U.S. Government Accountability Office

National Alzheimer's Project: HHS Needs to Better Assess and Communicate Progress

GAO-26-108498 [Accessible Version]
Q&A Report to Congressional Requesters
June 29, 2026

Why This Matters

One in three older Americans dies with Alzheimer's disease or a related dementia. The number of individuals with Alzheimer's and related dementias is expected to nearly double by 2050 as the U.S. population ages, according to research funded by the National Institutes of Health (NIH). This likely means increasing nationwide costs for care. Medicare and Medicaid spending for services and supports for Alzheimer's and related dementias were estimated at $246 billion in 2025 alone. Additionally, NIH research funding for Alzheimer's and related dementias—including research aimed towards finding treatments—has increased from $448 million in 2011 to $3.9 billion in 2024, per agency data.

Enacted in 2011, the National Alzheimer's Project Act required the Department of Health and Human Services (HHS) to implement a project to coordinate federal research and services for Alzheimer's and related dementias. The project includes an Advisory Council that is required to make annual recommendations to improve the project. In 2024, Congress reauthorized the project through 2035.

We were asked to review the National Alzheimer's Project. This report describes the project's achievements and examines HHS efforts to provide updates on council recommendations and assess project progress.

Key Takeaways

Project documentation, HHS officials, Advisory Council members, and non-federal stakeholders highlighted numerous key achievements of the National Alzheimer's Project, including the first two approved treatments aimed at slowing progression for early-stage Alzheimer's disease.

The Advisory Council has made 285 recommendations to HHS and others to improve the project through 2024. HHS provides periodic updates on recent federal actions informed by some of these recommendations, but having more detailed information on the implementation status of individual recommendations would help the council identify and prioritize issues.

HHS has provided annual updates on the project but has not fully followed key practices to assess progress toward its long-term goals for the project, including curing Alzheimer's. For example, it has not set near-term goals with performance measures and time frames at the project level.

We recommend HHS provide information on the implementation of individual council recommendations and take steps to improve how it assesses and communicates project progress.

What are Alzheimer's disease and related dementias?

Alzheimer's disease is a neurodegenerative disease that causes dementia symptoms, such as impaired memory, thought processes, and functioning,

primarily among older adults. Several related dementias cause symptoms similar to those caused by Alzheimer's disease. They include:

Frontotemporal dementias, which are marked by nerve cell loss in the frontal and temporal lobes of the brain and are a common cause of early-onset dementia.

Lewy body dementias, including dementia with Lewy bodies and Parkinson's disease dementia, which are marked by the presence of abnormal deposits of a specific protein in the brain, affecting thinking, reasoning, and movement.

Vascular contributions to cognitive impairment and dementia, which result from conditions that interrupt the supply of blood and oxygen to the brain, causing damage.

Mixed dementias, which are a combination of two or more types of dementia.

What is the National Alzheimer's Project?

The National Alzheimer's Project, established by the 2011 act, encompasses a range of federal activities related to Alzheimer's disease and related dementias, such as

research into methods to prevent, treat, and reduce the risk of developing Alzheimer's disease and related dementias,

grant programs supporting dementia-capable home- and community-based services and supports, such as home meal delivery, and

public education campaigns.[1]

The act did not provide appropriations for the National Alzheimer's Project's coordinating responsibilities, nor for agency programs related to the project. Rather, agencies that participate dedicate their own funding to their specific efforts related to Alzheimer's disease and related dementias. For example, one HHS agency has used some of its own funding for a grant program that provides services to people with Alzheimer's disease and related dementias and their caregivers.

The project involves a range of stakeholders, including both federal and non-federal.

Federal stakeholders include Congress and federal agencies.

Non-federal stakeholders include health care provider and patient groups, community organizations, and the general public, including caregivers and individuals living with Alzheimer's disease and related dementias.

The act also established the Advisory Council on Alzheimer's Research, Care, and Services (Advisory Council), which is required to annually evaluate and make recommendations to HHS to improve the project.[2]

Additionally, the act requires HHS to create and annually update a national plan.[3] The 2025 *National Plan to Address Alzheimer's Disease* (National Plan)—the most recently available update as of the time of our work—lays out six long-term goals for the project:

Prevent and effectively treat Alzheimer's disease and related dementias.

Enhance care quality and efficiency.

Expand supports for people with Alzheimer's disease and related dementias and their families.

Enhance public awareness and engagement.

Improve data to track progress.

Accelerate action to promote healthy aging and reduce risk factors for Alzheimer's disease and related dementias.

What federal agencies have been involved in the National Alzheimer's Project?

HHS and its agencies have administered and coordinated the majority of the National Alzheimer's Project's activities, per the 2024 National Plan update. For example:

The **Assistant Secretary for Planning and Evaluation (ASPE)** is responsible for leading the project overall, including compiling information for the annual updates.

NIH is responsible for managing research into methods to prevent, treat, and reduce the risk of developing Alzheimer's disease and related dementias and improve care and caregiving.

The **Administration for Community Living (ACL)** is responsible for improving care and support for people with Alzheimer's disease and related dementias and their caregivers.

The **Centers for Disease Control and Prevention (CDC)** is responsible for translating research into public health communications and interventions.

In addition to these agencies, other HHS agencies are involved in the project. For example, the 2024 National Plan update designated the Centers for Medicare & Medicaid Services to help make education and training available to caregivers. Further, other federal agencies outside of HHS have designated roles. For example, the 2024 National Plan update designated the Department of Veterans Affairs to provide information about the Veteran Caregiver Support Program for caregivers of veterans living with dementia. The 2024 National Plan update also designated federal agencies to coordinate activities with non-federal stakeholders, such as by designating ACL to promote the use of the National Alzheimer's Call Center in collaboration with the Alzheimer's Association.

The involvement of multiple federal agencies in the same broad area of national need—which GAO has defined as fragmentation—can be expected in this case due to the nature and breadth of federal efforts related to Alzheimer's disease and related dementias. Effectively managing fragmentation can help improve efficiency and performance and potentially result in cost savings, according to our prior work.[4]

What has the National Alzheimer's Project achieved?

The National Alzheimer's Project has contributed to numerous significant achievements to date, according to the National Plan. HHS officials, Advisory Council members, and non-federal stakeholders we interviewed highlighted the following areas in particular:

New diagnostic tools. Research has resulted in approved blood testing to detect biological hallmarks of Alzheimer's disease, which can help diagnose or rule out the disease with greater than 90 percent accuracy, according to clinical studies.[5] Previously, an Alzheimer's diagnosis required expensive neuroimaging or an invasive puncture in the lower back to collect spinal fluid.

New treatments. Research has resulted in the first two approved treatments aimed at slowing disease progression for early-stage Alzheimer's disease.[6] Additionally, as of June 2025, more than 100 new drugs targeting varying aspects of Alzheimer's disease treatment were being assessed in clinical trials.[7]

Increased understanding of risks. Research has revealed several key risk factors for Alzheimer's disease and related dementias; learning these factors has helped establish effective risk reduction strategies through lifestyle changes. For example, lowering blood pressure and participating in exercise have been found to reduce the risk of cognitive impairment, including Alzheimer's disease and related dementias.

Support for patients and caregivers. Research on comprehensive care models led to the implementation of HHS's "Guiding an Improved Dementia Experience (GUIDE) Model" pilot. The GUIDE Model is a voluntary, nationwide pilot that tests the impact of providing Medicare coverage for comprehensive services and support for those with Alzheimer's disease and related dementias and their caregivers. One such service is access to 24/7 support lines. The model is intended to improve quality of life and reduce Medicare and Medicaid costs. If successful, it could be rolled out to additional populations. In addition to the GUIDE Model, in 2025, ACL launched grants to fund the inclusion of community health workers in efforts to improve services and supports for patients and caregivers.

Enhanced awareness and collaboration. Enhanced awareness of Alzheimer's disease and related dementias and enhanced collaboration across federal agencies and among federal and non-federal stakeholders have been important project achievements as well, according to those we interviewed. For example:

NIH partnered with the Department of Veterans Affairs to enroll veterans in certain Alzheimer's disease studies, according to NIH officials. Officials noted these collaborations were especially important because veterans have unique risk factors for dementia. For example, veterans may be more likely to have experienced traumatic brain injury, which can increase dementia risk, according to research.

The Advisory Council regularly collaborated with public advocates at its public meetings. For example, the Advisory Council engaged with advocates from the Down syndrome community at Advisory Council meetings, as individuals with Down syndrome have an increased risk of developing Alzheimer's disease and related dementias. This led to Advisory Council recommendations on the topic, and HHS funded grants for research on the intersection of Down syndrome and Alzheimer's disease and related dementias, according to HHS documentation.

Alzheimer's disease and related dementias are complex diseases with varied causes and characteristics. Progress towards a cure is not made easily and is not predictable, according to HHS officials and non-federal stakeholder groups we spoke with. At the same time, non-federal stakeholder groups noted the benefits of this project towards advancing research. One group described the Alzheimer's research community as being on the cusp of major discoveries thanks in part to the efforts and achievements of the project.

What has been the role of the Advisory Council?

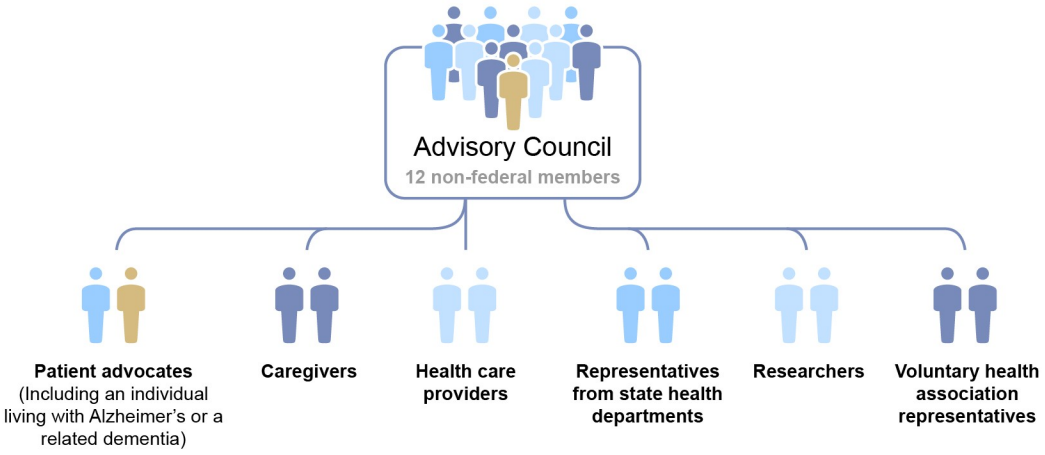
The National Alzheimer's Project Act established the Advisory Council to provide feedback on and develop recommendations for the project.

To ensure that the Advisory Council fosters collaboration across sectors, it has included 10 federal members and 12 non-federal members.[8]

Federal members primarily update the council on federal activities and provide guidance and subject matter expertise—such as clarifying agency responsibilities—to assist non-federal members in their work, according to recent council members.[9]

Non-federal members have been selected to encompass a broad range of experiences related to Alzheimer's disease and related dementias and have generally served four-year terms (see Figure 1). Non-federal members have typically applied to be selected through a nomination process and are appointed to the council by the Secretary of Health and Human Services.

Figure 1: Background of the Non-Federal Members of the Advisory Council, 2011-2024



Source: GAO analysis of documentation from the U.S. Department of Health and Human Services; GAO (illustration). | GAO-26-108498

Accessible Data for Figure 1: Background of the Non-Federal Members of the Advisory Council, 2011-2024

Specifically, the Advisory Council has 12 non-federal members:

- 2 patient advocates (Including an individual living with Alzheimer's or a related dementia)
- 2 caregivers
- 2 health care providers
- 2 representatives from state health departments
- 2 researchers, and
- 2 voluntary health association representatives

Source: GAO analysis of documentation from the U.S. Department of Health and Human Services; GAO (illustration). | GAO-26-108498

Note: The National Alzheimer's Project Act established the Advisory Council on Alzheimer's Research, Care, and Services (Advisory Council) to provide feedback on and develop recommendations for the project. It also has included 10 members from the federal government.

The full Advisory Council has held public meetings on a quarterly basis to share information, resources, and updates on recent federal activities. HHS has announced meeting dates in advance through Federal Register notices, and members of the public have had the opportunity to provide comments. In addition to its quarterly meetings, the council has divided work across four subcommittees that have met monthly and focused on the following topics: 1) clinical care, 2) long-term services and supports, 3) research, and 4) risk reduction.

The Advisory Council's subcommittees have led the annual process of developing recommendations. According to recent Advisory Council members, the non-federal members on each subcommittee identified existing challenges or gaps in National Alzheimer's Project efforts and solicited the perspectives of subject matter experts and affected populations to learn more about these issues and identify recommendations. The full council would then review each subcommittee's recommendations and provide input. As of April 2026, the Advisory Council has made 285 recommendations. (See app. I.)

The act requires that the council's finalized recommendations are provided to HHS and Congress annually. Additionally, the recommendations are posted to ASPE's website, and HHS officials said they also share the recommendations with other relevant stakeholders.

HHS paused the Advisory Council's public quarterly meetings after its January 2025 meeting until February 2026, and the council did not release recommendations in 2025. Additionally, in August 2025, 11 out of 12 non-federal council members were terminated, according to HHS officials and recent Advisory Council members, including some members who were partway through their expected term. During the February 2026 quarterly meeting, 11 new non-federal members were sworn in to fill these positions to make a total of 12.

How has HHS provided updates on the status of the Advisory Council's recommendations?

HHS has reported aggregate information on the implementation rate of prior Advisory Council recommendations but has not provided information on the status of individual recommendations back to the council, such as actions taken by agencies to address them.

HHS has used a publicly accessible federal database to document the implementation rate across all recommendations the Advisory Council has made to federal agencies.[10] According to this database, 72 (25 percent) of the 285 recommendations made by the council are fully implemented and 143 (50 percent) are partially implemented. This count of implemented recommendations includes those the council directed towards HHS and other federal agencies. The council has also made recommendations to Congress or non-federal stakeholders, which HHS officials noted are outside of their purview.

However, this aggregate information on the implementation rate does not specify the implementation status of individual recommendations. Additionally, it does not detail what actions, if any, have been taken related to an individual recommendation. HHS officials noted the council's federal members periodically provide updates on recent actions informed by some of the prior recommendations, such as at the council's public quarterly meetings and at monthly subcommittee meetings. Despite this, multiple recent council members told us having more detailed information for individual recommendations would help the council identify and prioritize remaining issues, and in 2024 the Advisory Council recommended HHS take steps to improve information it shares on the status of the council's recommendations. For example, HHS could provide the council with a crosswalk that lists recommendations to federal agencies from recent years and information on how each has been addressed, as applicable.

Sharing information on the implementation status of individual recommendations, including actions taken to address them, would be consistent with key practices for performance management. These practices emphasize the value of sharing relevant information such as this with stakeholders and decision-makers.[11]

When asked why they have not provided this information, HHS officials said Advisory Council recommendations can often be complex and contain many action items that may take multiple years to fully implement, making them difficult to track in detail. Additionally, HHS officials told us they have finite resources to manage the project, which could make assuming additional responsibilities such as this more challenging.

While providing this information may require resources, it would also better position the Advisory Council to make effective recommendations that could ultimately create efficiencies for the project overall. For example, in 2022 the Advisory Council recommended that HHS provide training to federally qualified

health centers to help underserved populations access key supports and services. Knowing whether this recommendation has been implemented and what actions, if any, have been taken to address it could help the council determine if it should make a similar recommendation again or prioritize a different aspect of the project.

This information on the implementation status of individual recommendations the Advisory Council has made to federal agencies could be particularly valuable as the Advisory Council resumes its activities in 2026. Specifically, this information could help new Advisory Council members identify remaining gaps and develop focused recommendations to improve project efforts.

How has HHS assessed the progress of the National Alzheimer's Project?

HHS has used its publicly available annual updates to the National Plan to assess the progress of and meet its statutory requirement to evaluate federally funded programs' efforts to address Alzheimer's disease and related dementias, according to HHS officials.[12] The most recent National Plan updates in 2024 and 2025 contained six long-term goals. The 2024 update also included detailed updates from agencies on activities they had conducted related to each long-term goal.

However, HHS has not fully followed key practices to assess progress, as outlined by our prior work on performance management, in its assessment of the progress of the National Alzheimer's Project.

Key performance management practices identified by GAO

Our prior work has shown that federal decision-makers need evidence about whether programs and activities are achieving intended results.[13] To do so, agencies should engage in performance management—a three-step process by which agencies assess the progress of efforts toward pre-established goals. Our past work has highlighted that this approach can be valuable at various organizational levels, from individual projects to efforts that span across agencies, like the National Alzheimer's Project.[14]

1. **Setting long-term and near-term goals.** For each long-term goal, an agency sets one or more near-term goals.
    - **Long-term goals**: Outcomes that an agency seeks to achieve through its programs and activities.
    - **Near-term goals**: Tangible, measurable results that an agency expects its programs to achieve. Near-term goals must be composed of a performance measure, a quantitative target level of performance, and a time frame by which to achieve the result.
2. **Information collection.** Agencies collect information to assess performance and progress toward goals. Agencies use the performance measures they identified when they set their near-term goals to communicate what information they will collect.
3. **Information use.** Agencies regularly use performance information
    - to assess progress toward goals and inform management decisions, such as expanding effective approaches, addressing performance gaps, or setting new goals; and
    - to effectively communicate results to help their stakeholders understand progress, how well they are performing, and decisions they have made to further improve results. Agencies tailor the frequency, method, and presentation by which they share information on progress to meet the needs of various stakeholders.

Setting long-term and near-term goals for the National Alzheimer's Project

While HHS has set long-term goals for the National Alzheimer's Project and documented them in the National Plan, the department has not set specific near-term goals with performance measures, quantitative targets, and time frames at the project level. (See table 1 for selected long-term goals in the National Plan and examples of potential near-term goals that we identified.)

Table 1: Examples of Potential Near-Term Goals Identified by GAO for Selected Long-Term Goals from the National Plan to Address Alzheimer's Disease

		GAO example of a potential near-term goal	
Selected long-term goal from the National Plan	**Near-term goal from the National Plan**	**Target and time frame**	**Measure**
Enhance care quality and efficiency	None listed	Increase number of nursing assistants who have received certification in dementia care to [quantitative target] by [date].	Number of nursing assistants who have received this certification.
Expand supports for people with Alzheimer's disease and related dementias and their families	None listed	Develop [quantitative target] evidence-based interventions for caregivers, such as strategies for stress reduction, by [date].	Number of such interventions developed.

Source: GAO analysis of the 2024 and 2025 updates to the National Plan to Address Alzheimer's Disease. | GAO-26-108498

HHS officials noted that for several years it included an appendix in the National Plan update with targets and time frames for some of its activities. HHS stopped including the appendix starting with the 2020 National Plan because it was onerous to do so, and because of a perceived lack of interest in the updates, according to officials. We reviewed the most recent version of the appendix that officials said contained this information and found it generally did not identify near-term goals with performance measures, quantitative targets, and time frames, as outlined in our key practices for performance management. These key practices also establish the importance of determining what information is required to collect, track, and report out on goals, as well as a department's capacity for doing so. This can help inform HHS's decisions as to which goals are most appropriate to set.

In addition, HHS officials said near-term goals are already established at the agency or program level, independent of the broader project, and thus do not need to be stated in the National Plan. However, because the project comprises multiple federal agencies and programs, setting near-term goals at only the agency and program level does not guarantee alignment with the project's long-term goals. It also makes it difficult to effectively determine the progress of the project as a whole, as required by the act. Setting near-term goals for the project as a whole could mean developing new near-term goals or, to the extent they align with the long-term goals of the project, leveraging any existing agency- or program-level near-term goals.

Moreover, of the three agencies (ACL, CDC, NIH) we reviewed, NIH and ACL had provided documentation of near-term goals with performance measures, quantitative targets, and time frames at the agency or program level, predominantly related to three of the six long-term goals.

Information collection and use for the National Alzheimer's Project

Because HHS has not set project-level near-term goals with performance measures, targets, and time frames that align with the project's long-term goals, the department is unable to determine what performance information it needs to collect to assess progress toward the project's goals and to inform management decisions to adjust efforts, as appropriate.

Furthermore, without project-level near-term goals and performance information, HHS has been unable to effectively communicate the progress of the National Alzheimer's Project to stakeholders. For example, some stakeholders told us the 2024 National Plan update—the most recently available vehicle for communicating progress at the time of our interviews—was long, technical, and difficult to digest, making it less useful. This could be addressed, for example, by creating and periodically updating a dashboard that tracks the progress of identified near-term goals, grouped by each long-term goal.

HHS officials told us they have similarly heard there is an overwhelming amount of information in the National Plan, though they have also received feedback from other stakeholders that it included important information. At the February 2026 meeting of the Advisory Council, HHS officials announced their intention to evaluate and potentially adjust the National Plan updates to better meet stakeholder needs going forward, and they requested input from the public. In April 2026, HHS released the 2025 update to the National Plan, which was significantly shorter than the previous update. However, the 2025 update did not include specific near-term goals with performance measures, quantitative targets, and time frames at the project level.

HHS officials also noted that there are no dedicated appropriations to support the department's efforts to coordinate the National Alzheimer's Project, including its work to annually update the National Plan. As a result, HHS must rely on existing staff and resources and balance its statutory requirements to maintain the National Plan with efforts to improve the project, such as by setting near-term goals at the project level and adjusting the plan to better meet stakeholder needs, according to officials. This may limit the feasibility of setting new near-term goals and collecting and using performance information, officials said.

While we understand the challenges of resource constraints, following key practices would help HHS more effectively assess its progress towards the project's goals and determine whether and where changes may be necessary. Following these key practices would also provide HHS with tools to more clearly communicate the project's progress. Clearly communicating the extent of progress would help stakeholders better understand the returns on federal investments in the project and is particularly important given the project comprises sometimes disparate activities spread across multiple federal agencies.

Conclusions

Alzheimer's disease and related dementias are a complex set of conditions that have increased in prevalence with the aging of the U.S. population. The work coordinated through the National Alzheimer's Project has led to numerous notable achievements, including new ways of diagnosing and treating Alzheimer's disease and related dementias. It has also led to expanded support for those with Alzheimer's disease and related dementias and their caregivers by providing Medicare coverage for comprehensive services and support under HHS's GUIDE Model pilot. In addition, the project's Advisory Council has made numerous recommendations to improve the project.

Our review shows HHS needs to strengthen its communication and assessment of the project's effectiveness and progress. This can be done by providing information on the implementation status of individual recommendations the Advisory Council has made, including actions taken to address them. It can also be done by following key practices of performance management. This includes setting near-term goals comprising performance measures, quantitative targets, and time frames, and collecting information to assess progress. It also includes

using information to support management decisions and to clearly communicate the extent of progress toward project goals to stakeholders.

Such an assessment would benefit federal and non-federal stakeholders alike. Federal agencies can use such an assessment to better prioritize their investments of finite resources spread across multiple federal agencies and programs to more effectively progress toward the project's long-term goals. In addition, by communicating this assessment in a clear, digestible format, HHS can help stakeholders, including Congress, better understand the returns on federal investments in the project.

HHS has a timely opportunity to address our recommendations given the appointment of new Advisory Council members, the reauthorization of the project through 2035, and HHS's stated intent to consider improvements to its communication.

Recommendations for Executive Action

The Secretary of Health and Human Services should provide the Advisory Council with information on the implementation status of individual recommendations the council has made to federal agencies, including information on the actions taken to address them. (Recommendation 1)

The Secretary of Health and Human Services should set near-term goals for each long-term goal of the National Alzheimer's Project, that comprise performance measures, quantitative target levels of performance, and time frames by which results are to be achieved. (Recommendation 2)

The Secretary of Health and Human Services should collect performance information for the National Alzheimer's Project and use it to assess progress toward near- and long-term goals of the project, and inform management decisions to adjust efforts, as appropriate. (Recommendation 3)

The Secretary of Health and Human Services should communicate project progress to National Alzheimer's Project stakeholders in a clear, digestible format. (Recommendation 4)

Agency Comments and Our Evaluation

We provided a draft copy of this report to HHS for comment. In its written comments, reproduced in appendix II, HHS noted that the National Plan serves as a coordinating framework and that ASPE will continue to provide meaningful updates through existing mechanisms consistent with its coordinating role and available resources. HHS neither agreed nor disagreed with our recommendations.

For the first recommendation related to providing individual implementation status information to the council, HHS noted its ongoing efforts to supply information on agency activities related to Advisory Council recommendations, such as presenting updates at council meetings. Our report acknowledges these efforts, and we maintain that having more detailed information for individual recommendations would help the council identify and prioritize remaining issues.

For the second and third recommendations to set near-term goals for the project and to collect and use performance information to assess progress, HHS noted that such goals are already established at the agency or program level and expressed concerns that project-level goals would be duplicative. However, as our report notes, because efforts are spread across multiple agencies, setting near-term goals at only the agency and program level makes it difficult to effectively determine the progress of the project as a whole, as required by the act. Subsequently, as we state in this report, the department is unable to

determine what performance information it needs to collect and use to assess progress and make improvements toward the broader project's long-term goals.

For our fourth recommendation to clearly communicate project progress, HHS mentioned its newly streamlined 2025 National Plan update, released while the report was with the department for comment. We have updated our report to reflect this new plan. However, the plan does not have near-term goals at the project level. Given this, communication on project progress remains limited.

HHS also provided technical comments, which we incorporated as appropriate.

How GAO Did This Study

To inform this report, we reviewed HHS documentation related to the Advisory Council, such as meeting materials, as well as documentation related to the implementation status of Advisory Council recommendations. Additionally, we reviewed annual updates of the National Plan to Address Alzheimer's Disease from 2012 through 2025, and other documentation related to summarizing and assessing the progress of the National Alzheimer's Project.

To further inform this report, we interviewed HHS officials from ASPE, NIH, and ACL. ASPE was selected because it leads the project. We also selected NIH, ACL, and CDC, as they were the most frequently named lead agencies for actions in the 2024 National Plan. However, CDC officials were not able to respond regarding the agency's National Alzheimer's Project efforts, citing the unavailability of subject matter experts due to recent reductions in force within the agency.

We also interviewed nine non-federal members of the Advisory Council and five other non-federal stakeholders. We selected Advisory Council members who served at any point between 2021 and 2025 in order to include those with recent council experience. We selected members based on factors including council leadership position, professional and personal background, and duration of membership. Our selection of members currently in service was limited due to the termination of most council members in August 2025. The additional non-federal stakeholders we interviewed included those representing health care providers, state aging and disability agencies, long-term-care consumers, caregivers, and patients with Alzheimer's disease related dementias. We interviewed these groups for their perspectives on the achievements of the project and on HHS's efforts to assess project progress and the methods used to communicate project efforts. In our interviews with council members, we also discussed the process for developing Advisory Council recommendations. Although the views of our selected participants were not representative of all stakeholders, they provided illustrative perspectives of non-federal stakeholders and council members.

We assessed project efforts against GAO's prior work on key practices for performance management.[15] These practices state that agencies should set long-term and near-term goals, collect information to assess progress, and use information to inform management decisions. This includes communicating information to stakeholders.

We conducted this performance audit from May 2025 to June 2026 in accordance with generally accepted government auditing standards. Those standards require that we plan and perform the audit to obtain sufficient, appropriate evidence to provide a reasonable basis for our findings and conclusions based on our audit objectives. We believe that the evidence obtained provides a reasonable basis for our findings and conclusions based on our audit objectives.

List of Addressees

The Honorable Susan M. Collins
Chair
Committee on Appropriations
United States Senate

The Honorable Rand Paul, M.D.
Chairman
Committee on Homeland Security and Governmental Affairs
United States Senate

We are sending copies of this report to the appropriate congressional committees, the Secretary of Health and Human Services, and other interested parties. In addition, the report is available at no charge on the GAO website at https://www.gao.gov.

Appendix I: Additional Information on Advisory Council Recommendations

Enacted in 2011, the National Alzheimer's Project Act required the Department of Health and Human Services (HHS) to establish and implement the National Alzheimer's Project. The act also established the Advisory Council on Alzheimer's Research, Care, and Services to make recommendations to expand, eliminate, coordinate, or condense efforts within the project, among other things.

We analyzed each of the council's recommendations and identified those that were intended to (1) expand investments for the project by directly recommending increased federal spending related to project efforts and (2) streamline the project by consolidating or eliminating existing efforts or reducing the regulatory obstacles associated with project efforts. In addition, we identified the suggested actors and related topic areas for each recommendation that met either of the above criteria.

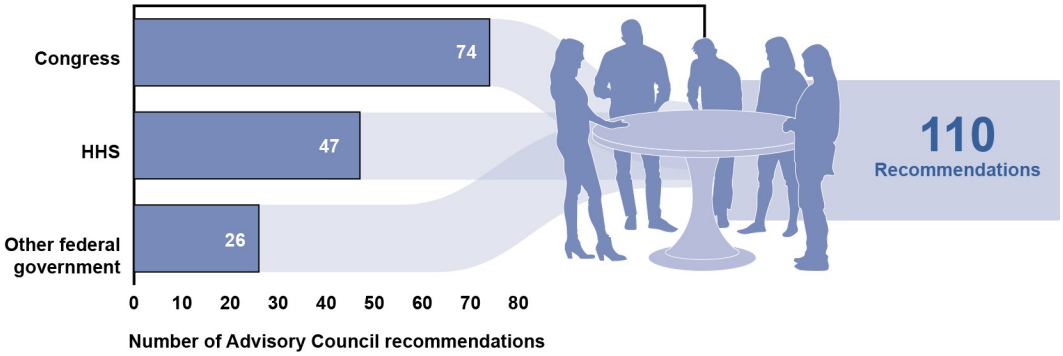
The Advisory Council made 285 recommendations between 2012 and 2024. The 285 recommendations often included multiple sub-recommendations. For the purposes of our analysis, if any sub-recommendation contained a provision to directly increase spending or to streamline project efforts, the broader recommendation was counted as doing so. Additionally, some of the recommendations contained multiple suggested actors or topic areas—in these cases, each unique actor or topic area was included in our total count. Some recommendations did not contain a suggested actor.

Recommendations to expand investments for National Alzheimer's Project efforts

We found that 110—about 39 percent—of the recommendations made by the Advisory Council through 2024 directly recommended increasing federal spending related to the National Alzheimer's Project.

The Advisory Council directed 74 of these recommendations to Congress as a suggested actor, while 47 were directed towards HHS or one or more of its component agencies, such as the National Institutes of Health. Additionally, other federal entities, such as the Department of Veterans Affairs, were suggested actors for 26 of these recommendations (see Figure 2).

Figure 2: Count of Advisory Council Recommendations to Increase Federal Spending for National Alzheimer's Project Efforts by Suggested Actor, 2012-2024



Source: GAO analysis of documentation from the Advisory Council on Alzheimer's Research, Care, and Services; GAO (illustration). | GAO-26-108498

Accessible Data for Figure 2: Count of Advisory Council Recommendations to Increase Federal Spending for National Alzheimer's Project Efforts by Suggested Actor, 2012-2024

Category	Number of recommendations
Congress	74
HHS	47
Other federal government	26

Source: GAO analysis of documentation from the Advisory Council on Alzheimer's Research, Care, and Services; GAO (illustration). | GAO-26-108498

Note: The Advisory Council on Alzheimer's Research, Care, and Services (Advisory Council) made 110 recommendations to increase federal spending related to the National Alzheimer's Project. The total count of recommendations across suggested actors in the figure above exceeds 110 because some of the recommendations included multiple suggested actors (e.g., the Department of Health and Human Services (HHS) and Congress) and therefore are counted more than once. In addition, some of the 110 recommendations did not include an explicit suggested actor. The HHS count includes recommendations directed to HHS as well as one or more of its component agencies (e.g., the National Institutes of Health).

The 110 recommendations to directly increase spending were most often related to ensuring individuals living with Alzheimer's disease and related dementias and their caregivers had access to supports and services, and to improving the research capacity of the federal government. See Table 2 for a complete breakdown of these recommendations by topic area.

Table 2: Count of Advisory Council Recommendations to Increase Federal Spending for National Alzheimer's Project Efforts by Related Topic, 2012-2024

Topic area	Count of related recommendations	Example of recommendation
Access to supports and services	45	Congress should appropriate additional funding to the Administration for Community Living for grants to provide comprehensive support and resources for caregivers of individuals with Down syndrome who may be at risk of or already experiencing Alzheimer's disease.
Research capacity	39	The National Institutes of Health should allocate funding to research to better understand how to address the impact of social isolation and loneliness on people with dementia and their unpaid caregivers.
Governance and coordination	21	The Department of Health and Human Services (HHS) should provide federal funds to support a state lead entity in every state and territory that will facilitate development of the state's dementia-capable systems.
Workforce development	19	The U.S. Department of Labor should award specific funding for long-term care workforce development, including the dementia care workforce.
Improving clinical care	15	HHS should create grants for pilot projects through the Center for Medicare and Medicaid Innovation to implement and evaluate ways to reduce preventable emergency department visits, hospitalizations, and length of hospital stays for individuals with Alzheimer's.

Topic area	Count of related recommendations	Example of recommendation
Prevention and early intervention	9	Congress should enhance appropriations of relevant existing federal programs—and fund additional new programs—that promote reducing risk of cognitive decline and dementia.
Public awareness and education	8	Congress should appropriate funding for dissemination of evidence-informed content—such as public service announcements—on brain health, risk reduction for memory loss, and the importance of decreasing stigma around Alzheimer's disease and related dementias.
National Alzheimer's Project administration	6	National Alzheimer's Project organizers, including the Assistant Secretary for Planning and Evaluation, should have increased resources to track the progress and milestones of prior Advisory Council recommendations with a goal to prioritize those with the largest potential impact.

Source: GAO analysis of documentation from the Advisory Council on Alzheimer's Research, Care, and Services. | GAO-26-108498

Note: The Advisory Council on Alzheimer's Research, Care, and Services (Advisory Council) made 110 recommendations to increase federal spending related to the National Alzheimer's Project. The total count of recommendations across topic areas exceeds 110 because some recommendations addressed multiple topic areas and are therefore counted more than once in the table above. The examples shown in the table may reflect the relevant sub-recommendation rather than the full recommendation text.

Recommendations to streamline the National Alzheimer's Project

We found that 33—about 12 percent—of the recommendations made by the Advisory Council through 2024 recommended streamlining project efforts by reducing regulatory obstacles. We did not identify any recommendations that recommended streamlining by consolidating or eliminating existing program efforts.

The Advisory Council directed 31 of these 33 recommendations to HHS or one or more of its component agencies as a suggested actor. Other federal government entities were a suggested actor for 12 of these recommendations.

The 33 recommendations intended to reduce regulatory obstacles targeted drug treatment and development, provider and caregiver flexibility, and regulatory alignment and collaboration. See table 3 for a breakdown of these 33 recommendations by topic area.

Table 3: Count of Advisory Council Recommendations to Reduce Regulatory Obstacles by Related Topic, 2012-2024

Topic area	Count of related recommendations	Example of recommendation
Drug and treatment development	16	The Department of Health and Human Services should take steps to accelerate public access to new therapeutic interventions by reducing the average time for regulatory review.
Provider and caregiving flexibility	16	Federal agencies should clarify Health Insurance Portability and Accountability Act protections to ensure that providers can effectively communicate with family members of those diagnosed with Alzheimer's disease.
Regulatory alignment and collaboration	6	The Administration should establish a Global Alzheimer's Action Plan to foster ongoing international dialogue and coordination on Alzheimer's regulatory reviews.

Source: GAO analysis of documentation from the Advisory Council on Alzheimer's Research, Care, and Services. | GAO-26-108498

Note: The Advisory Council on Alzheimer's Research, Care, and Services (Advisory Council) made 33 recommendations to reduce regulatory obstacles. The total count of recommendations across topic areas exceeds 33 because some recommendations addressed multiple topic areas and are therefore counted more than once in the table above. The examples shown in the table may reflect the relevant sub-recommendation rather than the full recommendation text.

Appendix II: Comments from the Department of Health and Human Services

DEPARTMENT OF HEALTH & HUMAN SERVICES — OFFICE OF THE SECRETARY

Assistant Secretary for Legislation
Washington, DC 20201

June 4, 2026

Mary Denigan-Macauley
Director
Health Care
U.S. Government Accountability Office
441 G Street NW
Washington, DC 20548

Dear Ms. Denigan-Macauley:

Attached are comments on the U.S. Government Accountability Office's (GAO) report entitled, **"National Alzheimer's Project: HHS Needs to Better Assess and Communicate Progress"** (GAO-26-108498).

The Department appreciates the opportunity to review this report prior to publication.

Sincerely,

Gary Andres
Assistant Secretary for Legislation

Attachment

GENERAL COMMENTS OF THE DEPARTMENT OF HEALTH AND HUMAN SERVICES (HHS) ON THE GOVERNMENT ACCOUNTABILITY OFFICE'S DRAFT REPORT ENTITLED – NATIONAL ALZHEIMER'S PROJECT: HHS NEEDS TO BETTER ASSESS AND COMMUNICATE PROGRESS (GAO-26-108498)

The U.S. Department of Health and Human Services (HHS) appreciates the opportunity to review and provide comments on the Government Accountability Office's (GAO) draft report.

The National Alzheimer's Project Act (NAPA) was established to assist federal agencies in coordinating efforts in addressing the needs of Alzheimer patients and other stakeholders. As a coordinating framework across multiple federal agencies the National Plan does not function as a programmatic or operational entity. It serves as a coordinating and reporting framework that synthesizes federal efforts across agencies. The plan is not intended to supplant individual agencies' work in this area. HHS would also like to share that the 2025 update to the National Plan was released on April 27, 2026.[1]

Additionally, ASPE supports NAPA activities within existing resources and staffing, including a team of two staff members, neither of whom are assigned full-time to NAPA-related work. There is no dedicated appropriation for these efforts. Any additional recommendation tracking would compound resource challenges and represents a different scope of activity than periodic coordination and extends beyond ASPE's coordinating role. Given the breadth of participating agencies, HHS will continue to provide meaningful updates through existing mechanisms consistent with ASPE's coordinating role and available resources.

Recommendation 1
The Secretary of Health and Human Services should provide the Advisory Council with information on the implementation status of individual recommendations the council has made to federal agencies, including information on the actions taken to address them.

HHS Response
HHS values the Advisory Council's input and considers its recommendations in ongoing program and policy development. HHS provides information on agency responses and activities related to Advisory Council recommendations through several existing mechanisms. HHS provides updates to the Advisory Council at meetings and highlights when agency actions align with recommendations, including legislative or programmatic developments.

Federal agencies provide feedback and responses to recommendations during the public meetings of the Advisory Council. Recommendations that are implemented are reflected in the update to the National Plan to Address Alzheimer's Disease, which is released annually. In addition, the four subcommittees of the Advisory Council meet monthly. The primary purpose of these meetings is to craft annual recommendations.

Federal agency staff provide very specific feedback on the previous year's recommendations, including what items are no longer needed because they have been implemented, as the subcommittee writes new or updated recommendations. ASPE reviews Advisory Council recommendations and incorporates them into federal planning and actions where feasible. Many

[1] *See* https://aspe.hhs.gov/sites/default/files/documents/b285be4a31850170c2bcad19eb80ebe4/FINAL%20FINAL%2020 25%20National%20Plan%20to%20Address%20Alzheimers%20Disease%20%281%29.pdf

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recommendations are complex, multi-component, and involve multiple agencies or external partners, which can affect both timing and scope of implementation.

Recommendation 2
The Secretary of Health and Human Services should set near-term goals for each long-term goal of the National Alzheimer's Project, that comprise performance measures, quantitative target levels of performance, and time frames by which results are to be achieved.

HHS Response
HHS acknowledges the importance of measurable performance goals with targets and time frames. The National Plan includes certain time-bound and outcome-oriented goals (e.g., preventing and effectively treating Alzheimer's disease and related dementias by 2025) and is supported by a range of strategies and actions that guide implementation. Most specific, measurable performance goals are established and tracked at the program or agency level, where implementation authority and subject matter expertise reside.

As a coordinating framework across multiple federal agencies the National Plan does not function as a programmatic or operational entity. It serves as a coordinating and reporting framework that synthesizes federal efforts across agencies. The measures are designed to support agency-specific program management and are not structured for centralized Plan-level performance management. Establishing additional Plan-level performance measures could be duplicative of existing efforts as current structures allow HHS to assess progress through agency-level reporting and annual updates to the National Plan, which reflect a coordinated view of federal efforts.

Recommendation 3
The Secretary of Health and Human Services should collect performance information for the National Alzheimer's Project and use it to assess progress toward near- and long-term goals of the project, and inform management decisions to adjust efforts, as appropriate.

HHS Response
HHS recognizes the importance of using performance information to support coordination, transparency, and awareness of federal activities related to Alzheimer's disease and related dementias. Federal agencies participating in the National Alzheimer's Project routinely collect and assess programmatic and research-related information within their respective authorities and areas of expertise. This information is used by agencies to monitor activities, evaluate progress, and inform programmatic decision-making.

For example, performance goals are established and monitored at the program or agency level, where planned and actual results are routinely compared to guide decision-making. For example, the AD and ADRD Research Implementation Milestones provide very specific details on the planned and actual results of research towards the goals of the National Plan. It would be redundant for ASPE to undertake the same effort and provide the same information.

The National Plan to Address Alzheimer's Disease serves primarily as a cross-agency coordinating framework intended to summarize and communicate federal efforts. The Plan reflects information and updates provided by participating agencies, including ongoing activities, milestones, and research developments. For example, the AD/ADRD Research Implementation Milestones provide detailed information on research progress and are regularly updated by the responsible agencies and subject matter experts.

Given the structure of implementation across federal agencies, HHS currently relies on agency-level performance and reporting processes to inform updates to the National Plan and broader coordination activities. HHS will continue to support coordination and transparency through existing reporting mechanisms and annual updates to the National Plan, consistent with ASPE's coordinating role and available resources.

Recommendation 4
The Secretary of Health and Human Services should communicate project progress to National Alzheimer's Project stakeholders in a clear, digestible format.

HHS Response
HHS recognizes the importance of effectively communicating progress to stakeholders. The National Plan includes summary information on key activities and progress through introductory sections of each annual update (e.g., the "2024 Update" subsection), which highlight major accomplishments and developments for the year. While not labeled as an executive summary, these sections are intended to provide stakeholders with a clear and consolidated overview of progress across federal efforts and are integrated within the broader narrative structure of the Plan. The 2025 National Plan update, released on April 27, 2026, reflects ongoing efforts to streamline presentation of information and improve clarity of annual reporting.

In addition, staff from HHS agencies and other Departments provide updates four times a year to the public during meetings of the Advisory Council on Alzheimer's Research, Care, and Services. Slides from each of these meetings, videos of the proceedings, and meeting summaries are available at: https://aspe.hhs.gov/collaborations-committees-advisory-groups/napa/napa-advisory-council/napa-advisory-council-meetings.

Accessible Text for Appendix II: Comments from the Department of Health and Human Services

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Endnotes

[1]The National Alzheimer's Project was established by the National Alzheimer's Project Act in 2011 and reauthorized through 2035 in 2024. Pub. L. No. 111-375, 124 Stat. 4100 (2011) (codified as amended at 42 U.S.C. § 11225); Pub. L. No. 118-92, 138 Stat. 1562 (2024).

[2]42 U.S.C. § 11225(e)(5).

[3]42 U.S.C. § 11225(d)(2).

[4]Fragmentation refers to circumstances in which more than one federal agency (or organization within an agency) is involved in the same broad area of national need. See GAO, *Fragmentation, Overlap, and* Duplication*: An Evaluation and Management Guide*, GAO-15-49SP (Washington, D.C.: April 14, 2015).

[5]See Justine Coppinger et al., "Independent Validation of the PrecivityAD2™ blood test to identify presence or absence of brain amyloid pathology in individuals with cognitive impairment," *npj Dementia* (2025), https://doi.org/10.1038/s44400-025-00026-y.

[6]See U.S. Department of Health and Human Services, Food and Drug Administration, FDA Approves Treatment for Adults with Alzheimer's Disease (July 2, 2024) and FDA Converts Novel Alzheimer's Disease Treatment to Traditional Approval (July 6, 2023).

[7]See Jeffrey L. Cummings et al., "Alzheimer's Disease Drug Development Pipeline: 2025," *Alzheimer's & Dementia: Translational Research and Clinical Interventions* (2025), https://doi.org/10.1002/trc2.70098.

[8]The reauthorization of the National Alzheimer's Project Act in 2024 expanded the Advisory Council to include three additional non-federal members: an additional researcher (with demonstrated experience in recruitment and retention of underrepresented groups into research or clinical trials related to dementia), one representative from a historically underserved population with a greater risk for developing Alzheimer's, and one dedicated spot for an individual living with Alzheimer's. It also expanded the count of federal members on the council from 10 to 15. Pub. L. No. 118-92, 138 Stat. 1562 (2024).

[9]For the purposes of this report, we interviewed selected Advisory Council members who served at any point between 2021 and 2025.

[10]See *Advisory Council on Alzheimer's Research, Care, and Services*, in the Federal Advisory Committee Act database, accessed January 30, 2026. https://www.facadatabase.gov/FACA/s/FACACommittee/a10t0000001gzvuAAA/com000777.

[11]See GAO, *Evidence-Based Policymaking: Practices to Help Manage and Assess the Results of Federal Efforts*, GAO-23-105460 (Washington, D.C.: July 12, 2023).

[12]42 U.S.C. § 11225(g)(1).

[13]See GAO-23-105460.

[14]Our leading practices for interagency collaboration reinforce the importance of this approach for cross-agency efforts. See, in particular, the practices to "define common outcomes" and "ensure accountability." GAO, *Government Performance Management: Leading Practices to Enhance Interagency Collaboration and Address Crosscutting Challenges*, GAO-23-105520 (Washington, D.C.: May 24, 2023).

[15]See GAO-23-105460.