

Before the
District of Columbia Council
Committee on Health

Testimony of
Dean R. Brenner
5044 Macomb Street, NW
Washington DC 20016

Performance Oversight Hearing
District of Columbia Department of Health

February 20, 2020

Chairman Gray and Committee Members, my name is Dean Brenner, and I live in Ward 3. Chairman Gray, thank you again for your tremendous leadership in the Council's last session in enacting the Dementia Services Coordinator Act of 2019.

Today, I'm focusing on two duties of the coordinator (the DSC) established in the law: that the DSC "shall be responsible for. . . implementing and updating the District of Columbia State Plan on Alzheimer's Disease;" and for "evaluating the District's dementia services." The purpose of creating and funding the DSC at over \$109,000 annually was for the Health Department to employ a coordinator who would have the authority, expertise, and autonomy to fulfill the law's duties to address DC's public health crisis caused by Alzheimer's. I look forward to meeting and working with DC's new DSC to help launch the person in this innovative position.

The law also requires the DSC to evaluate the District's dementia services. The current budget includes a one-time appropriation of \$245,000 for this evaluation. But, eight months after the budget was signed into law, the details of this well-funded evaluation are unclear.

In addition, the law requires the DSC to update DC's State Alzheimer's plan—something all 50 states have—which was one of the law's major purposes. DC's plan was prepared in 2013 and expired last year. Now, we don't have a plan. The 2013 plan listed many goals to address DC's Alzheimer's public health crisis, but seven years later, the results of the 2013 plan are unclear. This is precisely why the Council passed the law requiring an update of the 2013 plan and implementation of the new plan. The DSC is required to lead these initiatives. But, eight months after the budget became law, the details of the District's path to update the 2013 plan and implement a new plan are unclear.

While we don't have those details yet, we know that Alzheimer's continues to have a devastating impact on thousands of DC residents and their families, with a disproportionate impact on women, African Americans, and Hispanics. At least 8,900 DC residents are living with Alzheimer's and at least 29,000 family members are caring for them without pay. The cost of Alzheimer's in DC is skyrocketing. The annual cost in Medicaid alone is over \$122 million, and the cost in unpaid care is over \$415 million.

My mom Marilyn Brenner was a long-time, dedicated public official who died from Alzheimer's. My mom had no interest in anything that was symbolic or meaningless. I believe that your law establishing the DSC is not symbolic or meaningless. I hope the Administration will step up as required by law and will ensure that the DSC begins updating the DC Alzheimer's Plan. But if not, in the coming months, I urge the Council to work with the Alzheimer's Association and other stakeholders to draft legislation establishing a vision and a specific timeline for an updated Alzheimer's Plan, which will reduce costs and, even more importantly, improve so many lives.

Thank you.

Council of the District of Columbia
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Thursday, February 20, 2020

FY 2020 Performance Oversight Hearing for the Department of Health

Chairman Gray and Members of the Committee on Health, my name is Grace Williams, and I am a Ward 1 resident. As a molecular scientist, I would like to thank the Committee for focusing on Alzheimer's disease (AD), a chronic disease and escalating national epidemic that affects so many people in the District.

According to the National Institutes of Health, Alzheimer's disease is the sixth leading cause of death in the United States. AD is the only one of the top ten without a means to prevent, cure or slow its progression. Research has shown diabetes, high blood pressure, obesity and nutrition contributes to Alzheimer's disease risk. Just this week, American Heart Association News reported a clinical study linking diabetes and Alzheimer's disease to increased risk and severity of stroke. This risk is exacerbated for African American and Latino communities, who have the highest prevalence of diabetes and lack healthcare access and resources to prevent and manage the factors that contribute to Alzheimer's disease. Proper nutrition and healthy lifestyle choices are essential to managing and reducing Alzheimer's risk.

Alzheimer's Disease has been a part of my life for twenty years, when my father was diagnosed with early-onset Alzheimer's at the age of 56. Struggling to find an accurate definition, available providers, effective treatment, and care that ensured quality of life, my family faced what millions of Americans face daily when caring for a loved one with Alzheimer's and dementia.

For too many patients with Alzheimer's and their families, we are unnecessarily losing the battle against this devastating disease. As we discuss the Health Department's budget today, and how they have and should utilize the funds allotted by the Council, I urge the Department to consistently provide more information and support just like they do for anti-smoking campaigns and obesity initiatives.

Interventions that reduce heart disease and stroke may also make the development of AD and dementia less likely. Fostering healthy lifestyle choices such as exercise, healthy eating, weight loss, and decreasing smoking could reduce one's Alzheimer's risk. Unless we create an effective, dementia-capable system to: find new solutions to providing high quality care, provide community support services and programs, and address health disparities, Alzheimer's will overwhelm the District's healthcare system. Having a dedicated Dementia Services Coordinator allows for an interagency approach to addressing the needs of Alzheimer's and dementia patients, their families and caregivers, and develop the District's strategy—and indeed our next State Plan—to help individuals better manage this cruel disease.

We need to make sure that DC is doing all it can to best support those at-risk or living with the disease today. I would like to thank the Committee again for the opportunity to share my support for the work being done to address Alzheimer's disease. I strongly believe in the Dementia Services Coordinator position within the Department of Health and updating the DC state Alzheimer's Plan to provide the care and quality of life for those in the District living with Alzheimer's disease and dementia.

Thank you for your time.

Before the
District of Columbia Council
Committee on Health

Testimony of
Jennifer Van Oss
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Performance Oversight Hearing
District of Columbia Department of Health

February 20, 2020

Chairman Gray and Committee Members, my name is Jennifer Van Oss and I live in Ward 1. This is my first time in front of you, and I sincerely appreciate your time and attention on these critical matters.

I want to talk about data. The Behavioral Risk Factor Surveillance System, or the BRFSS, is a monthly phone survey that “collects data on chronic diseases and related health behaviors... The results [of which] are used to monitor trends and to guide policy and funding decisions.” All 50 states and DC participate in this survey, which consists of a set of 18 “core sections” that evaluate a number of health factors such as alcohol consumption and cancer screenings. In addition to this “core,” there are optional modules that address specific topics. In the past, DC has chosen to include various optional modules, and I would argue that the prevalence of dementia and unpaid family caregiving need to be added to that list, and—with the \$180,000 appropriation included in the most recent budget for the BRFSS—should be represented each year via the inclusion of the “Cognitive Decline” and “Caregiver” modules in the survey.

Dementia doesn’t manifest physically like other major illnesses, and thus it’s not obvious who is suffering. Likewise, many family caregivers don’t advertise their role as a caregiver. In order to assess how many people fall into one of these two categories—and the extent of their burdens—we need to regularly collect reliable data. In 2017, New Jersey discovered through the “Cognitive Decline” module that 1 in 10 people over age 45 experience “Subjective Cognitive Decline,” and less than half of them have addressed their symptoms with a healthcare provider. That information is critical. In the same vein, we need to know how DC is being affected by dementia each year. And we need to know how much of our population is spending their time caregiving without compensation. These are relevant issues, that are unfortunately only increasing in relevancy..

In addition to informing important policy and budget decisions, collecting and providing this data will help raise crucial awareness to the growing problem of dementia. As the sixth-leading cause of death in the US, 1 in 3 adults over 65 will develop Alzheimer’s. There’s a disturbing lack of awareness about this, especially among my generation. It’s a personal issue to me, as my dad developed early-onset Alzheimer’s in his forties. He was at the height of his professional success with two kids in grade school when he was diagnosed. He died at 55 when I was 17.

The devastating effects of dementia and the burdens of unexpectedly becoming a caregiver were impressed on me at a young age; but as I watch my mom, my husband’s parents, and my friends’ parents reach that 65 year milestone, I recognize the urgency of spreading accurate information about this problem, so we can band together and enact change before it cripples the next generation.

And change, in this case, begins with data.