PROJECTS – Policy & Advocacy
Time spent so far: 6 hours 38 min

The first summary will be on the National Plan to Address Alzheimer's Disease: 2020 Update. This was a very lengthy read, however very informing, it certainly added much more to my knowledge about the intervention process. I was both shocked and not so shocked reading this because of how extensive it is, yet for there to be change for something that is so important as Alzheimer's then of course there needs to be a very detailed set of steps to make change. Within this National Plan there was a set of 5 goals and each goal had many strategies listed. The goals listed were Prevent and Effectively Treat Alzheimer's Disease and Related Dementias by 2025, Enhance Care Quality and Efficiency, Expand Supports for People with Alzheimer's Disease and Related Dementia and Their Families, and Enhance Public Awareness and Engagement, Improve Data to Track Progress. Below I will begin to summarize the National Plan including the 5 goals listed.

Within the National Plan it stated that In 2011 the National Alzheimer's Project Act was created, this act defined "Alzheimer's" as Alzheimer's disease and related dementias. The Secretary of the U.S. Department of Health and Human services was then in charge of creating the National Alzheimer's Project. This includes creating a plan to address Alzheimer's disease (AD), coordinate research and services across federal agencies, prioritizing the development of treatments for Alzheimer's, improving the rate of early diagnosis, decreasing inequalities for AD within racial and ethnic minority populations, and working with international bodies to fight AD. Following this section the National Plan described what AD is including how many people are affected by this disease and how it affects someone. It continued with information on how families are affected by Alzheimer's and mentions the unfortunate reality of the costs for treating the affected person. When creating a plan as big as this one there is no doubt that there will be some challenges to face. The challenges that were presented were the following, there are no existing pharmacological or other interventions known to this day that can prevent/treat/cure Alzheimer's disease, while steps have been taken to develop the quality of measures or to assess dementia care there is still room for improvement, those who take responsibility of caring for a loved living with AD still need services and support, many stigmas and misconceptions still exist for AD, the data for the public and private sector should be coordinated and tracked. The plan also included a section on COVID-19 and its impacts on the healthcare system, highlighting the activities that have been undertaken to address the pandemics impact on those living with dementia and their caregivers.

Goal One: Prevent and Effectively Treat Alzheimer's Disease and Related Dementias by 2025

Strategy 1.A, was to identify research priorities and milestones. One of the ways to identify research priorities was to regularly bring together a meeting about Alzheimer's disease. This would include gathering experts on Alzheimer's disease to identify gaps in knowledge and to set priorities among the research community to find the correct resources, infrastructure and partnerships needed to continue important research. The next way to support this goal was to ask for the input of diverse communities on AD. To achieve this goal it would include asking for this information within the same meetings/summits mentioned previously. Data that has been collected in the past would need to be updated regularly to continue the improvement of the National Plan, and the strategies within this first goal would need to be refined. Another meeting/summit would be held specifically for discussing the care, services, and support for the people living with dementia and for their caregivers/partners. A plan should also be created and implemented for the Congressionally Directed Medical Research Program Peer Reviewed Alzheimer’s Research Program. The CDMRP is a partnership held between the U.S. Congress, the military, and the public. They fund innovative and research in target program areas, in this case it would be for Alzheimer’s disease. Lastly, the final strategy to achieve this goal was to create a survey for the general public concerning future research on dementia and where it should be headed.

Strategy 1.B, was to expand the research that is directed towards preventing and treating Alzheimer’s and related dementias. This list included identifying the molecular and cellular mechanisms related to Alzheimer’s and related dementias. After identifying that information it would need to be translated for the use of potential targets and interventions. The research on genetic epidemiology would need to be expanded to recognize the risk and protective factors for AD and related dementias. To further research on AD and related dementias the enrollment for clinical trials would need to be increased on the community, national, and international level. This would also involve racial and ethnic minorities within these clinical trials. Prioritizing the pharmacological interventions that appear to be the most promising would further expand the research of prevention and treatment. Research on those living with Down syndrome and how it intersects with Alzheimer's disease should have a focus as well. The last section for this strategy included the expansion of research for the caring and support of people who live with cognitive and behavioral symptoms that relate to brain injuries and dementia.

Strategy 1.C, was to accelerate efforts to identify early and presymptomatic stages of Alzheimer's disease and related dementias. The list for this section was shorter than the other ones containing two primary sections which were to recognize imaging and biomarkers to monitor the progression of Alzheimer’s disease and other related dementias. The other one was to increase the collaboration with federal agencies along with the private sector. Imaging and biomarkers are used for the brain, blood, and spinal fluid, there have been significant advances and those advances will hopefully make it possible to monitor how the treatments affect those living with Alzheimer’s disease. Before those advances were made the neurodegenerative processes were only evaluated in non-living tissues. Through accelerating the efforts of identification this will help in improving and the expansion of applying biomarkers in research/practice. This will also help in being able to conduct early diagnoses within a clinical setting and help in the development of interventions for Alzheimer’s disease to either slow down or delay the progression of it.

Strategy 1.D, was to coordinate research with international public and private entities. This list included an inventory about the investments of AD and related dementias. IADRP is a free database that contains an overview of Alzheimer's disease and related diseases, it contains research and funding. Advocates, researchers and funding organizations who have an interest in AD and related diseases have used IADRP to coordinate strategies, avoid duplication, identify promising areas of growth, and have leveraged resources. Expanding the outreach on an international level and to enhance collaboration was also mentioned within this strategy. Along with other methods of identifying research priorities through the use of surveys tracking the health conditions and risk factors of AD and related dementias.

Strategy 1.E, was to leverage public and private collaborations to facilitate dissemination, translation and implementation of research findings. This list contained strategies to leverage both public and private collaborations in order to ease the dissemination, implementation, and translation of research findings. The NIA has expanded and continues to expand its efforts in order to educate clinicians about current research findings. This also includes practice tools for assessment, training materials, diagnosis/management of cognitive impairment, even checklists for patients in both English and Spanish, and other resources that may be useful for clinicians. The strategies continued by stating that promoting the education about Alzheimer's disease should continue in order to improve the knowledge to the public. Offering guidance to those who take drugs for early stage AD was also of importance. While AD is at the top of the list it would also be crucial to expand the research concerning co-occurring conditions and dementias. The last strategies mentioned had to do with advocacy on AD through providing more information to the public about brain health and general health practice

Goal 2: Enhance Care Quality and Efficiency

Strategy 2.A was to build a workforce with the skills to provide high-quality care. The beginning of the main strategy started off with a list of providers that work with people living with AD and related dementias. Providers such as primary care physicians, psychiatrists, registered nurses, community health workers, etc. The goal here is for these providers to have accurate information about building the right care for those living with AD and related dementias. This includes things such as benefits of early diagnosis and how to address the physical, cognitive, emotional, and behavioral symptoms of the disease. Providing enhanced specialist training would also be useful to prepare providers with the special challenges faced with those living with AD and related dementias. Following the start of this second goal are the steps being taken to facilitate the specific type of training that they are looking for within care professionals to strengthen the workforce of these providers. With such an emphasis on providing high quality care the education of healthcare providers is also important. Reinforcing state aging, public health, along with intellectual/developmental disability workforces also falls under this goal. Creating a curriculum is sought after about AD and related dementias for care professionals and caregivers. In order to have quality education available this goal seeks to provide that information to aging and public health providers which includes research based and up to date information. Strengthening primary care teams in Indian Health Services/Tribal/Urban Indian health staff and their knowledge and understanding of caring for individuals with AD and related dementias to help them and the families they help. This strategy strives to improve support for clinicians in Tribal communities also through interdisciplinary team training that involves assessment, recognition, and the management of AD and related dementias. To keep up with the idea of quality care this would also mean to expand the specialized services and support to under-served populations. Lastly, knowing the impacts of minimum wage increases on nursing homes.

Strategy 2.B, was to ensure timely and accurate diagnosis. This is due to a large number of people not being diagnosed until their symptoms are too severe. Being diagnosed at an early stage will give the person with the condition along with their families to have time to prepare for the future which in turn will lead to a more positive outcome for both the person living with AD and their families. Even if individuals may have access to healthcare, providers also require the right tools to provide the person with an accurate and timely diagnosis. In order to complete this goal it requires identifying and disseminating the appropriate tools for assessment. A way of identifying AD and related diseases can also involve educating families on changes that could indicate the onset of dementia. This would increase the awareness of AD and related dementias, the plan would also like to provide this for Tribal and Urban Indian communities along with providing more available resources. Insurance providers would also need to be more aware that the need for early diagnosis is very important and having the right tools and resources to enable diagnosis and referral. Lastly this strategy aims to understand the discordance between reported diagnosis, claims, and functional assessment for people living with AD and related dementias

Strategy 2.C, was to educate and support people with Alzheimer's disease and related dementias and their families upon diagnosis. This short strategy involved the education of physicians and healthcare providers about how to access services and supports for the long-term. This is due to the fact that there are barriers in education sometimes, this then leads to providers not being as helpful as they could be to the families they are attending to. By doing so the plan states that it would be working with federal partners, the healthcare provider community, community organizations, and public and private entities. This strategy also aims to connect with American Indian and Alaska Natives to resources for Alzheimer's disease and related dementias.

Strategy 2.D, was to identify high-quality dementia care guidelines and measures across care settings. The reason for having quality guidelines is to deliver quality care and measures in order to ensure that people with Alzheimer's disease and related dementias receive the care they need that is culturally competent in the various settings where they receive services. They also need to be tailored to each stage of Alzheimer's in order to properly address the cognitive, physical, behavioral, and emotional symptoms that a person goes through. To ensure this, the strategy for this section will continue to explore dementia care guidelines and measures. It will also solicit stakeholder input on how to reach meaningful outcomes to drive quality measurement. The plan also aims to help Indian Health Service staff by improving training resources through person centered goals/strategies for improving care.

Strategy 2.E, was to explore the effectiveness of new models of care for people with Alzheimer's disease and related dementias. The actions this strategy would take is to assess how effective the relevant innovation center models are for those living with Alzheimer's disease and related dementias. Continuing that would be to assess how effective the independence at home demonstration is, this is a testing payment incentive/service delivery model that physicians and nurses use to coordinate home based primary care and home and based community services. This strategy aims to create a supported decision making model to use rather than guardianship. Understanding how certified community behavioral health clinics serve their role in providing access to care was also discussed in this strategy. Lastly in effort to explore the effectiveness of new models was to expand resources in order to assist person centered care.

Strategy 2.F, was to ensure that people with Alzheimer's disease and related dementias experience safe and effective transitions between care settings and systems. This is important because those living with AD and related dementias tend to have a higher rate of emergency room visits/hospitalizations. Within these types of settings they can be very stressful and they can subject the person into delirium and unnecessary complications. To combat this the strategy proposes to implement and assess new care models in order to provide care transitions with people living with AD and related dementias. It would also like to understand the action of facility-initiated involuntary discharges from nursing homes and advancing person-centered practices/systems. Lastly, focusing on a release of a guide to billing codes for dementia services, the guide would be for organizations that want to understand how to bill for their dementia services.

Strategy 2.G, was to advance coordinated and integrated health and long-term services and support for people living with Alzheimer's disease and related dementias. To begin this strategy the first action stated was to implement/evaluate care coordination styles. This was of importance because of the belief that the right coordination model can be a crucial component of caring for those in need, this can then lead to a better health outcome and satisfaction. The next action was to determine the standards of health information technology in order to support the needs of those living with Alzheimer's disease and related dementias. Continuing, the last action was to research and study how managed care impacts the outcomes of health and quality

Strategy 2. H, was to improve care for populations disproportionately affected by Alzheimer's disease and related dementias, and for populations facing care challenges. This is due because of the difference in care racial and ethnic minorities receive regarding AD/ADRD. Those in this minority have a greater risk for developing Alzheimer's disease and related dementias, and also face roadblocks when trying to receive a diagnosis or services after onset. To complete this strategy the plan stated that creating opportunities for funding within organizations could improve care for the individuals that fall under this population. The second action was to direct resources and knowledge about AD/ADRD. Lastly this strategy aimed towards reviewing and reporting federal programs/initiatives that are directed towards decreasing health disparities found within Alzheimer's disease and related dementias

Goal 3: Expand Supports for People with Alzheimer's Disease and Related Dementias and Their Families

Strategy 3.A, was to ensure receipt of culturally sensitive education, training, and support materials. This strategy was to be implemented because of the reports made by caregivers on feeling unprepared for the challenges involved in caring for a person living with Alzheimer's disease and related dementias. To tackle this problem the strategy sought towards distributing educational materials that were developed on a federal scale. Following this was to make use of health information technology for caregivers and those living with AD/ADRD. This would include increasing the awareness of how important brain health is within a culturally sensitive way. As well as increasing awareness for brain health within Tribal communities through a culturally sensitive way.

Strategy 3.B, was to enable family caregivers to continue to provide care while maintaining their own health and well-being. Caring for another person is a very important job especially caring for those living with AD/ADRD, that being said one has to be healthy themselves both physically and mentally. This strategy begins with developing and analyzing evidence based interventions for caregivers and for those living with AD/ADRD. Following that action was to create effective caregiver interventions through AD/ADRD systems. This next action also includes Tribal communities through collaboration of shared information concerning long term services and supports. To reach out to families this next action plans to promote the use of the National Alzheimer's Call Center to provide information and support for those with dementia or the caregiver. In order to help the caregivers some more the next action aims towards making a behavioral symptom management class which includes education and training. To amplify the caregivers' health within Tribal communities this next action was to adapt and implement resources for that group. Developing programs for information on AD/ADRD and on financial literacy and preparedness for caregivers was the last action for this strategy.

Strategy 3.C, was to assist families in planning for future care needs. Most people do not think or plan ahead for long term services and support they need, only up until the point that they experience the effects of Alzheimer's disease and related dementias. Unfortunately many believe that medicare will cover all of the costs involved with care services for AD/ADRD. Which is why it is important to educate people so they can have an advantage at planning ahead and preparing in a timely manner. This strategy included an action to recognize the trajectories of people who live with AD/ADRD. Following that would be to also recognize the risks and costs of cognitive impairments seen in Alzheimer's disease and related dementias. The strategy also wants to understand the availability that caregivers have for individuals needing long-term services and support needs. Lastly the strategy wants to empower the affected population to better inform them on health care decisions along with expanding the availability of care planning tools for those with Alzheimer’s disease and related dementias

Strategy 3.D, was to maintain the dignity, safety and rights of people with Alzheimer’s disease and related dementias. This is due to the fact that those living with AD/ADRD are a vulnerable population towards financial exploitation, physical or emotional abuse, or neglect from their families or caregivers. This strategy aims to monitor and report to reduce the inappropriate use of antipsychotics in nursing homes. Within Aging Network Activities the strategy wants to implement elder abuse awareness. Translating and disseminating information on abuse towards those living with Alzheimer’s disease and related dementias is of importance as well. One of the actions mentioned in this strategy sought towards improving the ability of legal services available to those living with AD/ADRD to address their needs. To reduce emotional or physical abuse the strategy is also concerned with educating law enforcement and other first responders on how to interact and treat those living with AD/ADRD. Lastly would be to work with the community to create the finest practices to protect people with AD/ADRD.

Strategy 3.E, was to assess and address the housing needs of people with Alzheimer’s disease and related dementias. This is because having stable housing is essential towards helping those living with AD/ADRD. Having stable housing is important towards the delivery of necessary health and supportive services. This begins with evaluating Support and Services at Home Program, this is an approach towards providing support services to older adults that have disabilities in order to provide affordable housing properties as a platform for service delivery. Following this would be to assess the application of home health benefits and to recognize the factors that contribute to policy implications of the closings of nursing facilities.

Goal 4: Enhance Public Awareness and Engagement

Strategy 4.A, was to educate the public about Alzheimer’s disease and related dementias. Generating public awareness and engagement is important because it can encourage families to seek more information, reduce isolation and misunderstandings that caregivers have. Public awareness will point people to the right information along with the resources and services that they need. This strategy wants to do so by enhancing the outreach they have towards the public concerning Alzheimer’s disease and related dementias. Following this would be to be on top of translating the data and surveillance to inform those who speak different languages.

Strategy 4.B, work with state, tribal, and local governments to improve coordination and identify model initiatives to advance Alzheimer’s disease and related dementia awareness and readiness across the government. The first action for this strategy would be the continuation of bringing together federal partners. Following this would be to learn from previous lessons to improve the capacity there is on a state and local level for dementia. In order to improve support for Tribal/Indian Health Service/Urban Indian Health programs this strategy aims towards gaining input from those groups about Alzheimer’s disease and related dementias. Developing a public health road map would be beneficial for the assistance of state, Tribal, and local health departments in order to prioritize their actions. Lastly would be the facilitation of translating the findings into the practice of public health within Tribal communities.

Strategy 4.C, was to coordinate United States efforts with those of the global community. This last strategy ends off with one action which is to collaborate with global partners in order to gather information from countries on dementia.

Goal 5: Improve Data to Track Progress

Strategy 5.A, was to enhance the federal government's ability to track progress. In order to accomplish this strategy the plan aims towards identifying the actions needed to be taken in order to improve the forms of tracking progress or making new additions to data. Following this would also be to make improvements to present data. Summarizing data on cognitive impairments across the U.S is also involved in this strategy. This strategy would also like to develop/disseminate the measures of awareness concerning Alzheimer's disease and related dementias along with summarizing existing data. Lastly would be to supply an analysis of BRFSS (Behavioral Risk Factor Surveillance System) data on those living with AD/ADRD along with their caregivers to provide a user-friendly format.

Strategy 5.B, was to monitor progress on the National Plan. This includes tracking its progress, updating it annually, and pointing out the key indicators of progress.

The plan ends with an appendix of participating departments/agencies and an appendix of implementation milestones.