

Good afternoon and thank you for the opportunity to speak with you today.

My name is Christopher Callahan and my work in Indiana focuses on the care of older adults. I serve as a clinician, researcher, and educator at the Indiana University School of Medicine. I have been on the faculty at Indiana University for almost 30 years. In my clinical role, I provide care for older adults with dementia at the Healthy Aging Brain Center at Eskenazi Health. In my research role, I am an investigator at the Regenstrief Institute and the Director of the Indiana University Center for Aging Research. I also serve as the Director of the Office of Applied Research at Eskenazi Health. In my education role, I mentor young doctors interested in pursuing careers in geriatric medicine and I mentor young faculty who are seeking to build careers in aging research. I would like to frame my comments this morning first from the perspective of a clinician, then as a researcher, and finally as an educator. I would like to speak in particular about how these roles inform my perspective about home and community based services. I intend to focus on the care of older adults with dementia. In Indiana, the number of these older adults will double over the next 20 years. Many will be dual-eligible and most will require substantial assistance over a disease course that last 5-10 years.

From my perspective as a clinician, I know that providing care to older adults with dementia requires a team effort. This includes teams based in the health care setting as well as teams working in social and community services. This also includes collaboration between the teams in the health care and community services sectors. Ideally, from a patient's perspective, care across these sectors would be seamless.

I would like to provide an example of excellent team care through the story of a patient we cared for at the Healthy Aging Brain Center at Eskenazi Health. Our team there consists of a physician, a nurse, a social worker, and community health workers with special training in the care of persons with dementia. However, our team also includes a social worker from CICOA who is embedded in our team and who can help bridge the medical team with the community services team. We have also developed close relationships with the Greater Indiana Chapter of the Alzheimer's Association. Notably, our team also includes the family caregivers who provide the majority of day-to-day care of persons with dementia in the home.

Mrs. G is an 82 year old mother who was providing care in her home for an adult child who suffered from a lifelong disability. Unfortunately, Mrs. G developed Alzheimer's disease and could no longer provide care for this adult child. Care for both fell to another child who was struggling with financial stressors and conflicts with her own child, and trying to maintain her employment. This family caregiver was overwhelmed and confused about what was happening to her mother. Without intervention, both the mother with dementia and her disabled adult child would have required skilled nursing home care. They were failing at home. Following an evaluation by our team at Eskenazi Health and the provision of needed medical care and caregiver education, we collaborated with our colleagues at CICOA to provide needed services

in the home. This included further caregiver education and support, a few home modifications, and also adult daycare services and assistance with obtaining Meals on Wheels. Over the course of several months, the medical team and the community services team, working together, help stabilize this family. Through these interventions, we avoided nursing home placement for two individuals.

We see cases like this frequently at the Healthy Aging Brain Center as do other memory care clinics and primary care clinics across Indiana. Unfortunately, too many Hoosiers do not have access to such services, too many primary care providers are under-resourced to provide these services, and too many older adults and their families find such care and support too late or maybe never.

"I wish we would have found you sooner." Every person involved in the care of older adults hears these eight words over and over again. The result is unnecessary suffering. Often the result is unnecessary costs to our State and Federal agencies. Often the result is unnecessary costs to families. Although Medicare payments for other common chronic conditions of aging are similar to payments for persons with dementia, out-of-pocket payments by families in support of care for persons with dementia are 81% higher. These payments consumed 32% of the household wealth measured 5 years before death of the person with dementia. These out of pocket costs not only pull resources away from the surviving spouse, they pull resources away from the next generation. For this reason, dementia casts a long economic shadow as well as a long caregiving burden. There is another problem with people finding these services too late. Several times a year, we care for older persons with dementia who have lost their savings through the heartless work of despicable scammers. Persons with dementia are the perfect target for fraud and abuse. As a clinician, it is easy to see that we need a new approach to care for older adults with dementia and we need this approach to be scalable statewide and we need it soon.

From my perspective as a researcher, we have been guided by three assumptions. First, the number of older Hoosiers with dementia will double in the next 20 years. Second, technology will not save us from needing to provide hands-on care for these older adults. Third, family caregivers are the only workforce available to provide this hands-on care in a truly scalable fashion. Therefore, we seek to develop new models of care that better integrate family caregivers and recognize their key strengths.

Over the past 20 years, we have been testing these new approaches at Indiana University and the Regenstrief Institute in collaboration with colleagues at Eskenazi Health. For example, we designed and tested an approach known as the "collaborative care model" through funding from the US Department of Health and Human Services. This new model of care provided primary care physicians and their older adult patients with an enhanced screening and diagnosis program for dementia. This program helped us find persons with dementia earlier because we identified them during their regular visits to their usual primary care physicians. For patients ultimately diagnosed with Alzheimer's disease through this program, the model provided care management by an interdisciplinary team led by an advanced practice nurse

working with the patient's family caregiver and integrated with their usual primary care provider. Families were referred to the Alzheimer's Association for additional support and we helped connect patients and families with community services. The main focus of the collaborative care model was providing the family caregiver with education and support and then integrating them with the medical care teams and community services teams. Just letting families know that services are available often breaks down a huge barrier to needed services. Data collected from this study proved that both patients and family caregivers improved with collaborative care and patients were less likely to receive harmful drugs and more likely to receive beneficial drugs.

Unfortunately, new models of care such as those tested at Eskenazi are not reaching the millions of Americans who could benefit. After the support of the federal grant ended, Eskenazi Health continued to provide this model of care even though most of the services in these new models of care are not reimbursed by third party payers. In addition, these models of care are difficult to scale because they require providers specially trained in geriatric medicine and dementia care. Older adults in rural Indiana may be a hundred miles away from such specialists. It has long been known that the US does not produce an adequate workforce of physicians with special training in care of older adults. It is less well known that we have an inadequate workforce in nursing, social work, and direct care workers to staff these models.

For this reason, scientists at Indiana University and the Regenstrief Institute have been exploring models to expand the reach of the limited professional workforce and improve the scalability of these models of care. This includes training nurses, social workers, or other professionals to provide these services as part of care teams, but it also means recruiting lay providers, volunteers, and community health workers to the effort. With support from the US Center for Medicare and Medicaid Innovation, scientists at the Indiana University Center for Aging Research tested this new workforce in the Aging Brain Care program. The project again included partners from the Regenstrief Institute and Eskenazi Health.

The partner organizations developed a specially designed, mobile electronic medical record and redesigned the collaborative care model to be mostly based on care provided in the patients' homes. We developed a new workforce of care coordinator assistants who had a minimum of a high-school diploma and were given special training in the care for older adults with dementia. The care coordinator assistants were supported by a nurse and social work team who themselves were supported by a geriatric medicine physician. The team worked with patients, families, primary care providers, and specialists to develop patient-specific care plans, deliver evidence-based protocols, and respond to real-time monitoring and feedback on key performance metrics. Some of the social workers were co-recruited and trained with CICOA. CICOA shared their approaches to larger scale training of persons providing care in the home.

Over 36 months, this program reached more than 3,000 Hoosiers with either dementia or late life depression receiving care from 8 primary care clinics in Indianapolis and five primary care clinics in Lafayette Indiana. Within the first 12 months, we demonstrated reductions in stress among the family caregivers and reduction in troubling behavioral symptoms among

patients. Family caregivers reported improved communication among patients, caregivers, community service agencies, and their medical care providers. Patients and family caregivers also developed better coping mechanisms. This program has continued to undergo continuous quality improvement and is now a flagship program for Eskenazi Health's new Sandra Eskenazi Center for Brain Care Innovation.

We have reported important results from other similar models of team-based care such as GRACE Team Care, the Physician House Calls Program, and the OPTIMISTIC program. Our scientists and clinicians continue to design and test better approaches to the care of older adults which address the need to scale up services quickly and broadly so that they are available to Hoosiers across the state.

From my perspective as a medical educator, I want to recommend that we need to think much more broadly in defining our learners. They are no longer limited to doctors and nurses. It is already too late to build an army of specialist geriatric providers to lead the care of Baby Boomers. The ratio of geriatric specialists to older adults will continue to fall over the next two decades as the number of older adults double while the number of specialist remains stagnant. If this is the case, then we need to imagine a new workforce to provide care for older Hoosiers and we need to imagine new ways to identify, educate, and support this new workforce. It is an opportunity to produce jobs for people in Indiana and improve care for older Hoosiers. We will need this workforce to include family caregivers and well as professional caregivers. We will need to educate physicians how to work in this new team approach to care and we need to provide the technology infrastructure to support coordination. We will need to educate everyone that patients prefer to age in place and society prefers to avoid premature nursing home placement.

Family caregivers are the hands, backbone, heart, and soul of the nation's workforce for older Americans. This will not change in the coming 25 years. The next largest workforce will be direct care workers assisting older adults and their families in the home. We need to quickly but safely shift resources out of high cost settings of medical care and into lower cost settings of care utilizing a new workforce and new technologies.

I will conclude my comments with a few recommendations to modernize home and community based services in Indiana.

1. Make it easier for family caregivers to be recognized as a key members of the care team. We can't do it without them.
2. Make it easier for families to access HCBS earlier. It is difficult to reduce the overall cost of care if these services are accessed late in the course of the illness or only in response to a crisis. This requires improving patients', providers', and families' knowledge of available services, reducing the administrative burdens of obtaining services, reducing the clinical requirements for services, and improving the supply of quality providers of these services.

3. Use HCBS to make it easier for family caregivers to remain in the workplace but still be involved in the care of their loved ones.
4. Expand training programs and career growth opportunities for the professional caregiver role in HCBS while simultaneously expanding the economic demand for these direct care workers.
5. Decrease the family out-of-pocket costs of providing care in the home by expanding coverage for services and supplies consistent with good care for older adults.
6. Make it easier for families to acquire temporary or permanent home modifications in support of providing care for older adults in the home.
7. Provide services, supports, incentives, and inducements for families to transition loved ones out of long term care and back into the home, where safe, appropriate, and consistent with the patient's goals.
8. Provide respite options and adult day care options
9. Increase support for transportation and make it easier to access.
10. Provide funding to design, test, and evaluate innovations in providing HCBS, including funding to build and maintain a data infrastructure to monitor the process and outcomes of HCBS.

Thank you again for the opportunity to speak with you today and I would be happy to respond to any questions.