



Barbara Riley, chair
ohagingadvocacy@gmail.com
facebook.com/ohioagingadvocacycoalition
@ohagingadvocacy

Ohio Aging Advocacy Coalition

Jane L. Taylor
Volunteer Advocate

Semanthie Brooks
Volunteer Advocate

TESTIMONY on HB 49
House Finance Health and Human Services Subcommittee
March 23, 2017

Chairman Romanchuk, Ranking Member Sykes, and members of the Subcommittee, thank you for the opportunity to speak to you today about HB 49. My name is Jane Taylor. Although now retired, my career was spent in the development of community-based programs designed to provide basic assistance so that older individuals could remain independent at home or in the community. I was involved in the meal program when it began in Franklin County and also served as the Director of the Ohio Association of Area Agencies on Aging. I retired two years ago after serving eight years as the State Director of AARP Ohio. Along with Ohio's 1.5 million AARP members and hundreds of advocates, we worked on long term care and many other consumer and caregiver issues facing our aging population.

It is the passion I continue to have about these issues that brings me here today – as a volunteer advocate representing the Ohio Aging Advocacy Coalition, headed by former Ohio Department of Aging Director Barbara Riley. The Ohio Aging Advocacy Coalition was formed by the major aging-related organizations so that the advocate voice could be heard and I commend them for that.

Our mission is “to advocate and share the voices of older Ohioans and our needs so we can age in a place we can call home.” We have heard from many consumers and caregivers who want to be involved – especially through our story collection and many Facebook followers. We continue to build our coalition of over 300 individuals, families and caregivers so that our mission is fulfilled.

You will hear from several consumers next week and today Semanthie Brooks and I are here to outline the concerns expressed by our Consumer Advisory Council regarding the state budget. I will begin with our deep concern about the dismantling of the PASSPORT system, and likely, the entire aging network. I know the budget does not say that, but the



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reality is that moving all of PASSPORT into managed care would impact those on Medicaid who depend on their current case managers and local providers. But it also impacts consumer and families not eligible for Medicaid who now have access to in-home assessments, information, education and coordination of care. We question that enough information and evaluation is available to know that consumers and caregivers will be well served by such a change. And, it is our understanding from the Governor's Office of Health Transformation policy papers, that no cost savings would even be realized from such a risky change.

As you have heard from other speakers, PASSPORT is an effective and efficient program that is critical to those who are low income and frail. They have a keen desire to stay in the community at a much lower cost than institutional settings. Operated through Ohio's Area Agencies on Aging (AAAs), communities depend on this program which has a strong network of providers giving basic care regardless of where you live in Ohio. Rural areas are served very well and case managers make certain services are delivered – be it from network providers, family, friends, businesses, local groups, etc. AAAs are experts in long-term care services. Managed care companies are in the health care business. They are very different. This budget proposal moves all PASSPORT consumers to managed care under yet a new program called Medicaid Managed Long-term Services and Supports. This change does not even attempt to coordinate care with Medicare – such has been the case in MyCare.

And, we are concerned that MyCare Ohio (the managed care demonstration) has not yet been evaluated. It is only the third year of a five year demonstration. It has caused some problems for consumers and providers of care. Managed care companies have relied heavily on the AAAs to straighten out issues. You will hear more specifics from consumers next week. You will also hear from providers where there are major concerns about rates and payments. To recruit, train, and retain quality staff, rates must be competitive and payments, timely. We support a fair evaluation that identifies issues and determines a path forward that actually works for your constituents and their families.

Our coalition stands ready to work with you on this issue and others to be discussed by Semanthie Brooks to be certain the strong aging network is there to respond to individuals as their long term care situations arise.

I am eager for you to hear from Semanthie who, along with her husband, are extraordinary caregivers. In my case I serve as a long distance support to my caregiver sister. Her husband has Parkinson's and requires 24 hour supervision. We are both pleased to be part of the Ohio Aging Advocacy Coalition so the consumer voice can be heard. Thank you very much.



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Chairman Mark J. Romanchuk and members of the House and Human Services Sub-Committee, thank you very much for the opportunity to testify as you consider the State Operating Budget for FY 2018-2019. My name is Semanthie Brooks. I am a community volunteer, testifying today as a member of the Ohio Aging Advocacy Coalition.

In addition to this coalition, I sit on our State's AARP Executive Council; I am a member the Senior Voice Coalition in Cleveland, the Western Reserve Area Agency on Aging Public Policy committee, a board member with the Consortium Against Adult Abuse, and a member of the Alzheimer's Association Government Affairs committee. I sit on the Council on Older Persons (COOP) in Cuyahoga County and I am a member of the Cuyahoga County Conference on Social Welfare Annual Conference committee. However, the most important role that I currently have is that of a caregiver.

Until recently, my husband and I provided a home and care for three older adults: my father, mother, and mother-in-law. Today, there are two. My father died last December just shy of his 95th birthday. My mother, who is 95 and my mother-in-law age 90, continue to live with us. Unlike my father who was a double amputee and suffered from multiple chronic diseases, my mother and mother-in-law are relatively healthy; however, both have been diagnosed with dementia: my mother with advanced stage probable Alzheimer's and my mother-in-law with moderate confusion, memory loss, and agitation most likely Alzheimer's with an overlay of depression and failure to thrive. Getting her to eat is a daily challenge.

My husband is an only child and because of his commitment to his mother, he stopped working at the age of 60. He is an attorney and was the Assistant National Director for the UAW Legal Services Plan. Along with a paid caregiver, my husband was home to care for our parents while I continued to work as the Director of Community Advocacy for the Benjamin Rose Institute on Aging. I retired in December as the care for our parents now requires 24 hour supervision, and all of you probably are aware that caring for someone diagnosed with dementia requires a 36 hour day.

In Ohio, 210,000 individuals are living with Alzheimer's. By 2025, this number is expected to increase by 19%. Alzheimer's is the 6th leading cause of death in our state. The National Alzheimer's Association estimates that in 2017 Ohio will spend over 2 billion Medicaid dollars in care for people with Alzheimer's, and this cost is expected to increase 27.2% by 2025.



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In 2016, 597,000 Ohioans provided care to someone diagnosed with Alzheimer's disease, providing a total of 680,000,000 hours of care, with a total value of unpaid care of \$8,598,000,000.

We are not alone. In the United States over 5 million Americans are living with Alzheimer's, and as many as 16 million will have the disease in 2050. Every 66 seconds someone in the US develops the disease. The cost of caring for those with Alzheimer's and other dementias is estimated to total \$236 billion in 2016, increasing to \$1.1 trillion (in today's dollars) by mid-century. Nearly one in every three seniors who dies each year has Alzheimer's or another dementia. Since 2000 the number of people dying from heart disease has decreased by 19%; in the same period of time the number of people dying from Alzheimer's disease has increased by 89%.

Thirty-five percent of caregivers caring for someone with dementia report that their health has gotten worse compared to 19% of caregivers caring for an older adult without dementia. In 2016, the cost of healthcare for caregivers in Ohio was estimated to be \$421,000,000.

The Ohio Aging Advocacy Coalition commends the launch of the Speaker's Task Force on Alzheimer's and Dementia. Recognizing that Ohio is one of three states without an Alzheimer's state plan, our hope is that one of the outcomes of the task force will be a state plan that will help to achieve the vision of Speaker Rosenberger. The Speaker states that this task force will provide an opportunity to dive deeper into the effects of a growing population of older adults with a dementia related diseases and will work to find solutions to this pressing issue and collaborate with experts and interested parties to increase our understanding of dementias in order to forge a productive pathway forward.

At the same time, however, the Alzheimer's Respite line-item (ALI 490-414) is flat funded. This program helps to provide choice by helping older adults with dementia to remain at home in addition to supporting caregivers. In Cuyahoga County this limited funding provides much needed respite opportunities for unpaid caregivers. Failure of state community resources to keep pace with the growing numbers of older adults with dementia puts older adults at greater risk for nursing home placement. Research indicates that with in-home supports and respite for caregivers, older adults are maintained in the community for longer periods of time.

Given the current uncertainty of federal proposals to slash health and social programs, I commend Ohio for expanding Medicaid and taking advantage of federal funding to modernize our Medicaid program which addresses the healthcare needs of all adults.



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Providing insurance and pathways for care throughout the lifespan increases the probability that Ohioans will age into their 70's, 80's and 90's in better health with much improved outcomes. Opportunities exist with the 2018-2019 biennial budgets to continue Ohio's pathway to address the physical, mental, and social needs of our citizenry.

After years of decline, under the Governor's proposed budget the Senior Community Block Grant (ALI 490-411) is flat funded. This line-item supports home-delivered meals, transportation, and personal care. These services help prevent functional and financial decline that can lead to poverty and Medicaid dependence. On top of that, elimination of tax reimbursements has taken \$11 million a year out of local seniors' levies across the state. Governor Kasich's budget continues the trend of ongoing reduction in Senior Community Services (2017 Policy Matters, Cleveland, www.policymattersohio.org/budget-bite-senior-services-march17).

Finally, the Ohio Aging Advocacy Coalition believes that an explicit goal to protect vulnerable elderly must become a legislative priority that is adequately funded. As our current budget debate so painfully underscores the need of multiple populations and age groups, the fact is Ohio must believe that maintaining and improving the safety net of services to older adults cannot be overlooked.

Thank you for your time and commitment. If you have any questions, please feel free to contact Ohio Aging Advocacy Coalition Chairwoman Barbara Riley at ohagingadvocacy@gmail.com.