

House Ways & Means Committee

Caring for Aging Americans

November 14, 2019

10:00 am, 1100 Longworth House Office Building

Purpose

The purpose of this hearing was to help the committee better understand the difficulties of navigating end of life care and the burden placed on care givers.

Members Present

Chairman Neal, Ranking member Brady, Rep. Sanchez, Lewis, Buchanan, Doggett, Smith, Thompson, Marchant, Larson, Reed, Blumenauer, Kelly, Kind, Smith, Pascrell, Davis, LaHood, Sanchez, Delbene, Schweikert, Chu, Walorski, Moore, Evans, Arrington, Beyer, Schneider, Winstrup, Suozzi, Panetta, Estes, Horsford and Murphy

Witnesses

Ms. Samantha Reid., Patient, Crohn's Disease

Ms. Kristina Brown., Caregiver, Medical Student

Mr. Robert Egge., Chief Public Policy Officer, Alzheimer's Association

Ms. Joanne Lynn, MA, MD., Director, Program to Improve Eldercare, Altarum

Mr. Robert Blancato., National Coordinator, Elder Justice Coalition

Mr. Richard J. Mollot., Executive Director, The Long Term Care Community Coalition

Mr. Edo Banach, JD., President & CEO, National Hospice and Palliative Care Organization

Opening Statements

Chairman Neal said that navigating a complicated and insufficient long-term care system adds an unnecessary burden to the lives of so many. Furthermore, most Americans want to age in their own home. But to do this requires the support of others. Uncompensated care givers are the unsung heroes in these situations. However, the burden placed on them often creates divides and tension among family members. They are living with the consequences of our system's failure.

Rep. Sanchez said that the burden caused by Alzheimer's is often times too great for families to bear. Furthermore, this disease is most prevalent in Latinos and African Americans. However, everyone in this country knows a story of someone with Alzheimer's or someone who has to take care of aging loved ones. The cost of uncompensated care among the elderly population is significant and represents a large burden for these individuals.

Ranking Member Brady said that Republicans have a long history of reaching across the aisle to protect elderly Americans. Furthermore, this committee remains dedicated to this goal and building upon past success. It is crucial that this committee does not look to overhaul the whole system but instead fill in the gaps where there are holes. America has a system that works but also one that has flaws. Together, Democrats and Republicans have the ability to do this. Congress cannot pass another partisan bill like H.R. 3.

Testimony

Ms. Brown said that she is a caregiver and medical student. When her mother was just 46, she developed multiple sclerosis and lost most of her functional ability. Ms. Brown became her full time caregiver. Despite common misconceptions, having a disability does not guarantee you support. She is ineligible for Medicare and Medicaid. Furthermore, her insurance company does not pay for daily care activities. This required Ms. Brown to sacrifice her life to take care of her mother. Her social isolation ruined her adolescence. This type of care giving fuels cycles of generational poverty, which disproportionately affect women and minorities. Medicaid eligibility should not be judged on income alone, but instead income in context of cost.

Mr. Egge said that without significant action, as many as 14 million Americans will have Alzheimer's in the near future. But this does not just present a burden on the individual level. Instead it financially affects families for years on end and leaves them in a cycle of poverty. Alzheimer's is the most expensive condition in America. This means that payers such as Medicare and Medicaid also have to pay a significant cost. Data shows that Dementia and Alzheimer's care planning is crucial to reducing hospitalization rates and keeping costs low. However, further analysis shows that less than 1% of individuals with Alzheimer's or dementia receive these services. The Improving Hope for Alzheimer's Act would require HHS to educate providers on the benefit of coordinated Alzheimer's care planning, and report to Congress the barriers individual's face when accessing these services.

Dr. Lynn said that the United States is facing a serious challenge because millions of Americans are arriving at old with inadequate finances and significant health problems. Without changes, most individuals who work their whole life in the middle class will not be able to afford housing in retirement. Of course there will be families that can help, but the burden placed on them is too great to stop there. We have already heard stories of how difficult it is for family members to sacrifice their life to care for aging loved ones. There are numerous paths forward that would help consumers save money and limit the costs taken on by the federal government. In order for there to be an effective savings plan, Congress needs to act now.

Mr. Blancato said that achieving quality care of elders is always the goal, but affording it is the barrier. To make care affordable, we must protect Medicare. This starts by refusing to put caps on Medicare costs and moving away from block grants. Reimbursement rates must also be increased for nursing home providers. Nursing homes are also an area of rampant abuse. While there are nursing homes that do a tremendous job there must be more significant oversight of these facilities. Additionally, there needs to be a greater emphasis on rural health and the quality of life for aging adults in rural areas. Furthermore, last year 5.5 million older adults were food insecure. It is true that food insecurity leads to poor health outcomes. There are numerous paths forward but we must act quickly.

Mr. Mollot said that nursing home and assisted living safety is of the utmost importance. Far too often the promises of safety and stability in nursing homes are broken. The

absence of effective enforcement leads to abusive practices and neglect. These actions are crimes and should be treated as such. These facilities put profits over patients. It doesn't have to be this way. But to fix it, we need strong federal oversight and enforcement. Seniors and their families deserve better.

Mr. Banach said that hospice never has been and never should be a partisan issue. Hospice care is something that almost every American will use. For many people hospice provides the right level of care at the right time. At best, it is person centered. However there are challenges. However, many people do not get access to hospice. This can be due to cost, lack of transportation or lack of resources. We need to do better at expanding this service to everyone who needs it.

Questions and Answers

Chairman Neal asked what Congress should do about the fact that most retired Americans are very low income. **Dr. Lynn** said there needs to be governmental action. That could mean a federal backstop on long-term care. **Chairman Neal** asked how to ensure that seniors have enough to eat. **Mr. Blencato** said that we need to monitor Medicare Advantage closely. Medicare Advantage can and should offer services that deliver food to beneficiaries home. If this program is successful it should then be applied to fee-for-service Medicare. Medicare should also add a dental benefit. **Chairman Neal** asked how to crack down on the inappropriate use of anti-psychotic drugs in nursing homes. **Mr. Mollot** said that Congress should pass an informed consent bill.

Ranking member Brady asked how important it is to have innovation for Alzheimer's patients. **Mr. Egge** said innovation is important, but access is also important. **Ranking member Brady** asked if it would be helpful for Congress to equip CMS with additional oversight over hospice facilities. **Mr. Banach** said that yes.

Rep. Lewis asked Ms. Brown to share more about the challenges she has faced. **Ms. Brown** said in addition to financial challenges, she frequently worries about her education and career. Her whole family has had to make significant sacrifices. **Rep. Lewis** asked how Congress can ease the burden of individuals in Ms. Brown's shoes. **Dr. Lynn** said that Congress can appropriate money for the National Community Care Core. Care givers should also be supported and compensated more; they need protections.

Rep. Buchanan asked if time is being spent researching Alzheimer's prevention. **Mr. Egge** said yes. He said that there is a lot of research coming out suggesting that there are steps individuals can take to reduce their risk of Alzheimer's.

Rep. Doggett asked effect private equity has had on nursing homes. **Mr. Blencato** said he was not sure. **Mr. Mollot** said that the investment by private equity has savaged the quality of care provided by nursing homes across the country.

Rep. Smith asked what role tele-medicine plays in the future of elderly care. **Dr. Lynn** said telemedicine is very important to the future of elderly care. However, we should also have actual in home services.

Rep. Thompson asked how work force shortages affect access to hospice care and the quality of that care. **Mr. Banach** said that workforce shortages restrict access and reduce the quality of care that hospice services can provide. We need job training programs and competitive pay. **Mr. Thompson** asked if skilled nursing facilities have the same problem. **Mr. Mollot** said yes. Historically nursing homes are one of the worst places to work. Increasing salary is very important. **Mr. Thompson** asked how Congress can ensure that hospice facilities are prepared for national disasters. **Mr. Banach** said that Congress should include hospice facilities in disaster release funds.

Rep. Reed asked how we should view hospice and palliative care. **Mr. Banach** said that there is a stigma surrounding hospice because you have to give up cure seeking care. We also start talking about advanced illness care far too late. We should be talking about this service as something that is good and remove the barriers to accessing it. **Mr. Reed** asked if reforms to the Medicare system could save money on hospice spending down the road. **Mr. Banach** said yes.

Rep. Blumenauer asked about the PACE waiver that has been rejected by CMS. **Dr. Lynn** said that they have submitted two waivers and both were rejected by CMS.

Rep. Kelly asked how to make end of life care a sustainable business model. **Dr. Lynn** said that we need an era of substantial innovation. There is already a tremendous amount of money going into the system, it is just going into the wrong place. For example, it is easy to get a thousand dollar drug but not get dinner.

Rep. Kind asked what the state of the long term care market is. **Dr. Lynn** said that the long term market place is in huge risk. Furthermore, there is no predictability surrounding the availability of affordable long term care at any given time. **Rep. Kind** asked if it is possible for Medicare to work efficiently in the system without blowing the whole system up. **Mr. Blencato** said yes, but there needs to be more consumer input.

Rep. Smith asked about the impact of workforce shortages. **Mr. Banach** said that there is very little investment in community health workers. We should shift resources from inpatient settings to community settings where individuals want to spend their last remaining days.

Rep. Pascrell asked how CMS can improve data audits and enforcement measures so consumers can make more informed decisions. **Mr. Blencato** said that CMS now places an icon to indicate abuse or neglect next to a facilities name. However, there is no continual scheduled audit which makes the data incomplete.

Rep. Davis asked how access to more care givers help relieve the burden on care givers as a whole. **Dr. Lynn** said that it helps them enjoy job flexibility. Furthermore, on a whole care givers need to earn more.

Rep. LaHood asked how to increase the public awareness of services for end of life care. **Mr. Egge** said that primarily we need to make clinicians aware of it.

Rep. Sanchez asked what unique needs care givers have. **Mr. Egge** said living through the changes of disease states is very difficult for care givers emotionally. They often are not connected to available support services. We need a person centered approach to care and to caring for care givers. **Rep. Sanchez** asked what opportunities Ms. Brown has missed due to her obligation to take care of her mother. **Ms. Brown** said that she missed educational goals and the general opportunity of being a young person. She had to quit sports and could not spend time with her friends. She said that she lost the end of her childhood. **Rep. Sanchez** asked if these missed opportunities have impacted her financial future. **Ms. Brown** said yes.

Rep. Delbene asked how the federal government can build on state efforts to empower Medicare beneficiaries. **Dr. Lynn** said there is a need to improve data collection capabilities. The federal government should also identify state programs that are working well and expand them to federal programs.

Rep. Schweikert asked how the consolidation of community resources can provide necessary services. **Mr. Blancato** said there are many tech startups that are entering the market and are making a significant impact. This is cause for optimism. **Dr. Lynn** said yes, this hearing is a start because people need to pay attention. **Mr. Banach** said it is encouraging that Amazon is entering the market and trying to innovate.

Rep. Chu asked if paid family leave would help mitigate the burden that families face when caring for aging loved ones. **Ms. Brown** said yes. **Dr. Lynn** said yes, but more needs to be done. It will only be a small fix. **Rep. Chu** asked how Congress and CMS can strengthen minimum standards in long term care facilities. **Mr. Mollot** said that there are already really strong standards, but they are not enforced. CMS needs to enforce these standards.

Rep. Walorski asked what statutory barrier currently prevents hospice patients from seeing their primary care provider in a federally qualified health center. **Mr. Banach** said that patients who get their primary care from a federally qualified health center must choose between continuing to receive care at the health center or choose to get hospice. They cannot choose both.

Rep. Moore asked what the reduction of Medicaid payments to long term health providers would mean. **Dr. Lynn** said that since Medicaid rates are already so low, cuts to these rates would be devastating to providers. Earned income tax credits is also a step in the right direction.

Rep. Evans asked what Congress should do to help people like Ms. Brown. **Ms. Brown** said that Congress needs to address the gaps in Medicaid and Medicare eligibility. There should be a greater investment in home and community based services. Finally, there should be greater support for care givers over all. **Rep. Evans** asked how to mitigate disparities in long term care. **Dr. Lynn** said we need to address generational wealth.

Rep. Beyer asked how to hold costs down in long term care. **Mr. Blancato** said home and community based services will be much cheaper than inpatient services. **Dr. Lynn** said that investing in social services will help to reduce overall costs as well.

Rep. Schneider asked if there are any demonstration projects that have been successful at caring for long term elderly patients. **Mr. Egge** said yes. Programs like 'Reach VA' are very

effective. **Rep. Schneider** asked if there is a need for support services for young care givers. **Ms. Brown** said yes. To start, there needs to be more awareness surrounding this issue.

Rep. Winstrop asked what challenges exist specifically in rural America. **Mr. Banach** said the biggest challenge in rural America is actually being able to see a provider or care giver. This is why telemedicine is important. Furtherer more there is a lot of social isolation in rural communities.

Rep. Suozzi asked if anyone would be interested in participating in creating a pilot program. **Dr. Lynn** said yes. **Mr. Blacato** said yes. **Mr. Egge** said yes.

Rep. Panetta asked how hospice providers will adapt to new sanctions. **Mr. Banach** said hospice providers will have to adapt. Providers that are doing the right way welcome these intermediate sanctions. It will help to reduce abuse and fraud.

Rep. Estes asked if the definitions of abuse and neglect are defined correctly. **Mr. Mollot** said they are good definitions but the definitions are not enforced. **Rep. Estes** asked if we should have uniform definitions across facilities. **Mr. Mollot** said he is not an expert in other provider settings, but he believes so.

Rep. Horsford asked how Congress can improve access to nursing home alternatives. **Mr. Mollot** said that Medicaid assisted living is a good avenue to expand.