December 2017

Iowa House File 653, Sec. 97. Access to Dementia-Specific Care: Final Report

NASUAD
National Association of States
United for Aging and Disabilities

The National Association of States United for Aging and Disabilities (NASUAD) represents the nation’s 56 state and territorial agencies on aging and disabilities and supports visionary state leadership, the advancement of state systems innovation and the articulation of national policies that support home and community based services for older adults and individuals with disabilities. NASUAD’s members oversee the implementation of the Older Americans Act (OAA), and many also function as the operating agency in their state for Medicaid waivers that serve older adults and individuals with disabilities. Together with its members, the mission of the organization is to design, improve, and sustain state systems delivering home and community based services and supports for people who are older or have a disability, and their caregivers.

Access to Dementia-Specific Care
2017 NASUAD Report

INTRODUCTION

This report is being written in response to House File 653, Sec. 97. ACCESS TO DEMENTIA-SPECIFIC CARE. "*The department on aging, the department of public health, the department of inspections and appeals, and the department of human services shall jointly analyze and make recommendations regarding options for coordination between state agencies and private entities to promote increased access to dementia-specific care in both residential and home and community-based settings. The analyses and recommendations shall address barriers to, gaps in, and opportunities for increased access, the availability of services in home and community-based settings as an alternative to residential settings, and any changes in law necessary to better address the needs of individuals with dementia and their families. The departments shall submit a joint report of findings and recommendations to the governor and the general assembly by December 15, 2017.*"

The Governor assigned the Department on Aging to lead the effort, and the Department on Aging contracted with the National Association of States United for Aging and Disabilities to draft this report. The National Association of States United for Aging and Disabilities (NASUAD) is a nonpartisan association representing the nation's 56 state and territorial agencies on aging and disabilities. NASUAD works to support visionary state leadership, the advancement of state systems innovation, and the development of national policies that support home and community-based services for older adults and individuals with disabilities. NASUAD members administer a wide range of services and supports for older adults and people with disabilities, including Medicaid long-term services and supports (LTSS), the Older Americans Act (OAA), and a variety of other health and human services programs. NASUAD works to design, improve, and sustain state systems delivering home and community-based services and supports for people who are older or have a disability and for their caregivers.

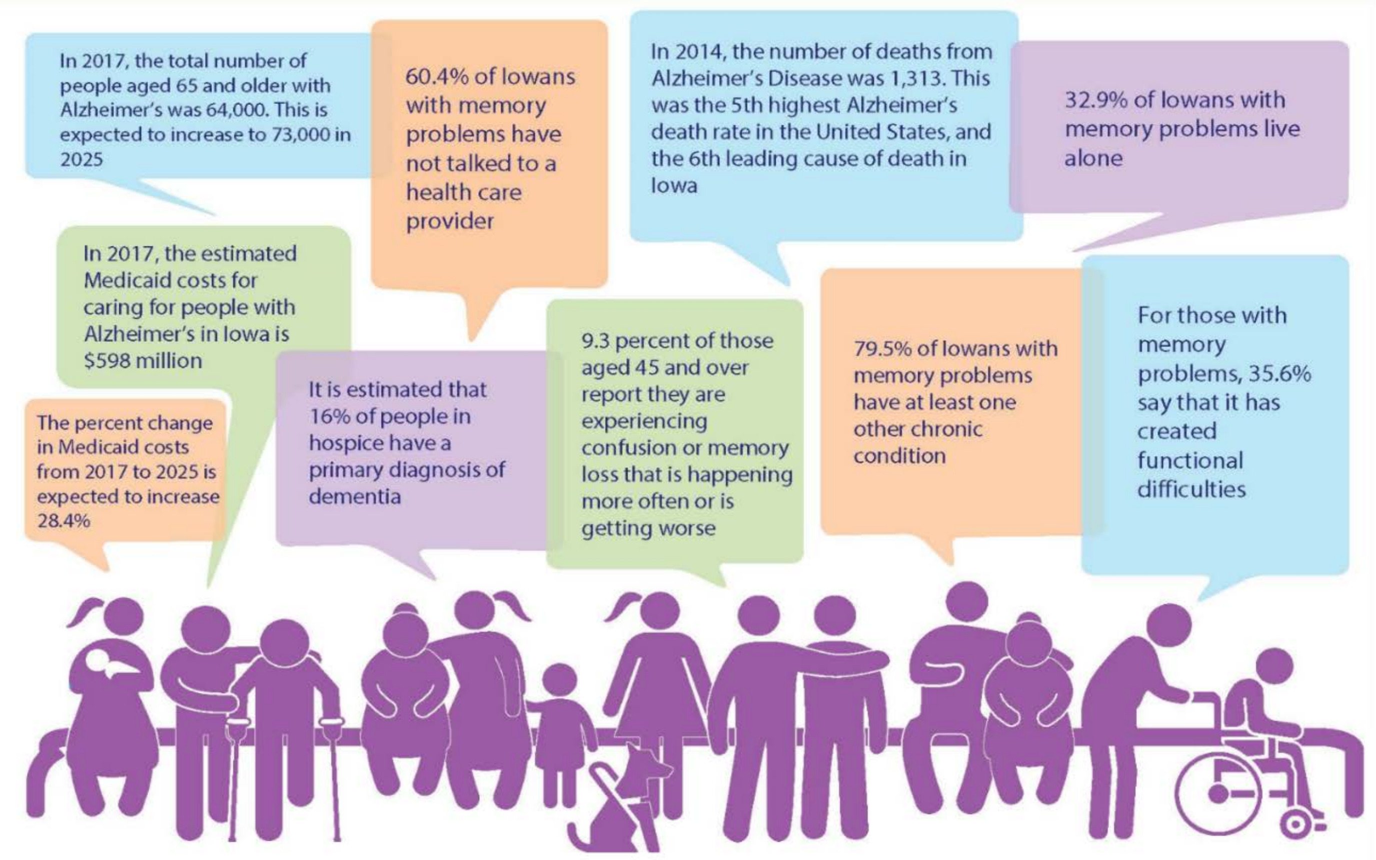
Background

Alzheimer's disease is a progressive disease that destroys memory and other important mental functions. At first, someone with Alzheimer's disease may notice mild confusion and difficulty remembering. Eventually, people with the disease may even forget important people in their lives and undergo dramatic personality changes.

Alzheimer's disease is the most common cause of dementia— a group of brain disorders that cause the loss of intellectual and social skills. In Alzheimer's disease, the brain cells degenerate and die, causing a steady decline in memory and mental function.[1] Individuals with Alzheimer's and related dementia face a slow loss of memory and other cognitive abilities that eventually become significant enough to interfere with daily life that requires assistance.

According to the Alzheimer's Association, in 2017 the number of Iowa residents with Alzheimer's and related dementia over age 65 was approximately 64,000, and that number is expected to continue to increase—putting additional pressure on family caregivers, providers, and the state's budget. The illustration below provides just a sampling of the alarming statistics on the impact of this disease for Iowa. Of particular note are the high number of Iowa residents with Alzheimer's who reside alone.

Profile of Dementia and Cognitive Decline in Iowa[2]



In 2017, the total number of people aged 65 and older with Alzheimer's was 64,000. This is expected to increase to 73,000 in 2025

60.4% of Iowans with memory problems have not talked to a health care provider

In 2014, the number of deaths from Alzheimer's Disease was 1,313. This was the 5th highest Alzheimer's death rate in the United States, and the 6th leading cause of death in Iowa

32.9% of Iowans with memory problems live alone

In 2017, the estimated Medicaid costs for caring for people with Alzheimer's in Iowa is $598 million

The percent change in Medicaid costs from 2017 to 2025 is expected to increase 28.4%

It is estimated that 16% of people in hospice have a primary diagnosis of dementia

9.3 percent of those aged 45 and over report they are experiencing confusion or memory loss that is happening more often or is getting worse

79.5% of Iowans with memory problems have at least one other chronic condition

For those with memory problems, 35.6% say that it has created functional difficulties

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[1] https://www.mayoclinic.org/diseases-conditions/alzheimers-disease/symptoms-causes/syc-20350447

[2] Alzheimer's Association. 2015. *Cognitive Decline in Iowa*. Retrieved from https://www.alz.org/publichealth/downloads/iowa_2015.pdf; Alzheimer's Association. 2017. *Alzheimer's Statistics: Iowa*. Retrieved from https://www.alz.org/greateriowa/documents/statesheet_iowa(1).pdf and https://alz.org/greateriowa/documents/Spring_2010_newsletter.pdf

Prior Efforts

The State of Iowa has taken part in a number of activities with the overarching goal of improving the lives of residents living with Alzheimer’s disease and related dementias and their caregivers. These efforts included task forces relating specifically to Alzheimer’s disease, workforce, and elder abuse.

In 2007, the State’s Alzheimer’s Disease Task Force Report recommended the following items be addressed by 2009. These items included:

1. Establish an office for Alzheimer’s disease or related disorders within state government. This office would not replace or duplicate any services currently offered by the Area Agencies on Aging, the Alzheimer’s Association, or other agencies, but would act as a referral source to local services.
2. Increase and enhance training and education requirements about Alzheimer’s disease or related disorders for all direct care employees including, but not limited to, long-term care settings, assisted living, elder group homes, residential care, adult day facilities, and home health care.
3. Broaden the spectrum of people who are required to receive training specific to Alzheimer’s disease or related disorders to those who work in direct contact with people diagnosed with Alzheimer’s disease including but not limited to administrators, directors, dietary staff, administrative and management staff, hospital direct care staff, state employees with responsibility for long-term care oversight/monitoring, and Ombudsmen.
4. Ensure that all recommendations coalesce with other initiatives and programs within the state, such as the Direct Care Worker Task Force Recommendations, Alzheimer’s Association, Area Agencies on Aging, the Hartford Center Grant, Iowa Respite and Crisis Care Coalition, and the UI Center on Aging and Geriatric Education Center.
5. Support and assist the rapidly increasing numbers of Iowans with Alzheimer’s disease or related disorder by providing a wide array of home and community based services such as adult day services, respite care, and affordable transportation as well as Assisted Living, occupational therapy, speech therapy, social work services, dieticians, and others as these may delay premature nursing facility placement.
6. Fund public awareness efforts and educational efforts for providers, caregivers, and state oversight and monitoring personnel.
7. Implement a statewide campaign to educate healthcare providers regarding early detection instruments, such as AD8 and Mini-Cog, as early detection could prepare patients and families for what to expect.
8. Make Medicaid Waivers a significant factor in helping address the many needs of Iowans dealing with problems associated with Alzheimer’s disease or related disorder, such as adult day services, assisted living, respite care, occupational therapy, speech therapy, social work services, dieticians, and affordable transportation as a means to delay premature institutionalization.
9. Given that the Medicaid Waiver is a long process, undertake a three step approach to address the

needs of persons with Alzheimer's disease or related dementia:

Step 1: Allow individuals with a diagnosis of early on-set Alzheimer's disease or related disorders to be served in excess of the current maximum number of clients under the Ill and Handicapped Waiver.

Step 2: Increase the expenditure limits under the Elderly Waiver to give parity with other waivers including but not limited to the Ill and Handicapped Waiver, the Brain Injury Waiver, and the Mental Retardation Waiver for persons with a diagnosis of Alzheimer's disease or related disorder. (This recommendation affects patients older than 65.)

Step 3: Establish an Alzheimer's disease or related disorder specific waiver to place greater importance on the issue and needs, comparable to the Brain Injury Waiver and the HIV/Aids waiver, and without regard to the age of the person with Alzheimer's disease or related disorder.

10. Compile an analysis of Iowa's population by county and age to determine current utilization and future service needs of caregivers and persons with Alzheimer's disease or related disorder to support development of programs and services.
11. Review current trends and the impact in the Long-Term Care rebalancing efforts affecting persons with Alzheimer's disease or related disorder.
12. Modify existing community needs assessment process to include questions that would identify and quantify at-risk people with Alzheimer's disease or related disorder.
13. Enhance capacity of services to meet the needs of persons with Alzheimer's disease or related disorder.
14. Establish Quality Care measures with system benchmarks for facility and community based care for persons with Alzheimer's disease or related disorder.
15. Address the preparedness of the workforce to provide care and services in support of persons with Alzheimer's disease or related disorder and their caregivers.
16. Establish Alzheimer's disease or related disorder Diagnostic Centers of Excellence strategically throughout the state that would serve as multi-disciplinary centers to serve patients with Alzheimer's disease or related disorder and their caregivers.
17. Convene a workgroup on a regular basis to address psychogeriatric needs of persons with Alzheimer's disease or related disorders in Iowa.
18. To keep Iowans healthier and reduce the risk for developing Alzheimer's disease or related disorders:
    a. Provide physical and mental activity programs using evidence-based programs designed for older adults such as Enhance Fitness, Eat Better & Move More, and Healthy Aging.
    b. Provide chronic disease self-management programs using evidence-based health promotion programs such as Stanford Chronic Disease Self-Management.
    c. Promote dietary quality for older Iowans through provision of nutrition education programs such as Eat Better & Move More.
    d. Provide nutrition counseling by registered dietitians to older adults determined to be at high nutrition risk.
    e. Provide brain health education programs to help Iowans reduce their risk of Alzheimer's disease or related disorders.

In 2011, an Alzheimer's Work Group was created with the Iowa General Assembly's passage of House File 390. This legislation required a strategy to respond to the needs of Iowans living with Alzheimer's disease and other forms of dementia. As a result of this legislation, six goals were developed by the Alzheimer's Work Group:

- Develop the infrastructure necessary to support and fund Alzheimer's activities;
- Address stigma with awareness and education;
- Provide immediate information and resources to individuals and families;
- Address workforce challenges specific to Alzheimer's disease needs;
- Increase access to services most in need; and
- Improve data collection on Alzheimer's disease in Iowa.

Iowa Department on Aging was also successful in obtaining a grant from the Administration on Community Living to create a Dementia-capable HCBS System in Iowa. The goal of the grant was to support the advancement of the evidence-informed Health and Resilience Outreach project, which improves caregiver resilience and supports their ability to manage the care of the person with dementia.

In 2012, the State was successful in funding the Office of Substitute Decision Maker for the fiscal year of 2013. The purpose of this office is to serve the population of Iowa adults ages 18 and older who are unable to meet essential requirements to maintain their physical health or to manage essential aspects of their finances. This population includes those living with Alzheimer's disease and other forms of dementia.

Senate File 446, Section 50 mandated that the Department on Aging continue the Elder Abuse Intervention and Prevention task force. This task force focused on a variety of topics in relation to elder abuse, including: the definition of elder abuse; safeguards from financial exploitation laws related to Powers of Attorney; conservatorship abuse; and the Office of the Substitute Decision Maker. Within these topics, educating dementia professionals was also a focus, specifically for mandatory reporters. This included reviewing the current curriculum for mandatory reporters, and conducting research on dementia and other cognitive impairments.

The state has also had a focus on educating dementia professionals. In 2013, it created an Elder Abuse task force that focused on creating a core curriculum and training for mandatory reporters. Within this process, research on dementia and other cognitive impairments was conducted to add or change the current curriculum for training mandatory reporters. In 2015, previous recommendations for educating and training dementia professionals (i.e. doctors, nurses, CNA staff, social workers, etc.) were revised to include the following topics:

- Dementia, including the progression of the disease and psychiatric and behavioral symptoms;
- Strategies for person-centered care;

- Communication;
- Understanding and approaching behavioral symptoms, including alternatives to physical and chemical restraints;
- Social needs and meaningful activities;
- Care and safety; and
- Ethics.

The State also mandated in 2014 in Section 30 of Senate file 2239 that the Department on Aging, Department of Human Services, Department of Inspections and Appeals, Department of Public Health, and the Office of the Attorney General collaborate on written recommendations for strengthening Iowa's elder abuse prevention, detection, and intervention efforts.

2017 DEMENTIA TASK FORCE

Building on prior efforts, and as directed by the Governor in response to House File 653, Section 97, the Department on Aging hosted a daylong meeting on November 17, 2017. The meeting brought together key stakeholders, policymakers, academics, and caregivers to share thoughts on what additional efforts the state should undertake to improve services and supports for individuals with dementia.

Iowa Leaders Discussion

Iowa Department of Public Health Director Gerd Clabaugh shared statistics from the public health perspective. Director Clabaugh used the information collected from the Behavioral Risk Factor Surveillance System (BRFFS) survey regarding Iowa's Alzheimer's and related dementia issues. According to the most recent BRFFS:

- 9.3% of those 45 and older are experiencing increased confusion or memory loss in Iowa.
  - 60% of those have not talked to a doctor about the issue.
  - 1 in 4 say that the memory loss impacts activities of daily living.
  - 1 in 3 live alone.
  - 1 in 9 Iowans will develop Alzheimer's disease in their lifetime.

Director Clabaugh also stated there is a workforce shortage to deal with this crisis and cited Bureau of Labor Statistics that show that the demand for personal care attendant/aids are growing faster than most jobs that the Bureau tracks. Director Clabaugh estimated approximately 40,000 Iowans work in some type of caregiving occupation, but also shared that it is difficult to track the number.

Director Clabaugh shared his agency will continue to work on the issues of Alzheimer's and related dementia as public health issues, and the Department will be issuing a report on the connection between dementia and palliative care in December 2017.

Department on Inspections and Appeals

Department of Inspections and Appeals Director Rod Roberts shared with the meeting his agency's role in the long-term care space is to inspect the long-term care facilities and report findings to the Centers for Medicare and Medicaid Services (CMS). Director Roberts shared Iowa has worked in partnership with the federal government on a number of key initiatives relating to dementia care, including a project in 2014 on how to best care for residents in nursing facilities with dementia. He explained providers are experiencing complications dealing with individuals with dementia, as they often can become combative and challenging as their disease progresses. Director Roberts shared his agency will continue to look for promising ways to protect the dignity of the resident, while also ensuring those who care for the residents are not harmed.

Mental Health and Disability Services Division

The Mental Health and Disability Services Division Administrator Richard Shults shared with stakeholders his agency is dealing with some of the most challenging cases of dementia because these individuals also have intellectual/developmental disabilities (ID/DD) and/or behavioral health challenges as their underlying condition. He shared his agency will need to continue to seek ways to provide services for this growing population. He stressed there is a lack of training and understanding of how to serve individuals with dementia who also have behavioral health needs, and therefore individuals may not be receiving the appropriate level of care or they may not be in the right place for that care. Administrator Shults asserted many people with dementia are given psychiatric treatment, which is not an effective nor efficient service for their condition.

National Discussion and Overview

One of the most challenging public policy questions nationally is *how* to care and serve individuals with dementia. To begin, the diagnosis of individuals with dementia is often a lengthy process, following a period of confusion for the individual and their loved ones when they may need assistance and/or referrals to programs; but, without being able to put a name to the condition, they often lack understanding of the types of services and supports that are available. Then, once diagnosed, individuals need and search for access to professionals that can provide them with information and referral to appropriate services and supports. Perhaps the most difficult aspect, the diagnosed individual's needs will change over time, requiring a supportive system that can adjust to the unique aspects of each person.

In the beginning period of the disease, most individuals are able to fully function in society with minor assistance; however, as shown in the graphic below, towards later stages and through the seventh stage of the disease, the recipient will become more dependent on having all of his/her needs attended to.

Stages of Dementia

- Stage 1: No impairment
- Stage 2: Very mild decline
  - may lose things around house
- Stage 3: Mild decline
  - family notices
  - loses important things
  - can't remember words
  - can't plan/organize
- Stage 4: Moderate decline
  - very poor short-term memory
  - can't manage bills
  - difficulty with arithmetic
- Stage 5: Moderate severe decline
  - difficulty dressing
  - can't remember phone number
  - significant confusion
  - can still bathe/ toilet independently
- Stage 6: Severe decline
  - requires constant supervision
  - will need assistance with bathing/ toileting/ eating
  - will not recognize most people
  - wandering
- Stage 7: Very severe decline
  - no insight into their condition
  - will need assistance with all activities of daily living
  - may no longer be able to swallow

In order to begin to tackle how to better provide care and service for individuals with dementia, it is necessary to conduct a review of how other state agencies on aging and disability are handling the dementia population. Below is a summary of ways in which state programs could be matched to consumers during the progression of the disease:

- **Stage 1:** The individual may begin to notice things are not the same, but will attribute it to normal forgetfulness.
- **Stage 2:** Family members may start to realize the individual is acting differently than previously, but they will not know what the problem is. Loved ones may believe the person is just having a “senior moment,” is tired, or having an “off day.” The family may reach out to friends and colleagues to share their concerns and frustrations, but they will likely not reach out to the state or local programs for assistance.
- **Stage 3**: By stage three, the family has noticed a pattern of continually losing items, an inability to find the words, and an inability to do things that were once simple for the individual. The individual will likely talk with a physician, who will recognize that it is likely dementia. At this point, the individual will still be fully functioning in the community, but he/she will likely reach out to find out what resources are

available. This is the time when the state’s **No Wrong Door system/Aging and Disability Resource Center** (Lifelong Links) can help, by providing information and referral, **person-centered planning**, and options counseling for the person. Caregiving support programs can begin to be offered to family members. Appropriate information and resources should also be made available for those that are caregiving from a distance. Additional training on preparing advance directives and wills may also be useful for consumers at this time.

- **Stage 4:** If the diagnosed individual is still working, they will likely need to step back from employment. The caregiver will also have additional responsibilities for bill paying and other household tasks. If the caregiver is not yet involved in a **caregiver support** program, they may find it helpful to begin. The state may also begin to perform a caregiver needs assessment during this phase to ensure that the caregiver will receive the resources needed to continue providing care. If the individual’s needs meet the target group, the individual may also qualify for **Older Americans Act** services at this stage, including congregate meals, home-delivered meals, and/or other services that will allow him/her to remain independent.
- **Stage 5:** By stage five, the individual will need additional support for several activities of daily living, including things such as bathing and/or dressing. It may be helpful to involve the individual in **Adult Day Health/Social Programs**, in order to assist the caregiver with providing for increasing needs and to provide caregiver respite. At this stage, caregivers and the individual with dementia may consider alternative living arrangements, such as **Assisted Living** that can provide a greater level of support; alternatively, they may also seek in-home support such as **personal care attendant services** to assist with activities of daily living.
- **Stage 6:** Possibly the most exhausting for the caregiver, at this stage the individual will likely require constant supervision due to confusion and the propensity for wandering. Individuals at this stage are more likely to also put themselves in harm’s way, because they are unaware. For example, they may leave the stove on. This is often times the point at which the caregiver decides to move the recipient to a higher level of care, such as a **nursing facility**. Family caregiver support programs are critical support for the family caregivers at this stage of the disease.
- **Stage 7:** Stage seven is the final stage of the progression of the disease, and the recipient will need all of his/her needs attended to. This is normally when family members are advised to bring in palliative care to ensure that the recipient is not in pain.

Funding for Dementia Care

There are three major federal funding sources for dementia care. The first being Medicare, which is available to Americans 65 years or older. Medicare will pay for inpatient hospital care; some doctor's fees; some medical items; outpatient medications; and some home health (under certain conditions)—but notably, it will not pay for activities of daily living on a long-term basis, nor will Medicare pay for long-term stay nursing home care. The second funding source of dementia care is Medicaid. A person becomes eligible for Medicaid by meeting both functional and financial eligibility criteria, which varies by state. If a person is eligible, Medicaid will pay for nursing home care; and if qualified, it will pay for services in home and community-based settings. The third program that funds dementia care is open to all Americans 60 years or older, but it is limited in funding so individuals must meet certain targets. The Older Americans Act program provides for home and community-based programs and can offer several services that can help individuals remain in their homes and communities without becoming impoverished. Additional federal funding that supports dementia programs are offered through the Department of Public Health, the Department of Transportation, the Department of Welfare, and others.

There is a monumental cost to dementia care. According to the 2016 Genworth Cost of Care Survey conducted by CareScout, the national median cost of care for Adult Day health care, at its lowest cost option, is $17,680 per year based on receiving care five days per week. The next most reasonable option is Assisted Living, which is $43,539 annually. Utilizing homemaker services ($45,760) and/or home health aides ($46,332) come at similar costs, but allow for the individual to remain in their home. The most expensive options include semi-private nursing home care at a cost of $82,125 annually and private-room nursing home care at $92,373 a year.[3] It is important to mention these are national averages and are based on the average cost of care, regardless of payer. Those facilities serving Medicaid clients would likely see their reimbursements much lower. In Iowa, nearly 70 percent of Iowa Medicaid recipients over 65 receive services in institutional settings, according to the most recent expenditure data available from the Centers for Medicaid and Medicare Services.[4]

Unfortunately, the health status of clients with dementia is generally much poorer than those without dementia. Nearly 50 percent of individuals with dementia report having only fair or poor health. And 70 percent of those

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[3] http://newsroom.genworth.com/2016-05-10-Genworth-2016-Annual-Cost-of-Care-Study-Costs-Continue-to-Rise-Particularly-for-Services-in-Home

[4] Truven LTSS Expenditure Report 4/2017.

with Medicaid claim having only fair or poor health.[5] 85-90 percent of dementia clients report having three or more chronic conditions.

State Goals and Strategies

State aging and disability directors have listed the following overall goals for redesigning their long-term services and supports (LTSS) systems. These goals remain consistent, whether intending to redesign the system solely to better serve individuals with dementia or to redesign the LTSS system for other purposes. The goals include:

- Serve more consumers in home and community-based settings;
- Improve quality of care;
- Reduce Medicaid spending;
- Improve and maintain health of consumers; and
- Support caregivers.

States have developed a multi-tiered strategy designed to improve their overall LTSS systems. The state strategies include:

- Implement person-centered planning
- Improve HCBS settings
- Measure quality
- Support family caregivers
- Develop No Wrong Door system
- Utilize managed long-term services and supports
- Increase support to the pre-Medicaid population
- Realign state agencies
- Expand Older Americans Act programs

The graphic on the following page represents the most common strategies that states have used to improve their structures and to reach the goals outlined. These strategies can help the state to address the concerns outlined in House File 653, Sec. 97. Each strategy is explained in further detail in the paragraphs that follow.

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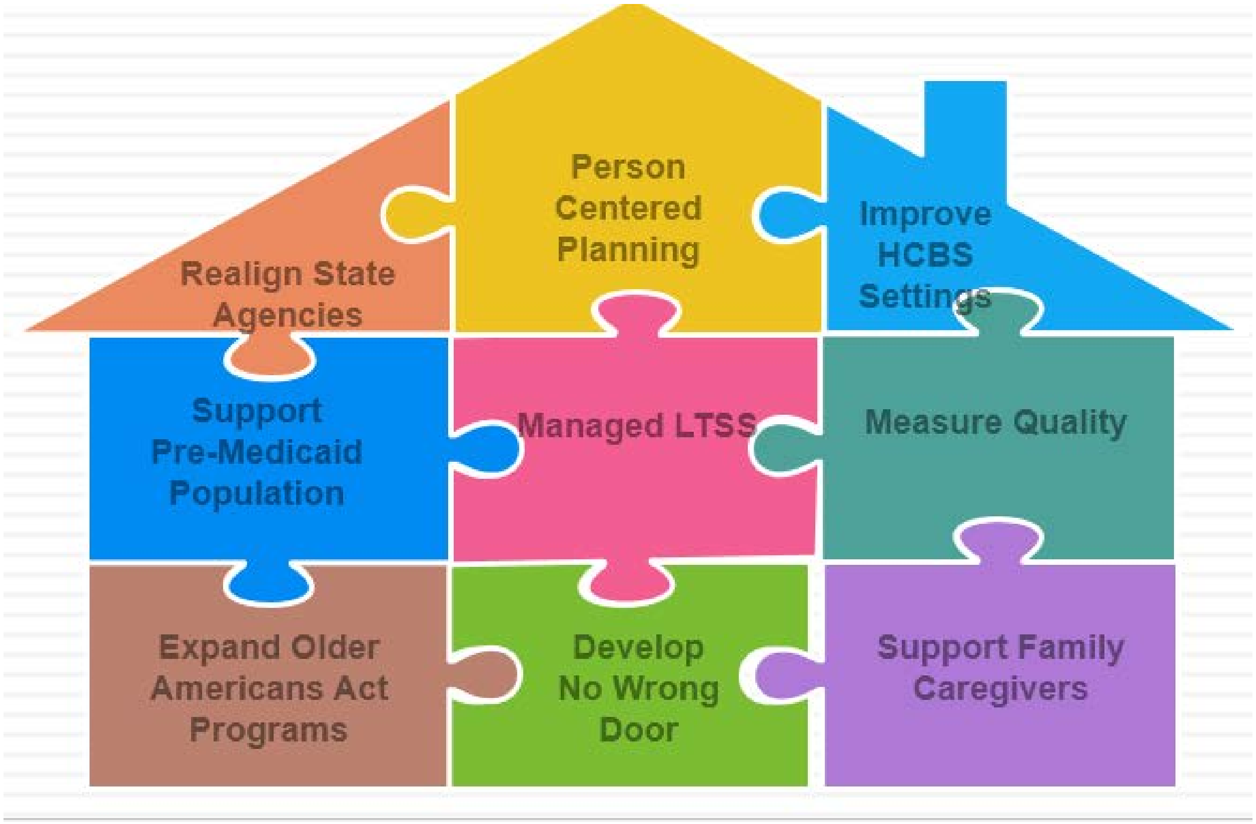
[5] KCMU analysis of 2010-2012 MEPS data.

State Strategies for Excellence in Long-Term Services and Supports



Person-Centered Planning

First, overarching the entire improvement of a state’s LTSS system is the development of a strong person-centered model of care. That person-centered model of care should be infused throughout the consumer’s experience in dealing with the state. From the initial contact throughout the course and progression of the individual’s disease, the plan developed should be in accordance with the consumer’s directed wants and desires. States that have implemented a strong person-centered planning process have often found that, through the use of guided planning and assessments, consumers will contribute personal resources and/or may choose not to avail themselves of all of the options that are available, which can save limited resources.

No Wrong Door System

Iowa has developed the beginning of a No Wrong Door system through the LifeLong Links. However, the federal grant funding that was initially available to support the program has been eliminated and to finish the development of the No Wrong Door and to expand it, the state will need additional resources. In a No Wrong Door system, if a consumer contacts any organization that is part of the No Wrong Door access network, he/she is able to be connected/referred/transferred to the person, organization, or resources needed, resulting in “no wrong door" for access to services and supports, regardless of age or disability. The No Wrong Door model also helps long distance caregivers who are seeking information to support their Iowa family members either through websites or 800 numbers. Successful No Wrong Door models have leadership support, create standards for person-centered practices, provide training for staff, help consumers maximize the use of private resources, and engage with consumers before they spend down into Medicaid.[6] A strong No Wrong Door system will be critical in the dementia solution for Iowa.

Managed Long-Term Services and Supports

The state has already migrated its system to Managed Long-Term Services and Supports (MLTSS). MLTSS is the delivery system for long-term services and supports through Medicaid managed care plans who are capitated and are at-risk for all covered benefits. States have migrated to MLTSS as a delivery model for the following reasons[7]:

1) Accountability and quality improvement rests with a single entity

- Integrating acute and long-term care makes the consumer (rather than their 'services') the focus.
- Improved quality can follow in all aspects of a consumer's life.
- Financial risk for the health plan provides opportunity to incentivize performance for health outcomes and quality of life.

2) Administrative simplification

- Eliminates the state's need to contract with and monitor hundreds/thousands of individual LTSS providers.
- State can build on managed care infrastructure to provide support to members.

3) Budget predictability

- Capitation payments greatly minimize unanticipated spending.
- Project costs can be more accurately predicted (especially with LTSS, as enrollment doesn't have as much variation based on economic circumstances).

4) Shift the focus of care to community settings

- Most consumers express preference for community-based services.
- Health plans may be able to effectuate transfers from institutions to community more easily.

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[6] For additional information: No Wrong Door: Person- and Family-Centered Practices in Long-Term Services and Supports, AARP Public Policy Institute, 2017.

[7] For additional information see: Demonstrating the Value of MLTSS; NASUAD 5-12-17.

States have also worked with their health plans on strategies to: increase the number of consumers served in HCBS settings; provide additional supports to family caregivers; and target and provide services to consumers who are at greater risk for hospitalizations, such as individuals with dementia with multiple chronic conditions.

Expand Older Americans Act Programs

At its core, the Older Americans Act (OAA) is designed to support seniors as they age in their homes and communities. The Older Americans Act provides critical services such as:

- Information and Referral
- Case management
- Homemaker
- Respite
- Senior Centers
- Meals on Wheels
- Family Caregiver Support
- Adult Day
- Evidenced-based health promotion

Because federal funding for the OAA is not sufficient to support the growing populations of seniors, many states have supplemented the OAA funding with state funding in order to support the programs in highest demand. For example, to support dementia programs, states have increased funding targeting dementia Adult Day programs, respite for family caregivers, training for family caregivers, and Meals on Wheels.

Improve HCBS Settings

In 2014, the Centers for Medicare and Medicaid Services (CMS) released a final rule defining for the first time what home and community-based settings should look like. This final regulation requires states to examine all of the locations in which HCBS services are being provided to ensure that they are offering services and supports in the least restrictive and most integrated setting possible. In the course of examining all of the settings in state systems, states have also sought to improve the overall settings. Two settings frequently used to assist individuals with dementia are Adult Day and Assisted Living. In many states, including Iowa, Adult Day and Assisted Living settings are coming into conflict with the CMS final regulation, mainly due to the requirement that the services be provided in settings that are not institutional in nature. Additional concerns relate to the lack of the services' community integration. States continue to look for services to support individuals with dementia in the least restrictive and most appropriate setting possible. As public policy evolves in this area, states will continue needing to seek settings that will meet the HCBS settings requirements.

Support Pre-Medicaid Population

Several states have recently developed long-term services and supports programs designed to allow seniors to reside in their homes who are at risk of becoming eligible for the full array of Medicaid services. The states that are operating these programs are doing so under demonstration authority under the Medicaid program. There are two ways that the states are structuring the programs:

- In Minnesota, the program supports older adults who meet two conditions: the senior must require nursing home level of care but prefer to receive care at home; and the senior must have assets above the limit requirements for Medicaid eligibility. In this case, Minnesota offers participants a limited Medicaid package of services designed to allow the participants to age in place. Those services can include: adult day services, case management, chore services, companion services, home health, homemaker, meal delivery, non-medical transportation, etc. Notably, Minnesota seniors are required to pay for a portion of the services they receive. By preventing and delaying transitions to a nursing facility, seniors do not deplete all of their assets, and the state benefits because it is not required to pay the higher cost of Medicaid nursing home placement. In Minnesota's fiscal year 2015, the average monthly cost per enrollee in their state's pre-Medicaid program was only $849, while the cost of a fully-eligible senior in a skilled nursing facility during the same period was $5,550.[8]
- In Arizona, Delaware, Hawaii, Tennessee, Vermont, and Rhode Island, Medicaid consumers who do not meet the institutional level of care requirement are eligible to receive home and community-based services, in hopes that they do not ever need to require additional nursing facility care.[9]

Support Family Caregivers

The economic value of family caregivers nationwide is estimated to be as enormous as the world's largest company—bigger than Medicaid and out-of-pocket spending on health care. As the growth of individuals needing long-term services and supports continues to grow, the role of the informal caregiver has grown exponentially, tasked with providing more instrumental activities of daily living to the loved one. These tasks initially might include performing household chores, providing transportation, etc. However, as the health of the individual with dementia continues to decline, the caregiver may be tasked with assisting in more personal activities of daily living, such as bathing, dressing, grooming, and feeding. The caregiver will also need to manage

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[8] https://mn.gov/dhs/people-we-serve/seniors/services/home-community/programs-and-services/alternative-care.jsp

[9] https://www.kff.org/report-section/medicaid-section-1115-managed-long-term-services-and-supports-waivers-appendices/

behavioral symptoms of dementia, such as potential aggression, wandering, and agitation. Additionally, the caregiver will have to provide all of the administrative support for the individual, such as managing finances, hiring and firing others who provide support, and making long-term decisions for the individual. Nationwide, 60 percent of caregivers are employed full-time, while also providing on average 35 hours of care per week.

The picture of the Iowa caregiver largely reflects the national trend in family caregiving. More than half of Iowa's 135,000 caregivers providing support to people with dementia report that they have provided care for more than two years. Nearly 35 percent of Iowa's caregivers are over 65, and nearly one-third report being depressed at some point. The value of the 154,000,000 hours of care that they provided in 2016 was estimated to be $1.9 billion.

This burden on the caregiver can lead to poor physical and mental health outcomes, burnout for the caregiver, and, in the worst cases, abuse and neglect of the individual needing care. It is for all of these reasons that states and health plans have focused on how to support the caregiver. Regrettably, despite the effectiveness of evidence-based caregiver supportive services, they are still not commonplace nor readily available to the friends and families who could benefit from them. In one national study of the Older Americans Act's National Family Caregiver Support Program, over half (52 percent) of Area Agencies on Aging reported that they did not offer any evidence-based caregiver training and education interventions to family caregivers in the community. And, for nearly half (45.5 percent) of family caregivers providing substantial assistance to older adults living in the community, the caregivers' use of supportive services was low.[10] Please see appendix A for a list of some of the more common evidence-based caregiver support initiatives.

Thirty-six states have enacted AARP's Caregiver Advise Record and Enable Act (CARE Act) in support of caregivers. The CARE Act requires hospitals to: record the name of the family caregiver on the medical record of your loved one; inform the family caregivers when their loved one is to be discharged; and provide the family caregiver with education and instruction of the medical tasks he or she will need to perform for the patient at home.

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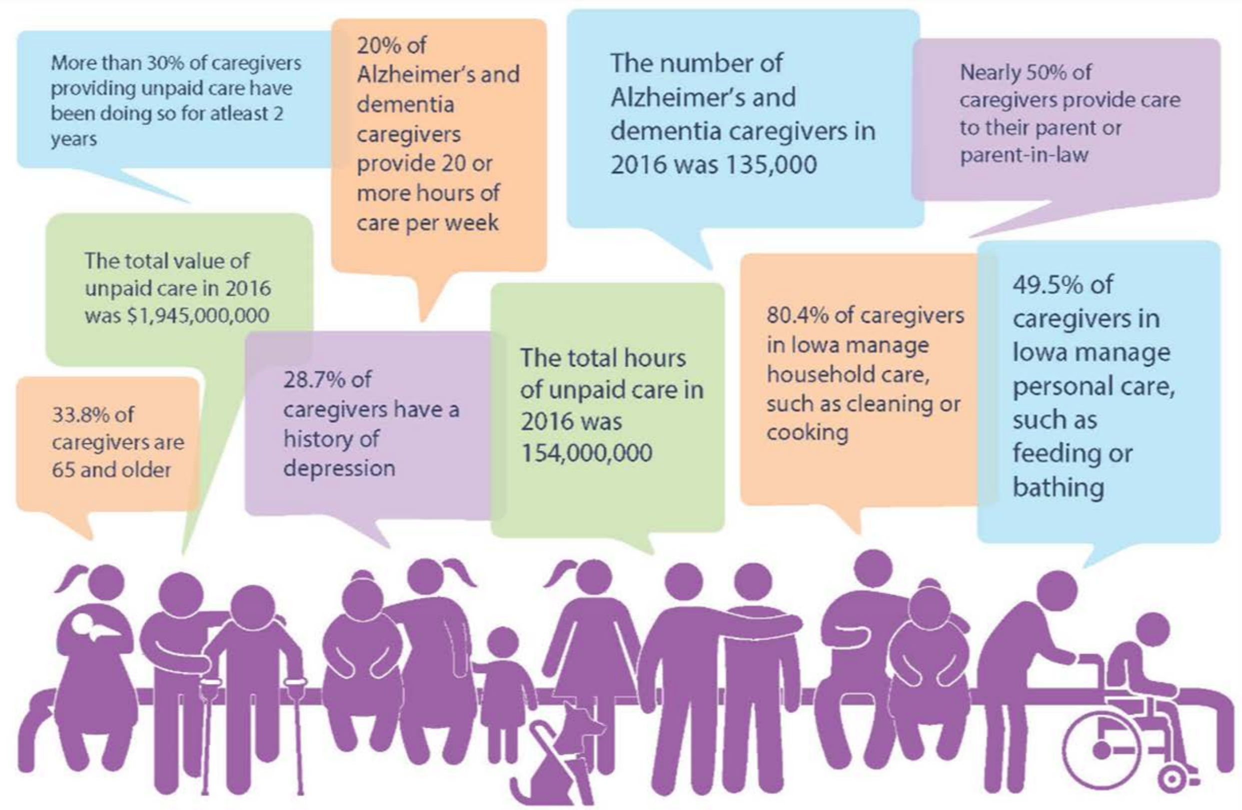
[10] *Best Practices for Caregivers Nationwide From Research to Standard Practice: Advancing Proven Programs to Support Family Caregivers of Persons Living with Dementia* (Friss Feinberg, 2017)

Profiles of Caregivers in Iowa[11]



Other states have worked on encouraging their managed care organizations to provide caregiving supports.

Although family caregiver support is not a common practice in managed LTSS, promising practices are emerging.

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[11] Alzheimer's Association, 2017a. *Alzheimer's Statistics: Iowa*. Retrieved from https://www.alz.org/greateriowa/documents/statesheet_iowa(1).pdf
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Below are examples of emerging promising practices that include state Medicaid managed LTSS programs in Tennessee and South Carolina, a large national health plan, and a dementia care project in California[12]:

- **TennCare** is a leading, progressive state Medicaid program in assessing and addressing family caregivers' needs. In 2016, TennCare added an additional requirement that the care coordinator must ensure that the identified family caregivers have the care coordinator's contact information. Family caregiver needs assessments are typically performed as part of the face-to-face assessment. Based on the identified needs of the caregiver, a plan is developed to address the health and wellbeing of each caregiver and sustain his or her ability to provide care to the member. Included as part of the plan of care is caregiver education, training, and other supportive services that aim to assist the caregiver to provide care for the member.

- **South Carolina Healthy Connections Prime** modeled its family caregiver assessment and supports after TennCare, and it is also recognized for its promising practices in this area. The contract requires that caregiver status and abilities should be assessed using the state's comprehensive assessment tool and should include the caregiver's capacity, qualifications, and risks. The health plans must provide a range of health promotion and wellness informational activities, including caregiver supports, for enrollees' family members or friends. South Carolina is a standout in its quality measurement of family caregiver supports. The state requires health plans to track the percentage of enrollees receiving home- and community based services who experience an increase or decrease in the authorization of respite hours (each reported separately). In addition, each health plan is required to have a caregiver quality improvement project.

- **UnitedHealthcare's Solutions for Caregivers** is a promising program that is offered to some of its Medicare members and its larger employers. UnitedHealthcare also offers family caregiver supports to meet the needs of some of its Medicaid populations.

    - **Solutions for Caregivers for UnitedHealthcare Medicare Advantage Plans**- Under these plans, Medicare members have toll-free telephone access to geriatric experts and coaching on family issues and the stress of caregiving. These experts can help identify services—such as meal delivery, transportation, and housekeeping—to fit a family's caregiving needs.

    - **Solutions for Caregivers for Large Employers**- In January 2016, UnitedHealthcare launched the Solutions for Caregivers Portal for large employers with self-funded health plans at no additional charge for employees to use the online services.60. It features in-person, phone, and online resources to help caregivers save money and provide help to the people for whom they are caring.

    - **Caregiver Support in Medicaid Programs**- Given differences in programs and benefit design, UnitedHealthcare offers caregiver supports that align with the needs of the Medicaid population it serves. As part of a managed LTSS comprehensive assessment process, care coordinators work with the individual and his or her support network to assess the existing support system. Through this process, UnitedHealthcare identifies caregivers who may benefit from additional support and refers them to its Caring for Caregivers program.

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[12] *Family Caregivers & Managed Long-Term Services and Supports* (Reinhard, Fox-Grage, and Friss Feinberg, 2016)

- **The Cal MediConnect Dementia Project** is a promising practice that provides critical assessment, services, and supports to the family caregivers of people with dementia who are participating in the state's Medicare-Medicaid duals demonstration. Cal MediConnect provides coordinated medical, behavioral health, long-term institutional, and home- and community-based services through managed care organizations to dually eligible beneficiaries in seven counties of the state.

Measuring Quality

Until recently, states did not have a formal way to measure quality in long-term services and supports. States measured *units of services* and not the *quality* of services that individuals received. However, over the past five years, two additional tools have become available for states to use to measure HCBS quality. The two surveys are: the Experience of Care Survey and the National Core Indicators – Aging and Disabilities and NCI tool:

- Experience of Care (EoC) Survey: The EoC survey elicits feedback on beneficiaries' experience with the services they receive in Medicaid CB-LTSS programs. The states participating in the TEFT project include: Arizona, Colorado, Connecticut, Georgia, Kentucky, Louisiana, Maryland, Minnesota, and New Hampshire.[13]

- National Core Indicators – Aging and Disabilities (NCI-AD)™: NCI and NCI-AD™ is a voluntary effort by State Medicaid, aging, and disability agencies to measure and track their own performance. For over 20 years, the NCI survey has been administered to individuals with intellectual and developmental disabilities (ID/DD). A companion survey was developed three years ago for individuals with disabilities and seniors called the NCI-AD. The NCI-AD tool can be used by states on recipients of OAA services and Medicaid services regardless of setting. The core indicators are standard measures used across states to assess the outcomes of service provided to individuals and families.[14] Iowa is one of four states that include Montana, North Dakota, and West Virginia that do not participate in any of the available national tools to measure quality in home and community based services.

States are utilizing the quality data to see where their programs may be falling short. For example, in one state they anticipated that participants would have more difficulty finding providers in rural settings versus large urban areas. When the results came in however, state officials were surprised that individuals in the urban areas actually reported significantly more difficulty finding providers than their peers in rural areas. The state is now setting the target of finding additional providers in urban settings.

Another state found that individuals who reported concerns about fears of falling also reported they received virtually no follow-up, even after those individuals actually fell and were in the hospital. The state is now working on strategies to do better outreach to consumers who are at high fall risk.

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[13] See www.medicaid.gov

[14] See www.nationalcoreindicators.org and www.nci-ad.org

Several states with robust MLTSS systems also did the survey in a way that will allow them to compare health plans so that consumers and policymakers can review the data to see which plans outperform their peers. In the future, states could also use the results to incentivize or penalize plans whose scores fall outside the norm of other plans.

Realign State Agencies

In the past decade, states have sought to realign agencies that provide long-term services and supports. At both the federal and state level, agencies have focused on integrated services and eliminating administrative barriers for program participants. Nationally, this focus on integration has been strongly influenced by the development of the Aging and Disability Resource Centers (ADRCs) and the program's evolution into the No Wrong Door system. Similarly, the establishment of MLTSS programs in many states has led to health plans being responsible for coordinating and delivering the services and supports for multiple populations, instead of through population-specific waivers. This trend began with the consolidation of aging and physical disability services. The Department of Health and Human Services then created the Administration for Community Living in 2012, which led to the consolidation of aging and disability policy and programming at the federal level, in addition to within many states.

In NASUAD's 2017 *State of the State's* survey, states continued to report on the reorganization efforts of their administrative structures, with expanded populations included in the consolidated agencies. The most notable change was the incorporation of services for ID/DD into the same agency as the agency on aging. More than half of the states now have agencies that serve all populations needing long-term services and supports. Most states have a wide range of policy and oversight responsibilities in LTSS.[15]

One benefit of consolidating agencies is that state Medicaid staff learn to appreciate the lower cost option of serving individuals through the Older Americans Act programs. Often times, providing long-term services and supports under OAA programs allows consumers to be served longer and with great success in their homes and communities, without needing to spend down their resources to become eligible for the Medicaid program. States can also learn to braid and blend federal programs together to offer a more robust long-term services system.

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[15] *State of the States in Aging and Disability 2017 Survey of State Agencies*, Terzaghi, Damon and Mosey, Adam, NASUAD.

Having a consolidated agency is also easier for consumers to understand because they will only be dealing with a single agency to meet all their long-term services and supports needs. Several states have also managed to develop an assessment tool that can be used for all clients, whether eligible for Medicaid or OAA services. This cuts down on the burden of multiple applications for consumers and caregivers, which could be very beneficial for consumers navigating through dementia.

POTENTIAL IOWA SOLUTIONS

During the daylong summit, participants were asked to discuss the four areas of concern identified by legislators, including:

1. Identify the options for coordination between state agencies and private entities to promote increased access to dementia-specific care in both residential and home and community-based settings.
2. What are the barriers to, gaps in, and opportunities for increased access to LTSS including dementia-specific care?
3. What is the availability of LTSS, including dementia-specific care, services in home and community-based settings as an alternative to residential settings?
4. What changes in law are necessary to better address the LTSS needs, including dementia-specific care, of individuals and their families?

Each of the task force participants was asked to provide a list of solutions for each of the four areas and then the entire group voted on the top issues for each area. The results of the discussion on solutions follows:

1. **Identify the options for coordination between state agencies and private entities to promote increased access to dementia-specific care in both residential and home and community-based settings.**

   The solutions provided include:

   -Developing a comprehensive effective reimbursement mechanism for Assisted Living Programs and for Adult Day programs. (20 votes)

   -Develop long-term services and supports financing options beyond Medicaid by potentially partnering with private, long-term care insurance plans. Potentially consider a state-sponsored catastrophic plan. Provide incentives for additional private funding. (19 votes)

   -Increase the use of telehealth not as a replacement for traditional medical support but in addition to traditional medical support. Increase the use of technology overall in the delivery of care. (13 votes)

-Develop a plan to grow and sustain the direct care workforce. Specifically, work with vendors to speed the background check process, develop training (both online and clinical) curriculum to encourage more workers to go into direct care as a profession. (12 votes)

2. **What are the barriers to, gaps in and opportunities for increased access to LTSS including dementia-specific care?**

The solutions provided include:

-Build capacity of Adult Day with a payment reimbursement model to support. (19 votes)

-People enter LTSS in crisis. Need public education and a better system of No Wrong Door/Aging and Disability Resource Centers to respond. Look to rural communities for solutions and best practices. Tap into older Iowans/caregivers for information; inform healthcare providers. (16 votes)

-Re-evaluate regulation and funding to allow increased flexibility in service provision; improve provider services with focus on existing providers through regulation changes and pilot programs; employ/re-evaluate regulation interpretation and consistent application; allow flexibility. (14 votes)

-Center of Excellence: Workforce innovation; education & interdisciplinary; research; innovations into practice; dementia research center; research-actionable solutions such as walkability. (12 votes)

3. **What is the availability of LTSS including dementia-specific care services in home and community-based settings as an alternative to residential settings?**

The solutions provided include:

-Chronic Confusion or Dementing Illness (CCDI) units are decreasing and memory care units in Assisted Living programs are growing. Need a place for those who need more care and have no place to go. (13 votes)

-Caregiver support groups/AAAs/'Alzheimer's Association/Powerful Tools. (11 votes)

-Look at creative ways to bring new practices into Iowa. (11 votes)

-Adult Day-lack of funding and lack of referrals. (9 votes)

-Elder Group Homes/critical review/Iowa models never went anywhere/what do other states successful elder group home models look like? (9 votes)

4. **What changes in law are necessary to better address the LTSS needs, including dementia-specific care, of individuals and their families?**

The solutions provided include:

-Work with Future Ready IA program to encourage more individuals to go into the Direct Care Workforce. Create grants or scholarships for individuals willing to work with individuals with dementia. Provide training for staff working in assisted living and nursing homes on how to deal with challenging behaviors associated with dementia. (12 votes)
-Review the state regulations and laws to update the definition of Assisted Living. Create a new category for housing with services. (10 votes)
-Restructure/realign state agencies so that there is one agency with responsibility over the LTSS population which would eliminate redundancies between departments. (10 votes)
-Pass the CARE Act, requiring hospitals to: Record the name of the family caregiver on the medical record of your loved one. Inform the family caregivers when their loved one is to be discharged. Provide the family caregiver with education and instruction of the medical tasks he or she will need to perform for the patient at home. (8 votes)

CONCLUSION

Iowa will continue to have significant growth in the number of individuals with Alzheimer's and related dementia. Improving the delivery of services and supports for this hard-to-serve population could benefit and improve the overall LTSS system in Iowa. After combining national promising strategies with the Iowa Dementia Task Force's recommendations, six key themes emerge:

1. **Redesign program options** to include appropriate reimbursement mechanisms for Adult Day programs (health and social), Assisted Living, and housing with services. In certain instances, this will require changing the statute or regulation.
2. **Develop a workforce strategy.** To support the direct care workforce, this strategy should include improving the application process for direct care workers that streamlines the background check process and provides for adequate training and career development to encourage direct care workers to stay engaged in the field. The state should consider partnering with Future Ready IA on this effort. The state should also consider expanding the use of telehealth to ensure an adequate number of specialty providers.
3. **Build upon the existing ADRC system to develop a robust No Wrong Door.** The No Wrong Door system will allow for consumers and caregivers to have access to support and assistance regardless of what entry point they use. The state will need to find additional resources to support this system and can look to other states for possible funding mechanisms.

4. **Import promising practices.** The state should continue to utilize the state universities and partnerships with national associations such as NASUAD to improve practices and policies, by utilizing ideas from other states.
5. **Support family caregivers.** The state should consider passing AARP’s CARE Act and other legislation to support family caregivers. Additionally, the state should support efforts to provide other evidence-based programs to support the family caregivers.
6. **Realign the state agency.** In order to improve services overall for LTSS consumers, the state should realign the state agencies so that there is one agency responsible for LTSS regardless of funding stream.

APPENDIX A: EXAMPLES OF EVIDENCE BASED CAREGIVING SUPPORT PROGRAMS

- **Benjamin Rose Institute (BRI) Care Consultation**—A telephone-based program using comprehensive assessments of both the person living with dementia and family caregiver to identify needed services and supports; then through personalized coaching, the program works to find solutions to address identified problems and unmet needs.
- **Care of Persons with Dementia and Their Environments (COPE)**—A home-based program designed to support the person living with dementia's abilities by reducing environmental stressors in the home, and improving the family caregiver's skills as well as problem-solving and coping strategies.
- **New York University Caregiver Intervention (NYUCI)**—A program for dementia caregivers offering individual and family counseling, support groups, and phone consultation to manage stress and improve problem-solving, manage problem behaviors of the person living with dementia, and promote communication and support among family members.
- **Resources for Enhancing Alzheimer's Caregiver Health (REACH II)**—An in-home and telephone based program for dementia caregivers using a structured assessment to identify problems and help the family caregiver understand and learn ways to manage unmet needs through education, support, and skills training. Such services are aimed to improve caregiver health, social support, depression, and handling of problem behaviors.
- **Savvy Caregiver**—An education and skills training program for dementia caregivers to improve caregiver knowledge, confidence and skills in managing caregiving tasks, and carrying out the caregiving role effectively.
- **Home-Based Counseling with Family Caregivers (STAR- C)**—A home-based counseling program for dementia caregivers using skills training to identify, reduce, and manage behavioral symptoms of the person living with dementia, improve family caregiver communication with the person with dementia, and improve quality of life for the individual and the family caregiver.

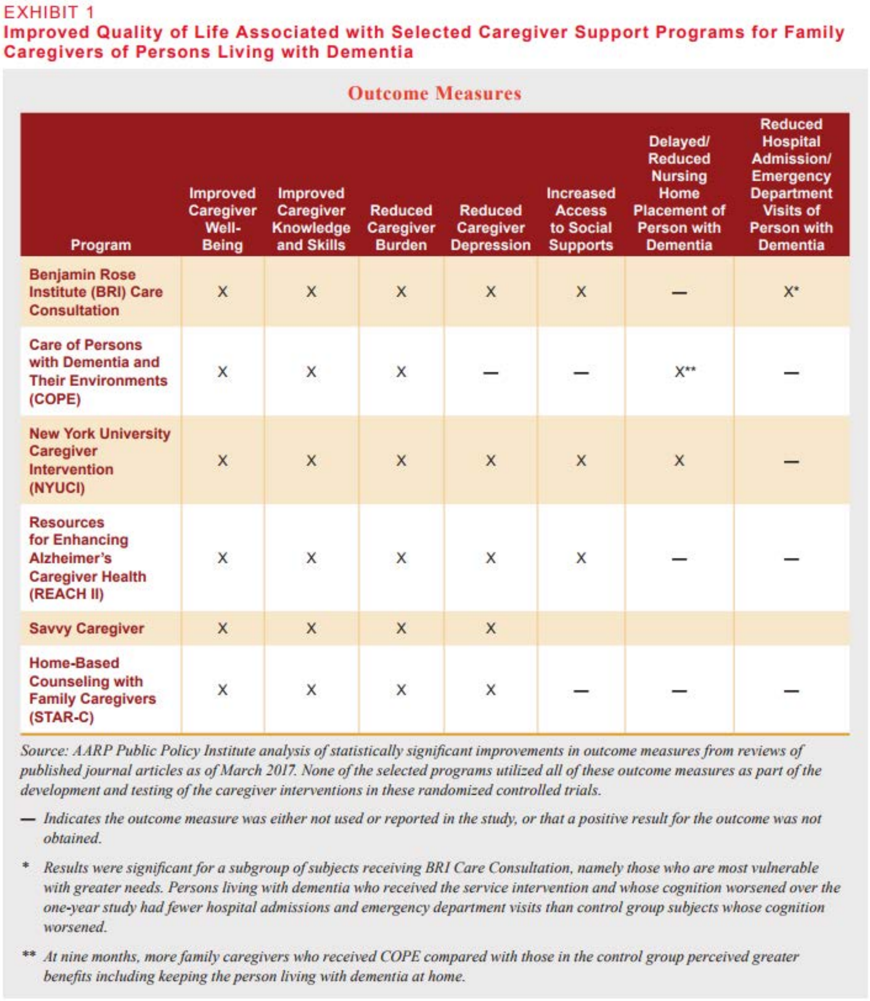

EXHIBIT 1

Improved Quality of Life Associated with Selected Caregiver Support Programs for Family Caregivers of Persons Living with Dementia

Outcome Measures

Program	Improved Caregiver Well-Being	Improved Caregiver Knowledge and Skills	Reduced Caregiver Burden	Reduced Caregiver Depression	Increased Access to Social Supports	Delayed/ Reduced Nursing Home Placement of Person with Dementia	Reduced Hospital Admission/ Emergency Department Visits of Person with Dementia
Benjamin Rose Institute (BRI) Care Consultation	X	X	X	X	X	—	X*
Care of Persons with Dementia and Their Environments (COPE)	X	X	X	—	—	X**	—
New York University Caregiver Intervention (NYUCI)	X	X	X	X	X	X	—
Resources for Enhancing Alzheimer's Caregiver Health (REACH II)	X	X	X	X	X	—	—
Savvy Caregiver	X	X	X	X			
Home-Based Counseling with Family Caregivers (STAR-C)	X	X	X	X	—	—	—

Source: AARP Public Policy Institute analysis of statistically significant improvements in outcome measures from reviews of published journal articles as of March 2017. None of the selected programs utilized all of these outcome measures as part of the development and testing of the caregiver interventions in these randomized controlled trials.

— *Indicates the outcome measure was either not used or reported in the study, or that a positive result for the outcome was not obtained.*

* *Results were significant for a subgroup of subjects receiving BRI Care Consultation, namely those who are most vulnerable with greater needs. Persons living with dementia who received the service intervention and whose cognition worsened over the one-year study had fewer hospital admissions and emergency department visits than control group subjects whose cognition worsened.*

** *At nine months, more family caregivers who received COPE compared with those in the control group perceived greater benefits including keeping the person living with dementia at home.*

- **Caregiver Education and Support Programs: Best Practice Models (Toseland, Ronald, 2004)**
  Five widely used caregiver education and support programs that have empirical evidence to support their effectiveness. The caregiver educational and support programs described below were selected after a careful review of the literature and discussion with experts in the field. The programs that were selected have been widely used, have at least some research evidence for their effectiveness, are available for distribution from a source that is likely to remain available for the foreseeable future, and contain well developed ready to use training materials.
- **American Red Cross Family Caregiving Program:** The Red Cross Family Caregiving Program is an interactive modular program targeted to caregivers who care for a relative or friend at home. Leaders who have attended a group orientation or completed a self-study facilitate the program's nine modules. Family Caregiving offers nine modules that help participants provide better care and gain an

understanding of safety, nutrition, and general care, legal and financial issues. In addition, a scripted leader curriculum is provided to facilitate the module presentations.

- **Caregiver Health Education Program:** The program is designed to help professionals lead education and support groups for caregivers of frail older persons with chronic disabilities. A version of the program has also been developed specifically for caregivers of persons with dementia. There is also a version of the program designed to be delivered by teleconference. This latter program is particularly useful for reaching out to rural caregivers and those who do not, or cannot, attend face-to-face groups.
- **Caring for You, Caring for Me: Education and Support for Family & Professional Caregivers, Second Edition:** The 10-hour program, conducted in five two hour modules, addresses the needs of family and professional caregivers by bringing them together in a relaxed setting to discuss common issues, share ideas, and gain a better understanding of each other's perspective on what it means to be a caregiver.
- **Coping with Caregiving:** This is a train-the-trainer education program that focuses exclusively on self-care for dementia family caregivers. Improving the self-care and self-efficacy of caregivers are primary goals. Coping with Caregiving focuses on the self-care needs of caregivers, not the care receivers. Classes emphasize the importance of taking care of one's own physical and mental health in order to better care for others. Practical skills for effective coping, stress reduction, improving self-confidence and communicating effectively are taught and reinforced in a group setting under the direction of Class Leaders.
- **Powerful Tools for Caregivers:** This is a train-the-trainer education program that focuses exclusively on self-care of family caregivers. Improving the self-care and self-efficacy of caregivers are primary goals. Powerful Tools for Caregivers focuses on the self-care needs of caregivers, not the care receivers. Classes emphasize the importance of taking care of one's own physical and mental health in order to better care for others. Practical skills for effective coping, stress reduction, improving self-confidence and communicating effectively are taught and reinforced in a group setting under the direction of class leaders.

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