

ADVISORY COUNCIL ON ALZHEIMER'S RESEARCH, CARE, AND SERVICES

Public Comments from Advisory Council Meeting, August 2024

List of Comments

- [M. Ellenbogen](#) | 8-5-24
- [A. Lasser](#) | 8-8-24
- [N. Murray](#) | 8-5-24

Comments and questions, or alerts to broken links, should be sent to napa@hhs.gov.

PLEASE NOTE: The Public Comments included here are not an endorsement of the views or information by National Alzheimer's Project Act, its Advisory Council members, the Administration or the federal agencies involved in this project.

A. Lasser | 8-8-2024

I serve as Public Policy Manager at the Alliance for Aging Research. Today, I would like to talk through three recommendations.

First, with regards to screening for cognitive impairment. The federal government needs to prioritize screening for cognitive impairment as an A or B recommendation with the USPSTF. It is inexcusable that the USPSTF has maintained an "insufficient" recommendation since 1996--despite scores of published studies showing the benefits of cognitive screening and early diagnosis. In the past, one of the main reasons given for this low score was the lack of available medical therapies. Now, there are two disease-modifying treatments that have received traditional approval from the FDA; as well as an on-label treatment for Alzheimer's disease agitation--with more on the way. This must be included in NAPA's official 2024 recommendations.

Second, CMS should be required to be transparent regarding its Medicare "coverage with evidence development" policy for monoclonal antibody treatments. Since they introduced the mandatory registry and clinical studies in July 2023, there has been no reporting or transparency by the agency. Instead, we have overblown estimates regarding the cost impact on the Medicare program which assume uptake numbers that have not materialized and place undue blame on AD patients for premium increases. CMS should be held responsible for the patient impact of this policy.

Lastly, CMS uses a poorly-targeted quality measure related to the use of antipsychotics to treat neuropsychiatric symptoms of ADRD. These measures unfairly penalize

smaller, rural facilities and facilities that focus on treating complex cases of neurocognitive decline. The measures used do nothing to distinguish between appropriate and inappropriate use of these medications. There is now an FDA approved treatment for agitation in AD patients, but patients have limited access to that care due to the outdated star rating metrics. We are also concerned the Agency has not disclosed data on how many residents are involuntarily discharged from nursing homes each year due to these policies and no transparency regarding residents being turned away at the door.

Thank you very much for your time and the opportunity to present.

N. Murray | 8-5-2024

Thank you for the opportunity to provide comments during the meeting of the Advisory Council on Alzheimer's Research, Care, and Services. I am a board member of the National Task Group on Intellectual Disabilities and Dementia Practices or the NTG. I am pleased to announce that the NTG was recently awarded a grant by Special Olympics for its project, "Changing Thinking! A National Initiative to Enhance Access to Critical Health Care and Supports for Adults with Intellectual and Developmental Disabilities and Dementia". This initiative will target GUIDE program care navigators, practitioners, and managers, offering culturally responsive educational materials, training, and protocols to address barriers to care disproportionately experienced by adults with ID and dementia from marginalized communities. We look forward to learning more about the work of the Advisory Council on the CMMI Guide Model.

My husband and I are the parents of three adult children with Down syndrome, one of who was recently diagnosed with mild cognitive delays. It is critically important that current and future clinical trials for medications that treat Alzheimer's disease include people with intellectual disabilities, especially adults with Down syndrome. Dementia appears in about 6% of the population of adults with intellectual disability over the age of 60 years, and 12% of the population over the age of 80 years. However, adults with Down syndrome show a much higher prevalence of about 60% among adults aged 60 and older. There is also a higher rate among younger age adults with Down syndrome -- about 20% among adults aged 40 and older.(1)

Research demonstrates that across the United States, approximately 60% of people with intellectual and developmental disabilities who receive a Medicaid funded service live with their families.(2) In part, this is due to long waiting lists for services. Caring for an adult with an intellectual disability for 50 or 60 years, coupled with dementia later in life, results in emotional, financial and physical strain on caregivers, especially on elderly caregivers. In conclusion, given the staggering percentage of people with ID, especially Down syndrome who will be diagnosed with dementia and the heart wrenching impact on families, it is time that adults with intellectual disabilities be included in clinical trials for medications that treat Alzheimer's disease.

Thank you.

NOTES:

1. National Task Group on Intellectual Disabilities and Dementia Practices (2022). *The NTG FAQ: Some Basic Questions about Adults with Intellectual/Developmental Disabilities Affected by Alzheimer's Disease or Other Dementias*.
2. Larson, S.A., Neidorf, J., Pettingell, S., & Sowers, M. (2022). *Long-term supports and services for persons with intellectual or developmental disabilities: Status and trends through 2019*. University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration. 10.13140/RG.2.2.23116.08320.

M. Ellenbogen | 8-5-2024

For a long time I have brought this up to NAPA. While some progress has been made, we are far from where we need to be. The most impressive part is seeing CMS considering the CMS-1808-P proposed rule.

While I believe it's a good first step, it falls very short of helping people with cognitive issues. If we really want to change what is needed for all people, we need to be bold and include the following, which UsAgaintsAlzheimers proposed to CMS.

They said it very clearly on what needs to be added to CMS-1808-P if we are really serious about changing the **trajectory of truly helping people with cognitive issues**.

We would support a final rule that does the following:

1. *Screens of admitted patients for cognitive issues, including dementia and delirium. Screening should include all patients over 65 **as well as younger patients who are at risk** for cognitive issues.*
2. *Develops ways of making hospital staff aware that a patient has been identified as likely having a cognitive issue.*
3. *Trains and educates hospital staff on the appropriate ways to care for patients with cognitive issues who are in the hospital.*

Please take advantage of the proposed new rules and include these suggestions. We have a true opportunity to really help not only people with dementia but so many others dealing with cognitive issues. This way they will get the help they all deserve.

Some additional comments. After attending AAIC 2024 I see from my perspective while many are trying to do great projects, they fail to have a business-minded project manager driving the initiative and fail to include people living with dementia. Adding these people will lead to more expedient outcomes.

I just formed a new world class dementia training program by bringing together top organizations to work as one new company. This is unheard of in this field and they are ready to train all staff in the hospital system in caring for those living with cognitive impairment. They all have Evidence-Based programs.

I am sending you a longer version to be added to the record.

I had requested the following to be read at the last meeting but for some reason that did not happen. Please add this to the record along with my comments above.

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Attachment:

The Failing Hospital System--*When it Comes to Cognitive Issues*

For about 15 years now I have been advocating for the dementia arena. I have been leaving bread crumbs all over the place with some of the highest levels of people in the world in hopes I can make a small difference for those impacted by this horrible disease.

I started doing this because there were not enough people, actually living with dementia, standing up for others. There was less than a handful of folks doing this from around the world. Today, I am glad to say, there are many out there stepping up to do their part, but sadly I still don't see the number of minority representatives I would like to see.

When I began this journey, I had a list of about 15 things to be accomplished that would lead to better support for those impacted by dementia. Over the years that list grew and I was very fortunate to get all but two items accomplished, with the help of many great people and organizations out there.

I believe we are living in exciting times as so many advancements have occurred in the last 5 years. People with cognitive issues will benefit greatly, and the possibility even exists that some living with dementia today will see a cure, or at least a way to slow it down within the next 10 years.

Currently there are some great programs being designed and considered to keep people living in their homes longer and being paid so they are not forced into seeking an assisted living facility or memory care unit.

There is a great deal of new education programs around dementia for hospitals and medical staff that did not exist a few years ago. Perhaps, early training and awareness is the answer? Yet, medical schools today are overburdened with meeting high accreditation standards for qualifying exams and less concerned with graduating doctors educated to address complex care pathways like dementia and cognitive disabilities. This includes places like Harvard, where I had the opportunity to speak with a class of students soon to graduate. It is sad to see our future physicians being trained as expert scientists rather than patient care stewards.

So how do we resolve some of these issues? I personally know that most medical staff is eager to learn more about dementia. But that comes at a cost to the institutions for which they work. I have been fortunate to speak to people at the highest level in government, related to healthcare, and they all agree we need to see changes for the better, especially in hospital systems.

While we have advanced in the last few years how do we ensure that people get this dementia training that has been designed and is ready for implementation? Hospital system management refuse to pay for this education and organizations, like The Joint Commission, refuse to create an accreditation requirement, or even a certification process which hospitals can apply for if they meet the education criteria.

What I find amazing is they already enforce an educational requirement for staff working in Assisted Living facilities but they don't feel it is needed in acute care hospitals. Not only do those living in Assisted Living facilities require acute hospital care, but also many with dementia still living at home. I have been working on this for 10 years without success and I know many others who have also failed.

Another issue that must be addressed concurrently is how to identify which hospital patients are living with dementia. Facing stigma in society is a huge problem and sadly leads to many not disclosing their dementia diagnosis to others. Also, about 50 percent of those living with some type of dementia don't even know they have it, as that is part of the problem with this condition. There are also many people with cognitive issues that could be reversed if they were able to seek a diagnosis. Not all cognitive issues are progressive so we must ensure quick diagnosis. Sadly, today many still feel cognitive decline is a normal result of aging. This is not true.

While everyone I have spoken with insists my idea of having a certification program for dementia in hospitals is the right thing to do, most feel it cannot be accomplished. They feel that the cost and time required will not be accepted by senior hospital management. To meet managers and administrators where they are, perhaps the answer is showing how certification can reduce cost and improve patient outcomes overtime. Yet, unless administrators are willing to think outside the traditional care pathways, systems will continue to sacrifice people's lives to avoid additional cost. I cannot stand idly by while knowing that some of the most important advances in hospital care required changes

and management approvals. Just think many of the standards we have today would not exist if we thought that way all the time.

If hospitals had these certifications programs, they could easily close the final gap that is needed to fix the entire system as it relates to patients with cognitive issues. I am not saying that hospitals should be mandated to get this certification. I believe, as we have seen in the past, that when certification programs exist, hospitals seek them out to show their community they offer high quality healthcare. I also believe this will create more competition among hospitals. Just as they do today for other certification programs that are tracked.

So, let's assume the hospital has a Certification program for dementia. Their admission work-up would include a 3-minute cognitive test. This will identify the patients that may need additional help while they are in the hospital. It will also determine if the patient needs further follow-up upon discharge to get the advanced care they need and deserve. Addressing patient needs upfront and early in the admission process will guide care planning as well as provide an appropriate pathway to discharge and advanced care planning if necessary.

Today we do not know when most people admitted to the hospital need additional help, which can contribute to medication errors, unnecessary or suboptimal treatments, increased stress and an unhappy patient. There are also financial implications from lawsuits and penalization in bill payment for hospital readmissions.

By instituting this quick test, hospitals may even increase volumes as they identify patients that may have an issue and require further work-up. This also benefits the patient who may have been unaware of their deficit. I hear from others often that they know something is wrong but are afraid to say something to their loved one for fear of causing an argument.

I have always been a visionary and out of the box thinker. While this idea came to me from my own hospital experience, over 12 years ago, I believe now is the time to close the loop and make the hospital system safer. I know hospitals that would seek out this certification if available.

There is a program that came out a few years ago gaining traction, but it only places a band aid on the problem and fails those living with dementia. It's called the "4Ms". The focus is on What Matters, Medication, Mentation, and Mobility. But it fails to identify the patients in need. What is the benefit of having a procedure in place if you can't identify when to implement it? Here is where a certification can guide clinics and hospitals through training on screening and new techniques for engaging people in conversations about cognitive health.

I am not one to reinvent the wheel and do not care where the credit will lie, but we must do something now and must hold our hospitals accountable for the safety of our patients. Let's stop talking about it and do the work that we know will be successful, not

just another program that sounds good. The existing systems fail our seniors and others living with cognitive challenges. People with cognitive issues deserve to be treated with respect and to receive the highest quality care possible.

Michael Ellenbogen - *living life to the fullest with dementia*

Comments from the experts:

I am fully on board with this. Especially now that there are treatments slowing Alzheimer's, the need for more people being diagnosed and earlier in the disease process is imperative. Half a million Americans die each year with significant cognitive impairment but most lack a diagnosis. We must do more, especially to raise awareness of health care providers.

David Morgan, PhD, MSU Foundation Professor of Translational Neuroscience, Director Alzheimer's Alliance, Michigan State University College of Human Medicine, Grand Rapids MI.

I fully support the need for more dementia-capable care for people living with dementia in the hospital, and the need for expanded training for hospital-based professionals.

Joseph E. Gaugler, PhD | Robert L. Kane Endowed Chair in LTC & Aging | Director, Center for Healthy Aging and Innovation | Distinguished McKnight University Professor | Director, BOLD Public Health Center of Excellence on Dementia Caregiving | Editor-in-Chief, the Gerontologist | Division of Health Policy and Management | School of Public Health | University of Minnesota.

The underdiagnosis and non-disclosure of Alzheimer's disease and other dementias is a big problem. Rewarding hospitals who do a good job identifying cognitive disorders that impact care is a good first step towards a solution.

David Weisman, MD. Director, ANA Clinical Research Center.

Michael has indeed identified two of the primary stumbling blocks to providing the necessary support and care when someone is living with the brain changes of a developing dementia: the lack of recognition that dementia has an active role in the situation, and the lack of training that involves both knowledge acquisition and skill demonstration. The current lack of any dementia recognition or training requirements for all personnel in hospital settings makes them some of the most dangerous and ill-informed places for someone who is living with this condition. As the numbers of individuals who are likely to experience some form of dementia in their lives is increasing, the ability to provide effective support and care is not keeping pace.

Improvement of dementia recognition and training are essential for providing quality interactions, treatment, and outcomes in our hospital systems. It is time to acknowledge the need for all health care settings, hospitals included, to participate in the recognition

and support of early indications, mid-state changes, and late state challenges of dementia and other neurodegenerative conditions.

Teepa Snow, MS, OTR/L, FAOTA, Founder and CEO of Positive Approach to Care®.

Michael describes in detail the sentiment I've heard from patients and families across the country. Cognitive health is not a priority in hospitals or in primary care. As he explains, this is not a result of bad physicians; rather, this is the result of a bad system of care. It is clear that the biomedical model rules medical school training. We also know that hospitals are guided by systems of payment and reimbursement. Levels of burnout across the U.S. demonstrate how systems focused on financial outcomes rather than the care or treatment of patients demoralizes physicians and the nurses on the front lines. Patients with cognitive health concerns are at the forefront of this imbalanced system. They are there because treatment costs time and attention. It requires compassion from a system that is inherently dispassionate. As a result hospitals are letting go of their responsibility to care for this population because they simply can't justify the costs. To meet this head on, we all must rethink our approach and argue with evidence that intentional and kind care saves money, lives, and improves outcomes.

Stuart W. Grande, Residential (MPH) Program Director, Public Health Administration Policy, Division of Health Policy and Management, The University of Minnesota, Twin Cities.

I agree whole heartily with your basic assessment of the dire need in hospital systems to do more awareness training, some kind of certification, provide short screenings to all those 50+ entering their care, and a wristband for staff awareness when needed. The real key is, if they perform an abridged mini screener, and find that there is a possible impairment, what steps they take with that knowledge. There is a lot to roadmap, unpack, and work through, but well worth the effort, and I am more than willing to lend my support.

Kevin Jameson, Volunteer, Founder, CEO, Dementia Society of America®.
