centered care, dignity and choice for all elders. Pioneer Network achieves this mission by convening researchers, policy makers, regulators, providers, and consumers with a nationwide network of state Culture Change Coalitions to design and deliver the highest quality, evidence-based, person-centered approaches to enhancing the lives of elders, wherever they may reside. In the context of this approach, we submit the following comments on the Draft Framework for consideration:

- 1) Appropriate Domains: Pioneer Network is fully supportive of the goals of the plan as well as its comprehensive approach. Any responsible strategy to address Alzheimer's disease in the 21st century must include the elements already represented in this draft framework, with approaches targeting: research to improve prevention and treatment, care and support for people living with the disease and their families, public awareness, and measureable milestones. We are excited to see an emphasis on each of these areas, as they are the key to addressing the disease.
- 2) Prioritizing the Person with Alzheimer's: There is no question that the need for increased investment in research to better prevent, diagnose and treat Alzheimer's is essential. In coming decades the impact of these efforts will be the ultimate discovery of a cure, with disease-modifying treatments in the interim. However, while strongly desired, such developments do not appear to be on the immediate horizon. Well in front of the horizon, presently straining our communities and healthcare system, are the more than five million people living with Alzheimer's today. These individuals and families need to know that while research moves us toward the future, their needs today remain a top priority; that they are not placed in second position to a potential greater good. Therefore, we recommend re-arranging the plan so that care for people with the disease is the #1 goal. By doing so, the plan sends a clear message that it is a top priority to serve people with the disease, by embracing, promoting and disseminating the many effective approaches to Alzheimer's care that are known today to improve quality of life.

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- 3) Person-Centered Care: In the section entitled *Enhancing Care Quality and Efficiency*, the concept of “person-centered approaches to care” is noticeably absent. Person-centered (or person-directed) care approaches are the cornerstone of high quality care for people with Alzheimer’s, as these approaches allow the individual continued autonomy to live their life in a manner consistent with their own values, preferences and desires. Alzheimer’s disease is a condition that robs individuals of many aspects of independence, yet does not have to remove their ability to receive care in their manner of choice. We view the concept of person-centered care as embedded so deeply in any approach to achieving quality care, that we recommend replacing section 2.D. *Identify and Implement High-Quality Dementia Care Guidelines and Measures Across Care Settings*, in the current document, with “*Promote Effective Person-Centered Approaches to Care Across Settings*.” First, we would note that evidence-based, consensus-approved guidelines for the care of people with dementia in many of the settings of interest already exist, including nursing homes, assisted living, and home care, with well established standards of care present in other settings as well. Thus, it is not the identification of guidelines that is the key success driver to quality care, but rather the use of the person-centered approaches that are included in the existing guidelines. Second, there are many resources and programs, developed by leading organizations in the field, currently available to guide organizations on how to provide person-centered approaches to care. Thus, stepping back to focus on guidelines is more of a regression than a progression in the field; the person-centered care paradigm already exists and is ready for dissemination. Thus, we recommend the change stated above to focus on bringing visibility to existing person-centered approaches and promoting their use as widely as possible in every care setting. Even if the Council considers this proposed change to the language of 2.D as being a step too far, in order to ensure that the document is relevant in the current care field it is important to include an emphasis on person-centered care, which should be highlighted as paramount in any approach to care outlined in this national plan.
- 4) Care Settings: Also in the section entitled *Enhancing Care Quality and Efficiency*, there is an important recognition that people with Alzheimer’s live and receive care in many different types of settings. However, it is particularly noticeable in the introduction to this section, as well as in other areas, that several key settings are omitted. “People’s homes, doctor’s offices, hospitals, and nursing homes” does not nearly cover the range of care settings available to meet the needs of people with Alzheimer’s. Certainly the inclusion of “nursing homes” is not intended by the authors to include all forms of residential care, given that it has a particular meaning in terms of licensure that does not include: assisted living, board and care homes, independent living, continuing care communities, or even memory care homes, all of which are settings in which people with Alzheimer’s live. Further, there is no recognition of the role of Alzheimer’s-specific (or general) adult day care settings. We recognize it could be cumbersome to list all possible care-related settings in a document such as this proposed plan, but would minimally suggest including assisted living, memory care and adult day care, or secondarily, replacing “nursing homes” with “long-term care residences,” “long-term services and supports,” or “adult day programs and various shared residential settings.” Any of these options would be preferable to simply neglecting these other important places where people with Alzheimer’s spend their time.
- 5) Importance of Language: Anyone who has been involved in the field of Alzheimer’s knows the importance of language; essentially the “PC of Alzheimer’s.” Language can be used to either empower people with the disease to maintain their personhood and dignity, or it can increase stigma and marginalize people with the disease. Overall, this document does a nice job with

language and is respectful of those affected by the disease. However, there are a couple points we have noticed where Pioneer Network suggests simple revisions to help make the plan more empowering for those it is intended to serve.

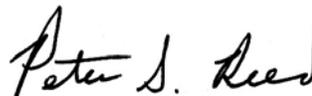
- Replace “Patient” with “Person with Alzheimer’s” or a similar derivation, in every case. While directly receiving care in an acute care setting, people with Alzheimer’s may in fact be “patients” of the healthcare providers; yet in the scope of their everyday life, this is a fairly infrequent occurrence. However, at all times, they remain the individuals they have always been, though now they are living with a disease. Referring to someone as a patient is depersonalizing and implies identification as a medical record number, rather than as an individual. On the other hand referring to someone with the disease as a person helps maintain their identity and promotes involvement in decisions about their own care and experience.
- Replace “facility” with “home” or “care community,” in every case. The word “facility” implies institutionalization, which promotes stigma in the sense of needing to remove people with Alzheimer’s from the general community. Despite the fact that assisted living residences or nursing homes offer support and care, they serve primarily as the person’s home. The person needs to live in this new supportive home for their own well being, not in order to remove them from interacting with the larger community.

Thank you very much for the opportunity to comment on this Draft Plan. Pioneer Network appreciates the chance to share our widely held perspective that caring for elders in the most effective and appropriate ways will not only enhance quality of life for individuals but make us stronger as a society. Our Network and its friends believe that people deserve the opportunity to continue to thrive and live up to their full potential until the end of life, despite their limitations, including those presented by Alzheimer’s disease. This plan represents an important chance to move the field and society forward in thinking about Alzheimer’s both in terms of the future impact of high-quality research and in terms of the present impact of high-quality care. Please feel free to contact the Pioneer Network with any questions, or to access the many resources available to promote quality of life for all elders.

Sincerely,



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President, Board of Directors



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