NATIONAL COUNCIL
FOR COMMUNITY BEHAVIORAL HEALTHCARE

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HHS Office of the Assistant Secretary for Planning and Evaluation
Room 424E, Humphrey Building
200 Independence Avenue, SW
Washington DC, 20201

COMMENTS ON THE DRAFT NATIONAL ALZHEIMER'S PLAN

Dear Ms. Lamont:

The National Council for Community Behavioral Healthcare appreciates the opportunity to comment on the draft National Alzheimer's Plan. Together, with our more than 1,900 member organizations, we serve our nation's most vulnerable citizens: more than 8 million adults and children with mental illness and substance use disorders. We are committed to providing comprehensive, quality care that affords every opportunity for recovery and inclusion in all aspects of community life.

The National Council is, of course, very pleased that the federal government is developing plans to address the needs of people with dementia and their families, a population that will grow substantially over the next quarter century because of the elder boom and because of increased life expectancy.

The National Council believes, however, that, as drafted, **the plan will fail to meet the needs—and to improve the quality of life--of millions of people who currently have dementia and their families as well as millions more who will develop dementia over the next decade and more**.

In these comments the National Council will address two major concerns: (1) unbalanced distribution of new funding and (2) the failure to address the behavioral health dimensions of Alzheimer's and other dementias.

Funding: Although the draft plan does not specify future funding, it does provide information about funding that has been committed prior to the finalization of the plan. Altogether $156 million will be added over the next two years. It will be distributed as follows:

Goals	**Amount**	**%**
Research	$130.0 million	83.3%
Expanded/Improved Support and Care	$ 10.5 million	6.7%
Enhanced Public Awareness and Engagement	$ 8.2 million	5.4%
Enhanced Provider Knowledge	$ 6.0 million	3.8%
Improved Data Collection and Analysis	$ 1.3 million	.8%
Total	**$156.0 million**	**100%**

If this reflects how funds will be distributed going forward, it is clear that research is the single priority of the Plan; its other four goals are evidently of very limited importance.

The National Council does not oppose increased spending on research seeking a cure, preventive interventions, or a way to substantially slow the growth of disability due to dementia. But achieving any of this by 2025 is probably wildly optimistic given the current state of research. And while we are waiting, 10's of millions of people with dementia and their families will not get the care and support that they need and deserve, resulting in avoidable suffering and missed opportunities for improved quality of life.

This plan appears to write off a generation or more of people with dementia and their families.

The National Council understands that those who want research to be the virtually exclusive priority of our nation's efforts could argue that funding for services is available elsewhere, but this is a partial truth. Medicare mostly does not cover long-term care or family support; and Medicaid is supposed to be for people with very limited means. Indeed, long-term care is one of the targets for cost cutting in Medicaid, and one of the proposals to cut Medicaid that resurfaces routinely is reducing the ability of people who are not extremely poor to become eligible for coverage of long-term care services.

The National Council strongly urges HHS to revisit the question of how new funds should be spent and to place much greater emphasis on improving care now and for the foreseeable future than this draft plan does.

Neglect of Behavioral Health

The summary of facts about dementia given near the beginning of the plan notes (1) that people with dementia experience "behavioral and psychiatric disorders", (2) that "personality and behavior changes may also occur", and (3) that family caregivers experience tremendous stress and "report symptoms of depression and anxiety and poorer health outcomes." But these very important facts are barely mentioned in the rest of the plan and, with the possible exception of family caregivers, are not addressed in any meaningful way.

This omission will result in certain failure to meet behavioral health needs that are common among people with dementia and their families.

Here are some sections of the plan that need to reflect behavioral health issues.

- **Framework and guiding principles**: This section lists service systems that are important to people with dementia and their families, mentioning health care, long-term care, home care, legal services, and social services. Mental health and substance abuse (behavioral health) systems are not mentioned.
- **Strategy 1.B: Expand research aimed at preventing and treating Alzheimer's disease**: This section mentions both pharmacological and non-pharmacological interventions (though it emphasizes biological research), but it does not mention the need for research regarding preventing and/or treating co-occurring mental or substance use disorders or the neuro-psychiatric symptoms that affect virtually all people with dementia.
- **Strategies 1.B. 3, 5, and 6: Expand clinical trials**: These sections fail to mention clinical trials of anti-psychotic and anti-depressant medications, which probably are over-used currently and are dangerous. Non-pharmacological, psychosocial interventions can be

enormously helpful to people with dementia and co-occurring psychiatric disorders. But it would be useful to develop medications that are safe and effective.

- **Strategy 1.E: Facilitate translation of findings into medical practice and public health programs**: This section lists fields and settings where findings of research should be disseminated so as to improve practice. Behavioral health settings are not mentioned.
- **Action 1.E.2, 3**: These sections mention a number of federal agencies that need to be involved. SAMHSA, NIMH, NIDA, and NIAAA are not mentioned.
- **Strategy 2.A: Build a workforce with skills to provide high-quality care**: This section notes, "Physicians need information on how to implement the new requirement regarding "detection of any cognitive impairment." They, and other health providers also need information about how to detect a co-occurring mental or substance use disorder and to distinguish their effects from those of dementia.
- **Strategy 2.B: Ensure timely and accurate diagnosis**: As noted, accurate diagnosis requires a very difficult differential diagnosis to distinguish between dementia, depression, and other psychiatric disorders.
- **Strategy 2.B.1: Link the public to diagnostic and treatment services**: This section notes opportunities to provide information and referral through NIA and AoA. It does not mention the National Suicide Prevention Lifeline, which is funded by SAMHSA, and which provides a national I&R network for help with any mental health issue—not just suicide. There are also local I&R systems focused on mental health and/or substance abuse, which are not mentioned in the draft plan.
- **Strategy 2.D: Identify high-quality dementia care guidelines and measures across care settings**: This section mentions "home, physician's office, and long-term care facility." It does not mention mental health settings such as clinics, day programs, inpatient units, psychiatric rehabilitation, crisis services, and case management programs. It should be noted at the very least that people with AD in crisis often are referred or taken to psychiatrists or other mental health professionals, who are expected to provide treatment.
- **Strategy 2.E: Explore the effectiveness of new models**: This section mentions "medical homes", which are required to integrate physical and behavioral health care, but there is no mention in the plan about this fact. The plan also does not note the emphasis in the Affordable Care Act on developing "health homes", for which many people with dementia will probably be eligible because they have multiple chronic conditions.
- **Strategy 2.F: Ensure that people with AD experience safe and effective transitions between care settings and systems**: Despite the fact that settings and systems officially charged with caring for people with dementia frequently turn to the mental health system when there are behavioral problems, there is no mention of how profoundly flawed transitions between the mental health and the long-term settings and systems are.
- **Strategy 2.F. 1: Identify and disseminate models of hospital safety for people with AD**: Despite the fact that many people with AD—with and without psychiatric disorders—end up in psychiatric inpatient units of hospitals due to behavioral problems, there is no mention of the need to address psychiatric hospitalization specifically.
- **Strategy 2.G: Advance coordinated and integrated health and long-term services**: This section and its subsections do not mention the **need to coordinate physical and behavioral health services**, which is particularly surprising since integration of this kind is a major goal of health care reform.
- **Strategy 2.H: Improve care for populations disproportionally affected by AD and for populations facing care challenges**: This section appropriately identifies "people with intellectual disabilities" as disproportionately affected by AD, but it fails to mention people with serious and persistent mental illnesses who do not recover over time, as is true for many

people with schizophrenia and other treatment refractory mental disorders. People with serious and persistent mental illness also often develop dementia, compounding causes of cognitive impairment and complicating care and treatment tremendously.

- **Goal 3: Expand Supports for People with AD and The Families**: This section does mention the mental health needs of family and other informal caregivers. They could get more attention than is in the plan, but it's there to some extent. However, this section vastly neglects the mental health needs of people with dementia.
- **Action 3.A.2: Distribute materials to caregivers**: This section calls for "dissemination through the Aging Network, state public health departments, and public websites." There is no mention of the mental health system, to which people with AD and their families frequently go for help.

  In addition, there is no mention of dissemination to people with dementia, most of whom can read and process information in the early and mid-phases of dementia.
- **Action 3.B.2: Identify and disseminate best practices for caregiver assessment and referral through the long-term care services and supports system**: Again, the plan fails to recognize the frequent use of the mental health system by people with AD and their families.
- **Action 3.B.5: Provide effective caregiver interventions through AD-capable systems**: This section says "AoA will expand efforts to develop more AD-capable long-term services and supports [for] AD caregivers." Although the section mentions the need for interventions regarding depression, it fails to mention anxiety disorders—which are very common. In addition it fails to mention the need for "AD-capable" behavioral health services.
- **Action 3.B.7: Support caregivers in crisis and emergency situations**: This section notes the importance of call centers, but does not reflect awareness of the National Suicide Prevention Lifeline, which could be an important resource during a crisis. This section also does not reflect the fact that, it is usually the psychiatric services in local hospitals or psychiatric mobile crisis teams that are called on to deal with a behavioral crisis.
- **Action 3.D: Maintain the dignity, safety and rights of people with AD**: This section appropriately notes the fact that people with dementia are vulnerable in many ways and that many need more protection than they get. (The inadequacy of many Adult Protective Services programs is particularly important to address.) However, there is nothing here to suggest that people with dementia need anything other than protection. Treating people still capable of some degree of self-care and of being helpful to others, solely as people in need of protection, diminishes them and deprives them of the dignity and rights that this section is supposed to address. **There needs to be a strengths-based model for dementia as increasingly there is for people with psychiatric and other disabilities.**
- **Action 3.D.2: Monitor, report, and reduce inappropriate use of anti-psychotics in nursing homes**: This is clearly important to do, but it is also important to address the use of anti-psychotics in other settings such as homes, assisted living facilities, senior housing, adult day care, etc. In addition, it is very important to **address the inappropriate use of anti-depressants** because recent studies suggest that anti-depressants have high risks and virtually no benefits for people with dementia.
- **Strategy 3.E: Assess and address the housing needs of people with AD**: Stable housing, as the plan says, is a critical need for people with dementia. But the plan seems to have a remarkably limited view of the kinds of stable housing that can be helpful—such as assisted living, continuing care communities, senior housing, supportive housing, and housing for people with serious mental illness.

  The draft plan fails to note that people with serious mental illness are frequently dumped out of housing they have had within the mental health system for many years and are sent to nursing homes when their dementia or physical disorders become too difficult for the mental health system—as it is currently organized—to care for. It should be possible for people with serious mental illness to stay or in their own homes or in the housing that has become their home rather than to be shunted off to a long-term care system that has very limited capacity to care for them.

  Finally, even though reducing the unnecessary use of nursing homes for people with dementia is a clear goal of this plan, there is no mention of the fact that there are now more people admitted to nursing homes with mental illness other than dementia than with dementia alone. Frequently they are people with co-occurring dementia and psychiatric disorders. Housing designed for this population is needed to help them avert admission to nursing homes.

- **Goal 4: Enhance Public Awareness and Engagement**: Public education should include information about the frequent overlap of mental disorders and dementia.
- **Goal 5: Improve Data To Track Progress**: Because this plan does not seem to reflect awareness of the important role the mental health system plays in helping people with dementia and their families, it seems likely that plans for improved data collection will overlook data related to psychiatric disorders and mental health settings. It is important to track progress regarding the behavioral health of people with dementia and their families.

The National Council hopes that you will find these comments on specific sections of the draft plan helpful in identifying what needs to be included in the final plan regarding the behavioral health needs of people with dementia and their families. The fact of the matter is that good care, care informed by understanding the psychological potential of people with dementia and the stress experienced by their family members, could result in vastly improved quality of life for them.

We do not have to wait for a cure to make life better, and we should not devote virtually all new resources to seeking a cure when so much could be accomplished with better care and support.

The National Council would be happy to help the group developing the plan to flesh out any of the suggestions included in this letter.

Sincerely,

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