



MISSOURI HOUSE OF REPRESENTATIVES
WITNESS APPEARANCE FORM

BILL NUMBER: HB 2071		DATE: 4/22/2024
COMMITTEE: Health and Mental Health Policy		
TESTIFYING: <input checked="" type="checkbox"/> IN SUPPORT OF <input type="checkbox"/> IN OPPOSITION TO <input type="checkbox"/> FOR INFORMATIONAL PURPOSES		
WITNESS NAME		
INDIVIDUAL:		
WITNESS NAME: ARNIE C.HONEST-ABE" DIENOFF-STATE PUBLIC ADVOCATE		PHONE NUMBER: 314-440-9000
BUSINESS/ORGANIZATION NAME:		TITLE:
ADDRESS: P.O. BOX #1535		
CITY: O' FALLON		STATE: MO
		ZIP: 63366
EMAIL: arniedienoff@mail.com	ATTENDANCE: submissionOnly	SUBMIT DATE: 4/15/2024 11:28 PM
THE INFORMATION ON THIS FORM IS PUBLIC RECORD UNDER CHAPTER 610, RSMo.		

I am in Support of this Bill and intension. But let's make ground and get Programs and Services to serve Missourians with "Alzheimer's" as soon as possible, when diagnosed. Let's make some great In-Roads with Research and joining efforts with State Universities with studies on this subject to find remedies.



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WITNESS NAME			
REGISTERED LOBBYIST:			
WITNESS NAME: CATHERINE ROEHL		PHONE NUMBER: 573-443-6922	
REPRESENTING: ALZHEIMER'S ASSOCIATION		TITLE: DIRECTOR OF STATE AFFAIRS	
ADDRESS: 1601 E BROADWAY, #245			
CITY: COLUMBIA		STATE: MO	ZIP: 65201
EMAIL: cjroehl@alz.org	ATTENDANCE: physical	SUBMIT DATE: 4/15/2024 2:03 AM	
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Good afternoon, Chairman Stephens and members of the Health and Mental Health Policy committee. Thank you for the opportunity to offer comments for a second time today. I would also like to thank Representative Mayhew for sponsoring this legislation. I'm Catherine Roehl and I am representing the Alzheimer's Association as the Director of State Affairs in support of HB 2837, to modify the establishing language of the Alzheimer's State Plan Task Force, with the amendment that the phrase "advice and consent of the senate" is removed from line 33 on page 2. As I mentioned a couple of minutes ago, the Alzheimer's Association is the leading voluntary health organization in Alzheimer's care, support, and research. We currently serve 115 counties in Missouri, and one of our goals is to ensure the state is equipped to handle the increasing number of individuals diagnosed with Alzheimer's and other dementias. One such initiative to do this, was the establishment of an Alzheimer's State Plan Task Force. It was originally passed in 2021, however, it was not appointed and needed to be reestablished with a new timeline in 2022. This was largely due to the lengthy appointment process each of the 21 members was required to go through, being a Senate confirmation hearing for members that are not part of the general assembly or department and division directors. While appointments were made from, roughly, October – December 2022, they were removed in the new year, after the State Plan was published on January 1, 2023. This has prohibited the Task Force from meeting in an official capacity and providing the annual update to the State Plan, as dictated in statute. It is my understanding that Senate confirmation hearings for individuals appointed to a task force is not common, and am asking that the language creating the requirement be removed to allow the group to remain appointed and keep the current State Plan up to date. The Association is also in support of the removal of the December 2027 expiration date and the subsequent requirement that a new State Plan be published every five years, starting in 2027. As there continue to be developments in Alzheimer's and dementia research, the challenges those living with the disease are also changing, and the numbers of those being diagnosed is only increasing. The guidance outlining how Missouri should address this public health crisis and support those living with the disease needs to remain up to date to reflect those changes. We have already seen positive outcomes from the current state plan, and want to make sure those benefits can be seen into the future. Instead of seeking to reestablish the Task Force every five years, the thought was to have a standing Task Force that could continuously be addressing these issues. We ask for your support of these modifications in the existing language relating to the Alzheimer's State Plan Task Force, and appreciate your time and consideration. I am happy to answer any questions.



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WITNESS NAME: GRACE ELAINE DAVIS		PHONE NUMBER: 573-825-1281	
BUSINESS/ORGANIZATION NAME:		TITLE:	
ADDRESS: 174 BROCH TUARACH PLACE			
CITY: JACKSON		STATE: MO	ZIP: 63755
EMAIL: graced@bradshawsteele.com	ATTENDANCE: submissionOnly	SUBMIT DATE: 4/12/2024 12:48 PM	
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My name is Grace Davis. I wrote in support of HB 2071, and my story is stated therein. I'm going to focus in this testimony on what I understand the facts of HB 2837 are, and the good that RSMo 191.116 has done thus far. The Alzheimer's State Plan Task Force has already been in action, and goes hand in hand with the work the State Coordinator would implement. The Missouri Alzheimer's State Plan Taskforce is a group that was commissioned by you all, the legislature, to assess the current and future impact of Alzheimer's on Missourians and offer solutions for the future. It involves the key agencies on the state / public side of Dementia care, including the Department of Health and Human Services, Social Services, Department of Mental Health, and the Veterans Commission. Members of your assembly, of the House of Representatives and Senate, are on the taskforce. Professionals who advocate for and work with people with Dementia are in the group. Caregivers are in the group. And at least one person with Alzheimer's or Dementia is there to bring an inside perspective on this horrible disease. The purpose of the Task force is to gather information, from a wide range of backgrounds and perspectives on the board, and from the public, and to assess the impact of Alzheimer's and Dementia on the people of our great state. The hope is that the Task Force can offer multifaceted and practical solutions. They put together the state plan, which is essential to allow each of you on this committee to address the policy side of the equation; to allow someone like the (hopeful) state coordinator to address the coordination of care, services, respite, and resources; to allow agencies to work in harmony and with a unified goal; to create accountability for all stakeholders; to allow a conversation about the suggestions put forth; and to provide transparency and a place for input for Missourians. The Task Force has hosted town halls, community forums, and heard directly from Missourians on the issues they are facing when confronted with Dementia. The Task Force identified concrete steps (that are more than attainable) which would directly impact these citizens, including education on early diagnosis, increasing respite grants for care providers who constantly put their health at risk to care for their loved ones, improving quality of care through continuing education of professionals and promoting workforce development, and coordinating care through a state coordinator. Re-establishing our task force is essential to continue such transparent, accountable, effective, up-to-date care to Missourians. It will ensure that we are able to put grants, like the CDC BOLD grant, to good use in our state. It will make sure that Missouri does not fall behind in its efforts to address Alzheimer's and all other dementia. Missourian's fight against the public health crisis that is Alzheimer's and Dementia is not set to expire anytime soon. Don't let one of the best tools to fight this crisis, the Task Force, expire as well. Please approve the Alzheimer's State Plan Task Force, and pass HB 2837.



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WITNESS NAME: MICHAEL DONNELLY		PHONE NUMBER: 314-363-0261	
BUSINESS/ORGANIZATION NAME:		TITLE:	
ADDRESS: 1437 REAUVILLE DR			
CITY: WARSON WOODS		STATE: MO	ZIP: 63122
EMAIL: michaelseandonnely@gmail.com	ATTENDANCE: submissionOnly	SUBMIT DATE: 4/12/2024 11:40 AM	
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I'm writing in support of this HB to further support those who care for those with dementia. Please consider this as a benefit to our state and it's citizens.



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I am in Support of this Bill and Legislation to create a New Office of "Dementia Services Coordinator" to assist Missouri Citizens through the maze of Red-Tape to get required and needed services as soon as possible to help deal with the awful disease of "Dementia."



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Good afternoon Chair Stephens and members of the Health and Mental Health Policy Committee. Thank you for the opportunity to offer comments today. And thank you to Representative Mayhew for sponsoring and supporting this legislation. I'm Catherine Roehl and I am representing the Alzheimer's Association, as the Director of State Affairs, in support of HB 2071, that would establish a state Dementia Service Coordinator position in the Department of Health & Senior Services. Alzheimer's is a public health crisis in Missouri that is devastating over 120,000 individuals aged 65 and older, and even more families, and these numbers are only expected to continue increasing. The Alzheimer's Association is the leading voluntary health organization in Alzheimer's care, support, and research. In Missouri, we have two chapters that, together, serve all 115 counties. I am also here as someone whose family has been impacted by this terrible disease seven times, on both my mom's and dad's side. I have seen firsthand the challenges faced by every member of the family when a loved one is diagnosed with dementia, and have witnessed many of our constituents go through similar, and worse, situations. In the last 12-18 months, many advancements have been made related to diagnosis and treatments for Alzheimer's. But we cannot stop there. We need to ensure Missouri is preparing to be dementia-capable as the number of those affected continues to grow. The creation of a Dementia Service Coordinator position would be the first full time state employee focused on dementia care and policy. This position would aim to create a coordinated, statewide response to Alzheimer's and other dementias in Missouri. Some of the ways the position would accomplish this is by:

- Providing support in the drafting, implementation, and evaluation of future Alzheimer's State Plans as well as for other annual reports
- Organizing community stakeholders and resources to identify proactive and effective solutions
- This is especially important in rural communities, where there is a significant lack of resources within a manageable distance
- Establishing and maintaining relationships with other agencies and organizations in the community in order to meet community needs and prevent duplication of services
- Evaluating existing Alzheimer's and dementia programs and services
- Programs exist across multiple state agencies and divisions, which makes it difficult to coordinate
- Ensuring that the existing state programs are being utilized to their full potential and are effective
- Identify gaps in services
- Increase awareness of and facilitate access to quality, coordinated care for people with dementia
- This includes many of the recommendation areas in the state plan, including, but not limited to, dementia specific training, aiming to keep people at home longer, which would limit future Medicaid spending, workforce development, etc.

We ask for your support of this legislation that would help address this growing public health crisis at the state level and thank you for your consideration of this initiative to create a Dementia Service Coordinator position. I am happy to answer any questions.



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My name is Grace Davis, and I am an attorney in Cape Girardeau, Missouri. I am a third generation Mizzou Tiger. The first one to go to Mizzou, in my family, was my Grandpa, my "Papa," the Rev. James Martin Shemwell. He died of Alzheimer's Dementia during my last year in law school. He was a giant to me. He served in the Army, preached all over Missouri, was a volunteer firefighter in his rural communities, and was a ride-along Chaplain for the Highway Patrol. He was smart, funny, and kind. He loved his dog, bike rides, and peanut butter sandwiches. But this all quickly faded. Alzheimer's Dementia took him from us, and we had a horrible experience with his dementia. We did not know where to turn, what resources were available, what care was needed, or how to handle the quick deterioration that this brilliant man was going through. He was scared, we were clueless. My grandmother, his main caretaker, missed her own cancer diagnosis because she was so busy caring for him. My parents would travel hours to go assist in caring for him. I took time in law school to visit and care for him. In the end, he lay there in the fetal position, unable to even open his eyes or talk. In the end, our family was exhausted, fractured, and my grandmother's health was ruined. All because we had no idea there were services, and no professionals in the field or in the rural doctors' offices told us. I threw myself into working with Alzheimer's and Dementia groups, hoping to learn more and make a difference. But when my Husband's grandfather fell victim to the same disease, I found that even with all my new knowledge, I was still clueless as to aspects of his care. This time, I could point my in-laws towards some resources, but the coordination of them was difficult. My mother in law wore out her tires running back and forth between Cape Girardeau and St. Charles. Her siblings were all juggling care, full time jobs, and families. Even getting a proper diagnosis was incredibly difficult. My family and my husband's family needed a central resource that was able to coordinate both private and public services, and refer us to the right ones. But not central resource exists yet in this state. We needed education, and many of the individual service providers needed education, on all aspects of dementia for the person living with it, their caregivers, and the other services available. This did not yet exist in this state. Coordination of care, coordination of services, coordination of benefits, education for the public and professionals, awareness for the public and professionals, and a central point of contact is crucial for ensuring that most Missourians facing this disease can get the help they need. Further, it is essential for state agencies, private organizations, and state programs to work together, instead of disjointedly with no communication. A team of horses is useless in pulling a cart without someone to hitch them together and guide them. Alzheimer's and Dementia are not going away anytime soon, and even if we get a cure in the future, people will still need a first step in accessing that care. A permanent state coordinator is necessary, and their services to vulnerable Missourians with memory loss needs to be protected from the budgetary whims of an agency. Please, don't let what happened to my family, happen to any more families. Don't let the advances in public and private care stay inaccessible and

unused. Appoint a Missouri Dementia Services Coordinator. Please, pass HB 2071.



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