

Alzheimer's & Related Dementia

TENNESSEE STATE PLAN

TN Alzheimer's and Related Dementia Advisory Council

January 15, 2020

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Executive Summary

This past April, the Tennessee General Assembly unanimously passed legislation creating the Alzheimer’s disease and related Dementia Advisory Council (Chapter 364 of the Public Acts of 2019). The Governor signed the bill on May 10, 2019 (see Appendix A).

This Act establishes the Advisory Council, administratively attach it to the Tennessee Commission on Aging and Disability (TCAD), and sets out the purpose of the council:

- 1) Continually assess the current status of Alzheimer’s disease and related dementia in this state and to assess the current and future impact of Alzheimer’s disease and dementia on Tennessee residents;
- 2) Examine the existing industries, services, and resources addressing the needs of persons, families, and caregivers affected by Alzheimer’s disease and related dementia;
- 3) Develop a strategy to mobilize a state response to matters regarding Alzheimer’s disease and related dementia; and
- 4) Provide recommendations to the governor and to the general assembly on issues related to its work.

Each year more than 3,500 Tennesseans die from Alzheimer’s Disease (12). Today, there are approximately 120,000 Tennesseans with Alzheimer’s Disease being cared for by 439,000 informal caregivers. Each year, these caregivers provide approximately 500 million hours of unpaid care in Tennessee at a value of \$6.324 billion.

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Through focus groups and a statewide online needs assessment, services and resources were often mentioned as a need within our state. These needs included awareness, availability, and affordability of these services and resources for Tennesseans living with dementia and their caregivers. Other findings included a need for workforce education and increased public awareness of the disease.

The Advisory Council was tasked to develop a strategy to mobilize a state response to matters regarding Alzheimer’s disease and related dementia. Through reviewing other states’ plans on Alzheimer’s Disease and related dementias, listening to testimony presented at the Advisory Council meetings, and analyzing data gathered during the needs assessment, the Advisory Council agreed upon four overarching goals for this strategy.

- Goal 1: Educate and Empower Tennessee to be “Dementia-Aware”
- Goal 2: Support and Empower Persons with Dementia and their Caregivers
- Goal 3: Ensure an adequately prepared workforce
- Goal 4: Research

The Advisory Council is committed to ongoing collaboration to include updating this state plan annually or as needed. As an ongoing entity, the Council looks forward to continuing this important work and providing recommendations to the Governor and the General Assembly on issues related to Alzheimer’s and related dementias in the State of Tennessee.

Introduction

This past April, the Tennessee General Assembly unanimously passed legislation creating the Alzheimer’s disease and related Dementia Advisory Council (Chapter 364 of the Public Acts of 2019). The Governor signed the bill on May 10, 2019 (see Appendix A).

This Act establishes the Advisory Council, administratively attach it to the Tennessee Commission on Aging and Disability (TCAD), and sets out the purpose of the council it to:

- 1) Continually assess the current status of Alzheimer’s disease and related dementia in this state and to assess the current and future impact of Alzheimer’s disease and dementia on Tennessee residents;
- 2) Examine the existing industries, services, and resources addressing the needs of persons, families, and caregivers affected by Alzheimer’s disease and related dementia;
- 3) Develop a strategy to mobilize a state response to matters regarding Alzheimer’s disease and related dementia; and
- 4) Provide recommendations to the governor and to the general assembly on issues related to its work.

The Act requires the council to develop and submit an Alzheimer's Disease State Plan to the general assembly by January 15, 2020 and update the plan and report to the general assembly on its progress no later than January 15 of each subsequent year. This report to the general assembly is to identify barriers to Alzheimer's disease care, analyze service utilization data, and include recommendations, metrics, and best practices to address gaps in service. This report serves as the initial state plan which can be updated annually or as needed.

To date, the Council has met four times. The early meetings focused on the first charge in the law, which was to “assess the current status of Alzheimer’s disease and related dementia in this state and to assess the current and future impact of Alzheimer’s disease and dementia on Tennessee residents.” The third and fourth meetings focused on the third and fourth charge of the law, “to develop a strategy to mobilize a state response” and to “provide recommendations to the governor and to the general assembly on issues related to its work.” Agendas from each of the meetings can be found in Appendix B. Detailed minutes available upon request.

The Advisory Council is committed to ongoing collaboration to include updating this state plan annually or as needed. As an ongoing entity, the Council looks forward to continuing this important work and providing recommendations to the Governor and the General Assembly on issues related to Alzheimer’s and related dementias in the State of Tennessee

Pursuant to statute, certain departments and entities were to be represented on the Council. The following individuals make up the Council:

Senator Rusty Crowe

Representative Sabi Kumar

Jim Shulman, Tennessee Commission on Aging and Disability

Patti Killingsworth, TennCare

Dennis Temple, Department of Mental Health & Substance Abuse Services

Sally Pitt, Tennessee Department of Health

Kirk Mason, CEO, Stones River Manor

Dr. Howard Kirshner, Vanderbilt University Medical Center

Janice Wade Whitehead, Alzheimer's Tennessee

Jesse Samples, Tennessee Health Care Association

Connie McCarter, Tennessee Nurses Association

Reverend Richard Brown, Payne Avenue Missionary Baptist Church

Chris Simmons, Alzheimer's Association TN Chapter Board of Directors

Van Cluck, LeadingAge TN Board of Directors

Barbara Bowden, family caregiver representative

Dr. David Compton, person living with Alzheimer's

Background

Alzheimer's and Related Dementias

Dementia is a specific type of degenerative brain disease that is irreversible and gets worse over time. There are various types of dementia; however, Alzheimer's Disease is the most common type of dementia, accounting for approximately 60 to 80 percent of all dementias (1 p. 9).. Other dementing illnesses include Parkinson's disease with dementia, Lewy body disease, Frontotemporal dementia, vascular dementia, and a few other, rarer disorders. In older people, vascular disease is often mixed with Alzheimer's disease pathology, and it seems to lower the threshold for dementia to develop. Dementia results in the loss of cognitive functioning such as thinking, reasoning, and remembering. These symptoms of dementia begin when neurons or cells within the brain have been damaged or stop working. However, brain changes begin long before symptoms and may begin up to 20 years prior to symptoms (2; 3; 4; 5).

Although dementia is more common with age, it is not a normal part of aging. Scientists do not currently know exactly what causes a person to develop Alzheimer's disease and related dementia (ADRD) or how to prevent it. However, literature suggests that certain risk factors increase an individual's risk of developing the disease. For instance some demographic groups such as older black / African Americans and Hispanics are more likely to develop dementia compared to their non-minority counterparts. (1) In addition, people with specific types of intellectual and developmental disabilities (IDD) such as Down Syndrome have a higher risk for Alzheimer's Disease and related dementia (7). Overall, the greatest known risk factor for developing ADRD is age; however, other factors may also increase one's risk of developing dementia. Some of these risk factors such as family history, or genetics are unable to be changed. However, other risk factors such as head injury obesity, specific cardiovascular diseases (mid-life hypertension, prehypertension, high cholesterol), and diet may be risk factors which are modifiable or able to be changed.

Though research is still evolving, evidence is strong that people can reduce their risk of future dementias by making key lifestyle changes including regular physical exercise, eating a heart-healthy diet, maintaining strong social connections, and keeping mentally active. Finally, there appears to be a strong link between future risk of Alzheimer's and serious head trauma, especially when injury involves loss of consciousness. Therefore, reducing the risk of head injury may also be a strategy to reduce the risk of future dementias.

ADRD is diagnosed by medical professionals; however, this is not done using a single test. Instead healthcare providers complete a medical assessment including medical history, physical exam, neurological exams, and other diagnostic tools (6).

There is currently no cure for ADRD and no proven way to stop the progression of the disease. However, there are both pharmacological and non-pharmacological treatments to help with symptoms associated with the disease. There are also services available to support family members and caregivers of persons with dementia. For the benefits to be realized, persons with dementia and their caregivers must be aware of these services and how to access them.

Alzheimer's and related dementias in the United States

Today, an estimated 5.6 million Americans aged 65 and older are living with Alzheimer's disease. This number is expected to grow to as many as 14 million Americans by 2050 (1). These individuals are being cared for by more than 16 million informal caregivers. These caregivers provide approximately 18.5 billion hours of care each year, valued at nearly \$234 billion nationally. ADRD is a leading cause of

disability and the 6th leading cause of death (1; 7). Although the impact of this disease is vast, less than half (47 percent) of older adults have ever discussed their thinking or memory abilities with a health care provider. Only 28 percent report ever having received an assessment for cognitive health. And even fewer—16 percent—receive regular cognitive assessments during routine health checkups (1). While almost all older adults (93 percent) say they trust their doctor to recommend testing if needed, less than half of primary care physicians say it is their standard protocol to assess older adults for cognitive impairment. Instead, many physicians wait for patients or their family members to bring the topic up first (1). This issue is further complicated by the well-documented shortage of healthcare professionals specializing in geriatrics and other Alzheimer’s related specialties.

Healthcare costs of both individuals living with dementia and their caregivers are significantly higher than their counterparts without dementia (1; 8; 9; 10; 11). In 2019, nationally the cost of caring for those with Alzheimer’s and other dementias will total an estimated \$290 billion. The annual out-of-pocket spending incurred by dementia caregivers—including household and personal care expenses—is nearly twice as high as that incurred by caregivers of people with other conditions (1).

Alzheimer’s and Related Dementias in Tennessee

Across the US, Tennessee has the 2nd highest age-adjusted mortality rate from dementia (12). Each year more than 3,500 Tennesseans die from Alzheimer’s Disease (12). In Tennessee today, there are approximately 120,000 individuals with Alzheimer’s Disease being cared for by 439,000

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informal caregivers. These caregivers provide approximately 500 million hours of unpaid care per year in Tennessee at a value of \$6.324 billion (1). Many adults in Tennessee report worsening or more frequent confusion or memory loss. This is often one of the earliest noticeable symptoms related to ADRD. In Tennessee, 14% of adults ages 45 and over have experienced these symptoms, yet, less than half of these individuals have talked about these symptoms with a health care provider (13). In addition, healthcare for persons living with dementia is costly to Tennessee’s healthcare system through increased healthcare expenditures as well as out-of-pocket healthcare costs (14; 8). In addition, caregivers often have negative health consequences related to their caregiving roles, therefore, caregivers also have higher health care costs. These health care costs are valued at \$291 million in the state of Tennessee (1 p. 37). These health-related costs have increased over the past 5 years and are projected to continue rising for at least the next 5 years as this population continues to grow (1; 15).

Needs Assessment

For the Alzheimer’s and Related Dementia Advisory Council to gain an understanding of the strengths, challenges, and needs of persons living with dementia, their families, and other stakeholders, an initial needs assessment was conducted and used in the development of the Council’s initial Alzheimer’s and Related Dementia State Plan. The goal of this needs assessment was to provide policy makers, service providers, and the general population with appropriate data about trends and implications for the current population. The Tennessee needs assessment was based upon similar needs assessments conducted in other states (16; 17). Future in-depth and representative needs assessment will be conducted, as needed, as the plan continues to evolve. Similar to recent Alzheimer’s State Plans in other states, the state needs assessment was based on a mixed-methods approach composed of three main components: (1) focus groups conducted by the Tennessee Department of Health in conjunction with the Tennessee State Health Plan; (2) an online statewide survey of older Tennesseans, advocates, persons with Alzheimer’s Disease,

caregivers, and service providers; and (3) analyses of additional data including those presented at meetings of the Tennessee Alzheimer’s and Related Dementia Advisory Council. The major findings from each component are included in this section. Copies of each survey instrument and key findings are included in the Appendices.

Focus Group

The 2019 Edition of the State Health Plan, developed by the Tennessee Department of Health (TDH), features a “deep-dive” into cognitive and brain health across the lifespan in Tennessee. This deep-dive was an opportunity for the Tennessee Department of Health to develop a strategic approach to address health across the lifespan by increasing awareness of how lifestyle behaviors in early and mid-life impact brain health throughout the aging process. These lifestyle behaviors include tobacco use, physical activity, substance misuse and abuse, diet, and traumatic brain injury. The Department hosted focus groups across the state with subject matter experts to develop a series of recommendations that will be implemented by TDH, in partnership with numerous public and private stakeholders, in the coming years.

TDH’s Offices of Health Planning, Patient Care and Advocacy, and Minority Health and Disparities Elimination conducted a series of 10 focus groups across the state. Focus group locations were chosen according to geographical location, Alzheimer’s prevalence, and diversity of population. Industry stakeholders, academic institutions, community members, faith leaders, and caregivers, among others, attended these meetings. Each meeting was formatted to include a presentation by TDH on the State Health Plan and aging across the lifespan, followed by breakout sessions discussing specific questions designed for the targeted audiences (Appendix C). In more populous counties two meetings were held, one for industry stakeholders and one for community members, caregivers, and faith-based leaders. In smaller communities these were held as joint meetings. Meeting attendees were asked to attend the meeting that best applied to their role in their respective community. In total, 168 individuals across the state attended the focus group meeting. Table 1 displays the number of meeting attendees in each county and categorizes the type of meeting.

Figure 1. Map of Focus Group Meeting Locations

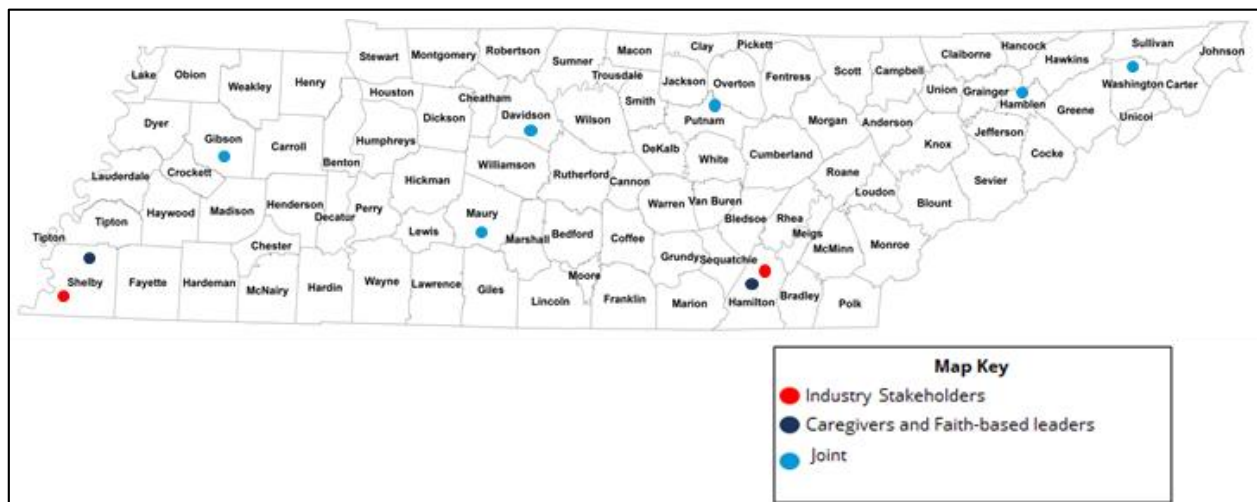


Table 1. Focus group meetings location and attendance

Meeting Location	Meeting Type	Total Attendees
Davidson County	Joint	26
Gibson County	Joint	15
Hamblen County	Joint	13
Hamilton County	Industry Stakeholders	27
Hamilton County	Caregivers and Faith Leaders	5
Mauy County	Joint	16
Putnam County	Joint	9
Shelby County	Industry Stakeholders	23
Shelby County	Caregivers and Faith-based leaders	22
Washington County	Joint	12
Total		168

Three separate sets of questions were developed: 1) advocacy groups, non-profit organizations, providers, payers, and government agencies, 2) caregivers, and 3) faith-based community members and leaders. Once the focus groups concluded, the most commonly reoccurring themes were extracted as recommended actions to be taken by TDH in collaboration with State partners. The top five recommended actions from each county are displayed in Table 2.

Table 2. Top 5 recommended actions per county

County	Five Actions
Davidson	<ol style="list-style-type: none"> 1. Dementia friendly communities 2. Cognitive screenings 3. Coordinated messaging and education for lifelong brain health 4. Statewide summit to break down silos 5. Cognitive screenings
Gibson	<ol style="list-style-type: none"> 1. Dementia friendly communities 2. Dissemination of information to faith-based communities and leaders 3. Coordinated messaging 4. Engaging and educating the workforce – caregivers, law enforcement, healthcare providers, and first responders 5. Caregiver support
Hamblen	<ol style="list-style-type: none"> 1. Education of providers and accommodation of seniors 2. Dealing with the “here and now” for patients and caregivers 3. Expanding home and community-based services 4. Support plans for caregivers 5. Engagement with those with cognitive decline
Hamilton	<ol style="list-style-type: none"> 1. PACE Model 2. Increase education and resources to communities 3. Physician awareness of the importance of screenings 4. Roadmap for preventative services 5. Referral from emergency department and first responders – provide education and navigation
Maury	<ol style="list-style-type: none"> 1. Increase provider screenings 2. Education related to prevention and symptoms 3. Decreasing stigma 4. Improved access to information and navigation resources 5. Support groups for caregivers
Putnam	<ol style="list-style-type: none"> 1. Coordinated statewide effort 2. Education and training families and communities’ faith-based communities 3. Increase preventative services and screenings 4. Healthcare provider education 5. Utilize faith-based communities for outreach and education
Shelby	<ol style="list-style-type: none"> 1. Electronic Medical Records <ol style="list-style-type: none"> a. Cognitive assessment b. Care planning and navigation resources c. Interoperability 2. Dementia Friendly Communities 3. Strategic messaging for existing programs 4. Healthy lifestyle education 5. Statewide symposium on brain health and healthy aging
Washington	<ol style="list-style-type: none"> 1. Annual statewide conference including healthcare providers, caregivers, active surveillance, and Alzheimer’s associations 2. Workforce training and development for healthcare, law enforcement, and support services 3. Coordinated statewide effort to implement action strategies 4. Education related to safety and awareness 5. Lifestyle and symptom education

Online Needs Assessment

An online statewide needs assessment survey was designed to reach a broad segment of Tennessee’s population. Specifically, it aimed to include individuals unable to attend Council or outside meetings due to caregiving or professional responsibilities. The survey was distributed using both purposive and convenience sampling. Survey respondents were recruited through Council members, Tennessee’s Aging Network, professional organizations, support groups, partners, and social media. Surveys were made available via an online link or paper copy.

Based upon suggestions from Advisory Council members, the survey instrument was based upon the Alzheimer’s Association Needs Assessment Toolkit and the South Dakota State Plan Questionnaire. The resulting Tennessee specific 17-question survey (Appendix D) included both open-ended and closed-ended questions (16; 17). Respondents were asked questions about current services, perceived needs, and recommendations for the State. A total of 936 Tennesseans completed the survey between October 18 and December 9, 2019.

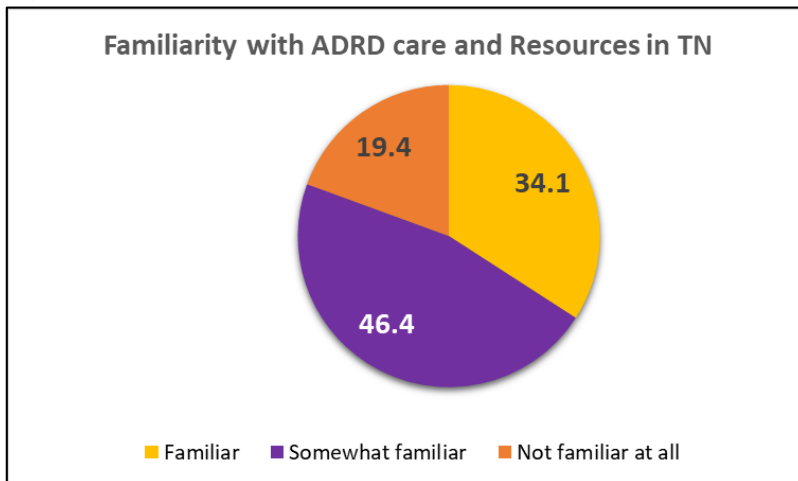
Results of Online Needs Assessment (Appendix E)

Survey respondents included 936 individuals across 81 counties representing all three grand divisions. The survey was available to Tennesseans age 18 and older. Ages ranged from 18 – 87 years with an average age of 54 years. Approximately 91% of respondents were white, and 81% were female. A total of 85% of respondents reported being “concerned” or “very concerned” about ADRD causing the death or disability of themselves or a loved one. This is likely related to the high response rate from individuals whose lives are directly impacted by ADRD as 94% had a connection to ADRD, either as a professional, friend, family member, or living with ADRD.

Occupation and employment status varied significantly across the group. However, those individuals who were working less than full time, between 25 and 29% stated that this change in employment status was influenced by having to care for someone with ADRD.

Despite most having a direct connection to ADRD, only 34% of respondents reported that they were “familiar” with care and resources available for ADRD in Tennessee. An additional 46% reported being “somewhat familiar” and still 19% reported “not being familiar at all”.

Figure 2. Familiarity with ADRD care and resources in TN



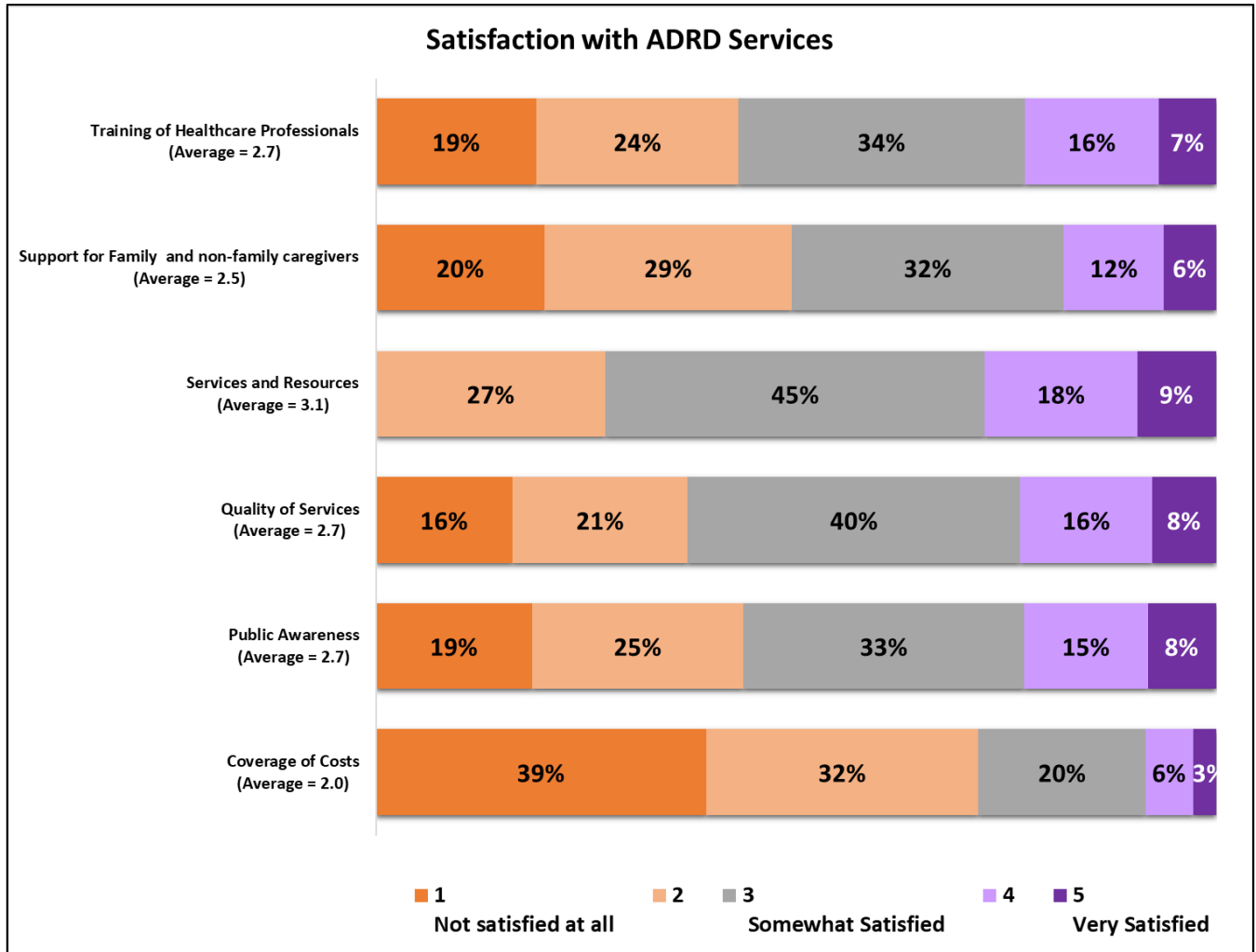
When asked “What are the three most pressing needs for persons in Tennessee impacted by Alzheimer’s disease or related dementias?” responses were distributed across all available response categories (Table 1); however, the most commonly reported needs were (1) coverage of costs for services and resources, (2) services and resources available, and (3) information about services and resources upon and beyond diagnosis.

Table 3. Three most pressing needs

“What are the three most pressing needs for persons in Tennessee impacted by Alzheimer’s disease or related dementias?”		
	#	%
Coverage of costs for services and resources	630	67.3%
Services and resources available in your area	432	46.2%
Information about services and resources upon and beyond diagnosis	421	45.0%
Community support for family and non-family caregivers	399	42.6%
Education and training of health care professionals and caregivers	355	37.9%
Quality of services and resources	348	37.2%
Public awareness of the disease	202	21.6%
Other	41	4.4%

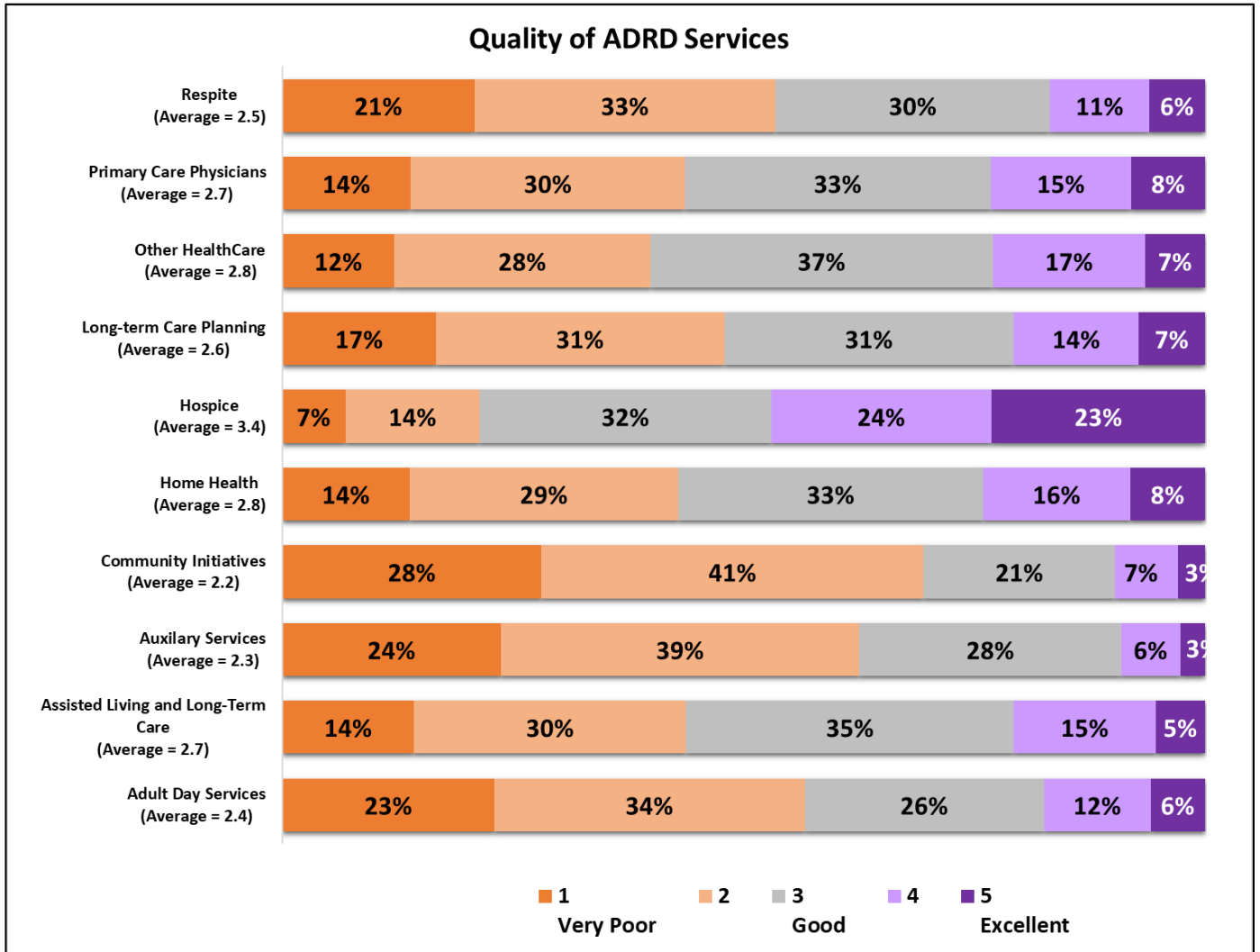
Survey participants were then asked, “On a scale of 1–5, with 5 being very satisfied, how satisfied have you been with the following aspects of Alzheimer’s disease and related dementias in Tennessee?” Average score by category ranged from 2.0 to 3.1.

Figure 2. Satisfaction with ADRD Services



Next, survey participants were asked “On a scale of 1–5, with 5 being excellent, how would you rate the quality of Alzheimer’s disease and related dementias care in Tennessee??” Average score by category ranged from 2.2 to 3.4.

Figure 4. Quality of ADRD Services



When asked where they would seek out information related to care and resources available for ADRD in TN if needed, responses varied. The most frequently reported resources were the Alzheimer’s Association (23%), the internet / google (18%), a health care provider or physician (17%), and Alzheimer’s Tennessee (11%). Significantly, 21% of all survey participants left this response blank or reported that they do not know where they would first seek out information.

Table 4. Information Resources

If you needed to seek out information related to care and resources available for Alzheimer’s disease and related dementias in Tennessee, where would you go first?		
	<u>#</u>	<u>%</u>
Alzheimer's Association	212	22.6%
Internet Search	156	16.7%
Physician	154	16.5%
Alzheimer’s Tennessee	102	10.9%
TCAD, AAAD, or Office on Aging	54	5.8%
Other	159	17.0%
No Response or Don't Know	194	20.7%

Data from open ended questions is being deidentified and processed for further analyses.

Analyses of Additional Data

Additional data analyzed included mortality rates, behavioral risk factor surveillance system (BRFSS), and Centers for Medicare and Medicaid Studies (CMS) datasets. Data showed that each year more than 3,500 Tennesseans die from Alzheimer’s Disease (12). In Tennessee, 14% of adults ages 45 and over report worsening or more frequent confusion or memory loss yet, less than half of these individuals have talked about these symptoms with a health care provider (13). In addition, healthcare for persons living with dementia is costly to Tennessee’s overall healthcare system (14).

Future analysis will be conducted to fulfill the role of this Advisory Council to “Continually assess the current status of Alzheimer’s disease and related dementia in this state and to assess the current and future impact of Alzheimer’s disease and dementia on Tennessee residents.” Potential data to be analyzed are included in Appendix F.

Summary of Key Findings

Finding 1: Alzheimer's and related dementias have a significant impact across Tennessee

Throughout advisory council meetings, a significant amount of data was presented that indicates Alzheimer's and related dementias have a significant impact across Tennessee. There are approximately 120,000 individuals with Alzheimer's Disease being cared for by 439,000 informal caregivers (1) In the online survey conducted as part of the statewide needs assessment 85% of respondents reported being "concerned" or "very concerned" about ADRD causing the death or disability of themselves or a loved one. Among survey respondents who work less than full time, more than 1 in 4 stated that this change in employment status was influenced by having to care for someone with ADRD.

Finding 2: Tennessee has a need for increased public education and awareness about Alzheimer's Disease and Related Dementia

In focus groups conducted by the Tennessee Department of Health, several counties identified increased education, outreach, and dementia-friendly communities as one of the top 5 recommended actions for their county. This theme was echoed in the online survey in which 22% of respondents stated that public awareness of ADRD was one of the most pressing needs for our State. Additionally, 77% of respondents stated that they were not fully satisfied with public awareness of dementia in Tennessee.

Finding 3: Services for Tennesseans living with dementia and their caregivers are necessary.

A common concern raised in Advisory Council meetings was ensuring adequate services are available for Tennesseans living with dementia and their caregivers. In focus groups conducted by the Tennessee Department of Health, several counties identified services as one of the top 5 recommended actions for their county. The online survey also found there to be a need for availability, awareness, quality, and coverage of services and resources. Although most survey respondents had a direct relation to dementia, only 34% reported being familiar with services and resources in our State.

Finding 4: An adequately prepared workforce will be necessary to ensure care is available Tennesseans with dementia and their caregivers.

Education and training of health care professionals and caregivers was a theme mentioned throughout Advisory Council meetings, online needs assessment, and focus groups. As the projected number of individuals with dementia continues to grow, an adequately prepared workforce will be necessary to ensure care is available. This will require cross sector collaboration among many partners and professions including government, private, not for profit, and others.

Goals and Recommendations

The Council's initial plan aims to establish a foundation off which to conduct additional needs assessments, build ongoing recommendations and strategies, and track progress toward achieving these goals. This will be informed by any future in-depth and representative needs assessments conducted, as needed, as the plan continues to evolve. Current recommendations aim to positively impact a broad range of stakeholders including persons living with dementia, families and caregivers, healthcare providers, policy makers, government agencies, and others.

The broad and complex nature of Alzheimer's Disease and this plan requires collaboration among many stakeholders. Therefore, overarching goals will be achieved through a series of strategies. During 2020 and prior to the 2021 annual update of this report, the Council will develop strategies and measurable action items for each strategy. Furthermore, the enacting legislation states that the purpose of the Alzheimer's disease and related dementia advisory council is to "(1) Continually assess the current status of Alzheimer's disease and related dementia in this state and to assess the current and future impact of Alzheimer's disease and dementia on Tennessee residents." Therefore, these needs, goals, and recommendations will be continuously reviewed and updated as needed to ensure the highest possible quality of life for Tennesseans with dementia, along with their families and caregivers.

Goals and recommendations were developed through a collaborative process. Advisory Council members listened to testimonies, read other states' plans, and reviewed data from the needs assessment. At the conclusion of this process Council members proposed that recommendations be structured under 4 overarching goals as other states had done previously. Next, TCAD staff reviewed all Advisory Council meeting notes to extract all recommendations proposed by council members throughout meetings. These recommendations were then grouped under the 4 overall goals. These draft goals and recommendations were then distributed electronically to all Council members. Council members were asked to review and provide edits. All edits were incorporated for discussion and approval at the January 7, 2019 Advisory Council meeting.

These recommendations and strategies will be achieved through collaborative efforts between not-for-profit organizations, private entities, government agencies, persons with dementia, caregivers, and other stakeholders across the State.

Goal 1: Educate and Empower Tennessee to be “Dementia-Aware”

Rationale

Public awareness of dementia is a challenge in our State. The public is often unaware of the potentially modifiable risk factors that may contribute to the development of dementia. Lack of awareness and understanding of ADRD can create barriers to diagnosis/care and impact families physically, mentally, and financially. Furthermore, lack of awareness and education can increase stigma surrounding dementia and create a more challenging environment for persons with dementia and their caregivers (18; 19; 20) Therefore, education and outreach can promote risk-reduction strategies, increase the likelihood of early diagnosis, and improve quality of life for Tennesseans living with dementia and their caregivers.

Recommendations

1. Continue meeting, at least quarterly, as the Alzheimer’s and Related Dementia Advisory Council
2. Regularly update and disseminate the Alzheimer’s and Related Dementia State Plan
3. Develop a communication strategy to increase public understanding of Alzheimer’s and other dementias
4. Using culturally appropriate communications, educate Tennesseans and raise awareness about brain health, potential risk reduction strategies, early warning signs, changes to discuss with a health professional, and benefits of early diagnosis.
5. Incorporate messages on brain health, including how to reduce the risk of cognitive decline, in existing, existing health communications, chronic condition management, and other relevant public health campaigns, particularly among communities at increased risk of ADRD.
6. Encourage incorporation of brain health, ADRD, and caregivers’ needs into plans of state and local government, health and social service organizations, research and educational institutions, businesses and faith communities.
7. Increase awareness and reduce stigma associated with a dementia diagnosis
8. Increase awareness and emphasize the importance of caregivers’ health and wellbeing in as they fulfill the crucial role of supporting individuals living with ADRD
9. Improve access to and use of evidence-informed interventions, services, and supports for people with dementia and their caregivers
10. Ensure that access to care and caregiver support is inclusive of all communities, including traditionally underserved populations
11. Develop resource guides for caregivers, health care professionals, family members of those living with Alzheimer’s disease, and the aging networks
12. Promote education about, and greater use of, care planning and related tools for individuals with ADRD.
13. Partner with civic organizations and faith-based communities to better coordinate education, outreach, and services.
14. Partner with law enforcement and first-responders to ensure communities are equipped to respond to emergency situations involving individuals living with ADRD.
15. Research best practices for emergency preparedness for individuals living with ADRD.
16. Identify strategies to prevent abuse, neglect, and exploitation of individuals living ADRD
17. Build upon successes of “purple cities” and support dementia friendly communities
18. Monitor federal and other grant announcements for potential funding

Goal 2: Support and Empower Persons with Dementia and their Caregivers

Rationale

There are an estimated 120,000 Tennesseans living with dementia and 439,000 caregivers for Tennesseans living with dementia, resulting in economic, social, and health impacts statewide (1). Results from needs assessment and testimony provided during the advisory council hearing suggest that the current infrastructure is inadequate to support this growing population. However, empowering and supporting persons with dementia and their caregivers, can improve the lives of both Tennesseans with dementia and their caregivers (21).

Recommendations

1. Conduct assessment to identify gaps in and barriers to services available in Tennessee including but not limited to those associated with costs
2. Create “one stop shop” or easy to find place for Tennesseans to find information on services available across the State
3. Increase access to quality coordinated care for individuals living with ADRD
4. Review eligibility requirements for federal and state funded programs
5. Increase access to home and community-based services, including adult day care and respite services, and ensure that those with Alzheimer's and other dementias have access to these services regardless of age, financial status, stage of cognitive impairment, geographic location,
6. Identify innovative dementia-care practice models such as telehealth to reach individuals with dementia at home and in rural areas
7. Increase coordination and continuity between hospitals and dementia service providers
8. Provide support and education for dementia caregivers in navigating services
9. Educate Tennesseans and caregivers of those at increased risk of dementia on communicating this concern with health care providers
10. Partner with veterans' organizations to ensure access to relevant veterans' benefits
11. Increase access to support for caregivers to enable them to remain in the workforce if they choose to do so
12. Increase geographic availability, visibility, and referral to support groups and peer-driven support for caregivers of individuals living with ADRD and cognitive impairment,
13. Increase availability, visibility, and referral to support groups and peer-driven support for individuals living with mild cognitive impairment and early forms of ADRD
14. Promote legal education and access for individuals living with ADRD and caregivers
15. Identify strategies to reduce cost-burden of care and support
16. Identify strategies for access to transportation for individuals living with ADRD and caregivers

Goal 3: Ensure an adequately prepared workforce

Rationale

The number of Tennesseans living with dementia continues to grow. When asked where they would seek out information related to care and resources available for ADRD, survey respondents frequently stated they would reach out to a healthcare provider first. However, the respondents were not satisfied with the training of providers and 38% rated this as a pressing ADRD-related need for our State. At taskforce meetings, workforce issues were frequently mentioned as a barrier to care and growing need for our State. Therefore, there must be an adequately prepared and dementia-capable workforce, including healthcare workers, allied professionals, administrators, nurses, social workers, clergy, first responders, and others for our State.

Recommendations

1. Foster continuing education to improve healthcare professionals' ability and willingness to support early diagnoses and disclosure of dementia, provide effective care planning at all stages of dementia, offer counseling and referral, and engage caregivers, as appropriate, in care management.
2. Increase access to competency-based, culturally-appropriate education and training for healthcare professionals and paraprofessionals including physicians, nurses, allied health, direct service workers, and others
3. Educate healthcare professionals across sectors about recognizing early signs and symptoms of ADRD among demographic groups (age, gender, socioeconomic status, IDD, etc.) with increased risk of dementia
4. Educate healthcare professionals about best practices on behavioral symptom management for individuals living with ADRD
5. Educate healthcare professionals on information related to caregivers, including health risks, available tools and information, and supportive programs and services
6. Explore the intersection of ADRD and palliative care including opportunities to improve quality of care and quality of life for individuals living with ADRD and their families
7. Increase awareness of available palliative care programs and care planning initiatives for individuals living with ADRD
8. Study potential opportunities and benefits of interdisciplinary approach including social workers, physician assistants, nurse practitioners, physical therapists, neurologists, psychologists, psychiatrists, and primary care physicians.
9. Assess Tennessee's health care system capacity to diagnose and provide care for individuals with dementia
10. Develop strategies to address the shortage of scientists, clinicians, and front-line health care workers who specialize in gerontology, geriatrics, and dementia care.
11. Examine and/or develop, as needed, dementia training standards to ensure consistency across disciplines and care settings, and bolster current person-centered training efforts
12. Partner with medical and healthcare professional organizations to promote advocacy and awareness of ADRD
13. Encourage academic programs, professional associations, and accreditation/certification entities to incorporate the best available science about brain health, cognitive impairment, and dementia into training for current and future workforces.
14. Encourage integration of a geriatric and ADRD component to curricula in elementary through secondary education

Goal 4: Research, Monitor, and Evaluate

Rationale

There is currently no cure for ADRD and no proven way to stop the progression of the disease. Through increased understanding of ADRD (brain health, prevention, care, and treatments), the Council is committed to the long-term goal of seeing Tennessee one day become a State in which ADRD can be successfully prevented, treated, and/or cured.

Recommendations

1. Identify and compile information on research studies and clinical trials being conducted across the state of TN
2. Ensure Tennesseans are aware of opportunities and benefits of participation in research studies, clinical trials, and tissue donation procedures
3. Identify strategies to increase enrollment of diverse populations to participate in research
4. Identify opportunities for additional data collection or analysis to inform future efforts
5. Recommend implementation of the Behavioral Risk Factor Surveillance System (BRFSS) optional module for Cognitive Decline and the BRFSS optional module for Caregiving
6. Identify health disparities in those with dementia in Tennessee through state and local needs assessments (geographic, socioeconomic, racial/ethnic, gender, LGBT older adults, etc.)
7. Use surveillance data gleaned from other sources to inform the public health and policy response to cognitive health, impairment, and caregiving

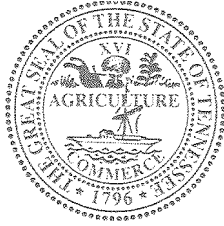
Glossary / Acronyms

- ADRD – Alzheimer’s Disease and Related Dementia
- IDD – Intellectual and Developmental Disability
- TCAD – Tennessee Commission on Aging and Disability
- PCP – Primary Care Physician

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State of Tennessee

PUBLIC CHAPTER NO. 364

SENATE BILL NO. 28

By Crowe, Robinson, Kyle, Johnson, Reeves, Dickerson, Bowling, Massey, White, Jackson, Haile, Hensley, Swann, Watson, Yarbro, Akbari, Roberts; Mr. Speaker McNally; Rose

Substituted for: House Bill No. 37

By Whitson; Mr. Speaker Casada; Hawk, Love, Hazlewood, Helton, Carter, Gant, Weaver, Beck, Hicks, Matthew Hill, Howell, Gloria Johnson, Ogles, Jernigan, Zachary, Dixie, Lamberth, Clemmons, Cooper, Sherrell, Hall, Byrd, Van Huss, Moon, Calfee, Lafferty, Freeman, Terry, Cepicky, Haston, Keisling, Littleton, Miller, Windle, Holsclaw, Ragan, Boyd, Camper, Marsh, Powell, Chism, Powers, Smith, Garrett, Shaw, Hodges, White, Faison, Hakeem, Bricken, Lamar, Hardaway, Cochran, Sanderson, Crawford, Doggett, Timothy Hill, Moody, Kumar, Hurt, Travis, Daniel, Towns, Williams, Coley, Parkinson, Thompson

AN ACT to amend Tennessee Code Annotated, Title 4; Title 68, Chapter 11, Part 14 and Title 71, relative to the creation of the state Alzheimer's disease and related dementia advisory council.

BE IT ENACTED BY THE GENERAL ASSEMBLY OF THE STATE OF TENNESSEE:

SECTION 1. Tennessee Code Annotated, Section 4-29-242(a), is amended by inserting the following as a new subdivision:

() State Alzheimer's disease and related dementia advisory council, created by § 71-2-117;

SECTION 2. Tennessee Code Annotated, Title 71, Chapter 2, Part 1, is amended by adding the following as a new section:

71-2-117.

(a) As used in this section:

(1) "Alzheimer's disease" means a progressive degenerative disease of the brain that leads to dementia, and is characterized by the finding of unusual helical protein filaments in nerve cells of the brain; and

(2) "Executive director" means the executive director of the Tennessee commission on aging and disability.

(b) There is created the state Alzheimer's disease and related dementia advisory council, referred to in this section as the "council."

(c)(1) The council shall be composed of no less than eleven (11) and no more than thirteen (13) members, which include:

(A) One (1) member of the health and welfare committee of the senate, to be appointed by the speaker of the senate;

(B) One (1) member of the health committee of the house of representatives, to be appointed by the speaker of the house of representatives;

(C) The commissioner of health, or the commissioner's designee, who serves as an ex officio voting member;

(D) One (1) person to be appointed by the governor;

(E) One (1) licensed medical professional with experience in Alzheimer's disease and related dementia care, to be appointed by the executive director;

(F) One (1) person diagnosed with Alzheimer's disease or related dementia, to be appointed by the executive director;

(G) A representative of Alzheimer's Tennessee, Inc., to be appointed by the executive director;

(H) A representative of the Alzheimer's Association, to be appointed by the executive director;

(I) A representative of the bureau of TennCare, to be appointed by the executive director;

(J) A representative of the Tennessee Health Care Association, to be appointed by the executive director;

(K) A representative of LeadingAge Tennessee, to be appointed by the executive director; and

(L) Any other person possessing relevant experience with Alzheimer's disease and related dementia care, to be appointed by the executive director.

(2)(A) The private citizen members listed in subdivisions (c)(1)(E)-(K) may be appointed by the executive director from lists of qualified nominees submitted by groups involved in the study of Alzheimer's disease and related dementia, including, but not limited to, the Alzheimer's Association, Alzheimer's Tennessee, the department of health, the bureau of TennCare, the Tennessee Health Care Association, the Tennessee Association for Home Care, and the Tennessee Nurses Association.

(B) The executive director shall consult with the interested groups listed in subdivision (c)(2)(A) to determine qualified persons to fill the positions as provided in this subsection (c).

(d)(1) The persons appointed under subdivisions (c)(1)(A) and (B) are nonvoting members of the council. They serve only so long as they remain members of the general assembly. Any legislative vacancy on the council shall be filled by the respective speaker, for the purpose of serving out the remainder of the unexpired term.

(2) The private citizen members appointed under subdivisions (c)(1)(O)-(K) are voting members and are eligible for reappointment to the council. Any vacancy among the private citizen members shall be filled by the respective appointing authority to serve for the remainder of the unexpired term.

(e) Except as provided in subsection (f) for initial appointments, the terms of the members of the council are for three (3) years.

(f)(1) In order to stagger the terms of the newly appointed council members, initial appointments shall be made as follows:

(A) The persons appointed under subdivision (c)(1)(D)-(F) serve an initial term of one (1) year, which expires on June 30, 2020;

(B) The persons appointed under subdivisions (c)(1)(G)-(I) serve an initial term of two (2) years, which expires on June 30, 2021; and

(C) The persons appointed under subdivisions (c)(1)(J) and (K) serve an initial term of three (3) years, which expires on June 30, 2022.

(2) Following the expiration of members' initial terms as prescribed in subdivision (f)(1), all three-year terms begin on July 1 and terminate on June 30, three (3) years later.

(g) The members shall elect a chair and a vice chair, whose duties are established by the council.

(h) In making the appointments under subsection (c), the executive director shall strive to ensure that the council is composed of persons who are diverse in professional or educational background, ethnicity, race, sex, geographic residency, heritage, perspective, and experience.

(i) The council shall fix a time and place for regular meetings and shall meet no less than twice yearly to review the state plan and all related metrics and outcomes. The executive director shall call the first meeting of the council. All other meetings of the council shall be at the call of the chair.

U) A majority of the voting members of the council constitutes a quorum, and all official action of the council requires a quorum.

(k) The respective appointing authority may remove a private citizen member of the council for misconduct, incapacity, or neglect of duty.

(1)(1) The legislative members of the council shall be reimbursed as members of the general assembly are paid for attending legislative meetings as provided in § 3-1-106.

(2) The private citizen members of the council do not receive travel expenses or compensation for their service.

(m) The purpose of the council is to:

(1) Continually assess the current status of Alzheimer's disease and related dementia in this state and to assess the current and future impact of Alzheimer's disease and dementia on Tennessee residents;

(2) Examine the existing industries, services, and resources addressing the needs of persons, families, and caregivers affected by Alzheimer's disease and related dementia;

(3) Develop a strategy to mobilize a state response to matters regarding Alzheimer's disease and related dementia; and

(4) Provide recommendations to the governor and to the general assembly on issues related to its work.

(n) The council is administratively attached to the commission on aging and disability. The council shall consult and advise the executive director on matters related to the establishment, maintenance, and operation of state initiatives related to Alzheimer's disease and related dementia.

(o) The commission and council shall make best efforts to engage the community at large in making its assessments and recommendations regarding Alzheimer's disease and related dementia.


(p) No later than January 15, 2020, the council shall develop and submit an Alzheimer's disease state plan to the chair of the government operations committee of the senate, the chair of the government operations committee of the house of representatives, the chair of the health and welfare committee of the senate, and the chair of the health committee of the house of representatives that identifies barriers to Alzheimer's disease care, analyzes service utilization data, and includes recommendations, metrics, and best practices to address gaps in service. The council shall update the plan and report to the chairs of such legislative committees on its progress no later than January 15 of each year.

SECTION 3. This act shall take effect upon becoming a law, the public welfare requiring it.


SENATE BILL NO. 28

PASSED: April 30, 2019


RANDY McNALLY
SPEAKER OF THE SENATE


C. £
GLEN CASADA, SPEAKER
HOUSE OF REPRESENTATIVES

APPROVED this *f}ifa* day of Mr11j 2019


BILL LEE, GOVERNOR

Alzheimer's disease and related dementia Advisory Council

Thursday, August 22nd, 2019

1:30 pm – 3:30 pm CST

Senate Hearing Room 1

Cordell Hull State Office Building

425 5th Ave N, Nashville, TN 37243

- I. Welcome** –Senator Rusty Crowe and Representative Sabi Kumar
- II. Review of Public Chapter 364** – Jim Shulman, Executive Director, Tennessee Commission on Aging and Disability
- III. Introductions**
- IV. Elect Chair and Vice Chair for Taskforce** – Jim Shulman, Executive Director, Tennessee Commission on Aging and Disability
- V. Discussion**
 - a. Purpose**
 - b. Future meeting topics, presentations, and speakers**
 - c. Future meeting logistics**
- VI. Announcements-all**
- VII. Other**
- VIII. Next meeting: Date, time, agenda items, and requests for presentations**

Alzheimer's disease and related dementia Advisory Council

Wednesday, October 16th, 2019

1:30 pm – 3:30 pm CST

Senate Hearing Room 1

Cordell Hull State Office Building

425 5th Ave N, Nashville, TN 37243

- I. Welcome** –Senator Rusty Crowe and Representative Sabi Kumar
- II. Review of previous meeting** – Chair Jim Shulman
- III. Presentation, Basics of Alzheimer's disease and related dementia** – Dr. William Petrie
- IV. Presentation, Tennessee Department of Health initiatives** – Chelsea Ridley, MPH, Dementia Friendly Community Coordinator, Office of Patient Care Advocacy, Tennessee Department of Health
- V. Presentation, Tennessee Commission on Aging and Disability programs and services** – Emily Long, MPH, Research and Policy Analyst and Tabitha Satterfield, Aging Program Director
- VI. Discussion – State Plan**
 - What general areas do we want our plan to cover (family caregiving, health professionals, professional caregiving-- nursing homes/assisted living, public health)?
 - What recommendations in the state plan(s) appear to be the most actionable for Tennessee?
- VII. Announcements-all**
- VIII. Other**
- IX. Next meeting: Date, time, agenda items, and requests for presentations**

Alzheimer's disease and related dementia Advisory Council

Tuesday, November 19th, 2019

8:30am - 10:30am CST

Senate Hearing Room 1

Cordell Hull State Office Building

425 5th Ave N, Nashville, TN 37243

- I. Welcome** –Senator Rusty Crowe and Representative Sabi Kumar
- II. Review of previous meeting** – Chair Jim Shulman
- III. Presentation, Overview of Alzheimer's Association** – Rachel Blackhurst, Director of Public Policy and Kelsey Williams, Manager of Development of Initiatives
- IV. Presentation, Overview of Alzheimer's Tennessee** – Janice Wade-Whitehead, CEO and President of Alzheimer's Tennessee
- V. Presentation, Caregiving Perspective** – Barbara Bowden
- VI. Discussion – State Plan**
 - What general areas do we want our plan to cover (family caregiving, health professionals, professional caregiving-- nursing homes/assisted living, public health)?
 - What recommendations in the state plan(s) appear to be the most actionable for Tennessee?
- VII. Announcements-all**
- VIII. Other**
- IX. Next meeting: Date, time, agenda items, and requests for presentations**

Alzheimer's disease and related dementia Advisory Council

Wednesday December 18th, 2019

8:30am - 10:30am CST

Senate Hearing Room 1

Cordell Hull State Office Building

425 5th Ave N, Nashville, TN 37243

8:30am – 8:40am Welcome –Senator Rusty Crowe and Representative Sabi Kumar

8:40am – 8:45am - Review of previous meeting – Chair Jim Shulman

8:45am – 9:15am Presentation, TennCare LTSS – Patti Killingsworth, Assistant Commissioner and Chief, Long-Term Services and Supports, Division of TennCare

9:15am – 9:30am Presentation, LeadingAge TN Purple Cities Initiative – Gwyn Earl, Executive Director, LeadingAge TN

9:30am – 10:30am Discussion – State Plan

- What general areas do we want our plan to cover (family caregiving, health professionals, professional caregiving-- nursing homes/assisted living, public health)?
- What recommendations in the state plan(s) appear to be the most actionable for Tennessee?

Next meeting: January 7, 1:00pm – 3:00pm, Senate Hearing Room 1, Cordell Hull Building

Questions for Associations, Organizations, and other Health Professionals

1. What Current health promotion activities are occurring within your organization?
2. What current activities are occurring within your organization or community to increase awareness of Alzheimer's disease, dementia, and brain health?
3. What current knowledge gaps exist in your organization or community around Alzheimer's disease, dementia and Brain health?
4. List five actions to promote brain health across the lifespan, expand early detection and diagnosis, improve safety and quality of care for people living with dementia, and attend to caregiver's health and well-being.

Questions for Caregivers

1. What have been your experiences as a caregiver?
2. What are some of the specific challenges in providing care to your loved one?
3. Are there particular resources you feel like you've lacked?
4. Do you feel well-informed by your loved one's primary healthcare provider?
5. Do you think there are adequate opportunities for people providing direct care to individuals with memory loss and dementia to participate in meaningful activities or to continue working?
6. Being a caretaker can be stressful. What, if anything, do you do for yourself to cope with these challenges?
7. What do you want your community to understand about caring for a loved one with memory loss or dementia?
8. What is the most important thing your community could do over the next year to better meet your needs?
9. Is there anything you'd like to discuss that we haven't covered?

Questions for Faith-Based Community Members and Leaders

1. As a faith-based organization, what current health promotion activities are occurring with your organization or community? Are any current health promotion activities specifically focused on brain health, memory loss, or dementia?
2. Do you feel your congregation has adequate knowledge and awareness of memory loss and dementia?
3. What are the three most important things that you want your congregation/community to know about brain health, memory loss or dementia disease, and brain health?
4. How can congregations mitigate the impact of memory loss for those living with memory loss, and what are the challenges?

5. What are your plans (if any) as a faith-based organization to respond to memory loss and dementia within the community?
6. If you have plans, what does your organization need to think about or do before your organization feels ready to take action?
7. What resources does your organization need in order to provide education, support, and potential programming to individuals living with dementia and their caregivers?

This survey is intended to gather information and perspective on needs relating to the experience and care of persons with Alzheimer's disease or a related dementia in Tennessee

Participation is voluntary. All responses will be kept confidential and used only to generate a collective report of findings to guide the working group to meaningful action. Your response to the survey will not be connected to your name in any way. Thank you for your time and valuable input.

Please only complete this survey if you are a Tennessee resident.

Paper Copies may be returned to:

TN Commission on Aging and Disability
Attn: Emily Long
502 Deaderick Street; 9th Floor
Nashville, TN 37243

Alzheimer's Disease and Related Dementia - Statewide Needs Assessment

1. What is your current age?* _____
2. In what county do you currently live?* _____
3. Sex
 - Male
 - Female
4. What is your race?
 - American Indian or Alaskan Native
 - Asian
 - Black or African American
 - Native Hawaiian or Other Pacific Islander
 - White
 - More than 1 race
5. What is your ethnicity?
 - Hispanic or Latino
 - Not Hispanic or Latino
6. What best describes your current or past field of occupation
 - Agriculture
 - Education
 - Social Services
 - Financial
 - Government (federal, state, or local)
 - Healthcare provider (nurse, physician, administrator, etc.)
 - Other: _____
7. Please indicate your current employment status
 - Full-time
 - Part-time
 - Not employed
 - Retired

7b. Is your current status influenced by having to care for someone with Alzheimer's disease or a related dementia?

- Yes
- No
- Maybe

8. Which of the following describes your PRIMARY connection to Alzheimer's disease or a related dementia?*

- I am a person diagnosed with Alzheimer's or a related dementia
- Spouse or partner of a person with Alzheimer's disease or a related dementia
- Son, daughter, or other family member of a person with Alzheimer's disease or a related dementia
- Friend or acquaintance of a person with Alzheimer's disease or a related dementia
- I work or have worked with people that have Alzheimer's disease or a related dementia
- I do not have a primary connection to Alzheimer's Disease or a related dementia
- Other:

9. Would you consider yourself to be or have been a caregiver for a person with Alzheimer's disease or a related dementia? (Select all that apply)*

- Yes, I am a professional caregiver
- Yes, I am a family or friend caregiver
- No, I have not been a caregiver
- We define a caregiver as an individual who provides paid or unpaid care to relatives, friends, or patients to help them take care of themselves. Family or friend caregiver activities include but are not limited to food preparation, transportation, behavior management, legal and financial management, and safety. Professional caregiver occupations include but are not limited to physicians, nurses, and social workers.

10. On a scale of 1-5, with 5 being very concerned, how concerned are you about Alzheimer's disease and a related dementia causing the death or disability of you or a loved one?

- 1 - Not concerned at all
- 2
- 3 - Somewhat concerned
- 4
- 5 - Very concerned
- I have not thought of how it might affect myself or a loved one.

11. How familiar are you with care and resources available for Alzheimer's disease and related dementias in Tennessee?

- Familiar
- Somewhat familiar
- Not familiar at all

12. What do you wish you knew and/or understood better about Alzheimer's disease and related dementias? _____

13. What are the three most pressing needs for persons in Tennessee impacted by Alzheimer's disease or related dementias?*

- Community support for family and non-family caregivers of persons with Alzheimer's disease or a related dementia
- Coverage of costs for services and resources
- Education and training of health care professionals and caregivers
- Quality of services and resources
- Public awareness of the disease
- Services and resources available in your area
- Information about services and resources upon and beyond diagnosis
- Other: _____

14. On a scale of 1–5, with 5 being very satisfied, how satisfied have you been with the following aspects of Alzheimer’s disease and related dementias in Tennessee?

	1 - Not satisfied at all	2	3 - Somewhat satisfied	4	5 - Very satisfied	I don't know
Information about and guidance in finding services and resources upon and beyond diagnosis	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Services and resources available in your area	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Coverage of costs for services and resources	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Quality of services and resources	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Public awareness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Education and training of health care professionals and caregivers	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Community support for family and non-family caregivers of persons with Alzheimer’s disease or a related dementia	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

15. On a scale of 1–5, with 5 being excellent, how would you rate the quality of Alzheimer’s disease and related dementias care in Tennessee?

	1 - Very poor	2	3 - Good	4	5 - Excellent	I don't know
Adult day services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Assisted/long-term care facilities	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Auxiliary services (drug treatment, behavioral health, etc.)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Community based initiatives (transportation, public service preparedness, etc.)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Home health care services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Hospice care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Long-term care planning or legal services	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Non-physician health care professional; i.e., nurses	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Primary care/family doctor involvement	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Respite Care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

16. If you needed to seek out information related to care and resources available for Alzheimer's disease and related dementias in Tennessee, where would you go first?

17. What recommendations do you have for improving the experience of Tennesseans living with Alzheimer's disease or a related dementia and their caregivers?

1. What is your current age?

- Average = 54
- Min = 18
- Max = 87

2. In what county do you currently live?*

- 936 Individuals
- 81 Counties across all 3 grand divisions

3. Sex

	#	Percent
Female	757	80.9
Male	179	19.1

4. What is your race?

<u>Race</u>	#	Percent
White	851	90.9
Black or African American	45	4.8
More than 1 race	18	1.9
No Response	11	1.2
American Indian or Alaskan Native	5	0.5
Asian	5	0.5
Native Hawaiian or Other Pacific Islander	1	0.1

5. What is your ethnicity?

<u>Ethnicity</u>	#	Percent
Not Hispanic or Latino	890	95.1
No Response	28	3.0
Hispanic or Latino	18	1.9

6. What best describes your current or past field of occupation

<u>Occupation</u>	<u>#</u>	<u>Percent</u>
Other	273	29.5
Healthcare provider (nurse, physician, administrator, etc)	255	27.2
Social Services	139	14.9
Government (federal, state, or local)	97	10.4
Education	94	10.0
Financial	59	6.3
No Response	10	1.1
Agriculture	9	1.0

7. Please indicate your current employment status

<u>Employment Status</u>	<u>#</u>	<u>Percent</u>
Full-time	576	61.5
Retired	223	23.8
Part-time	76	8.1
Not employed	50	5.3
No Response	11	1.2

7b. Is your current status influenced by having to care for someone with Alzheimer's disease or a related dementia? (if other than full-time)

	<u>#</u>	<u>Percent</u>
No	216	66.5
Yes	80	24.6
Maybe	29	8.9
No Response	54	

8. Which of the following describes your PRIMARY connection to Alzheimer's disease or a related dementia?*

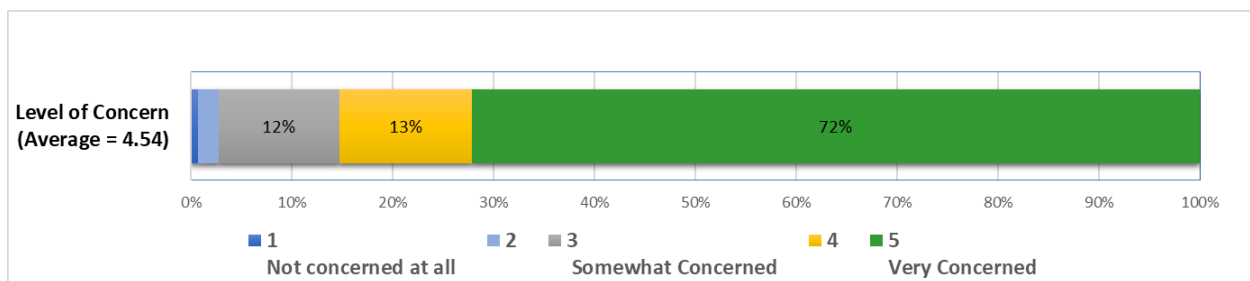
<u>Primary connection to ADRD</u>	<u>#</u>	<u>Percent</u>
Son, daughter, or other family member of a person with ADRD	379	40.5
I work or have worked with people that have ADRD	277	29.6
Friend or acquaintance of a person with ADRD	96	10.3
Spouse or partner of a person with ADRD	67	7.2
I do not have a primary connection to ADRD	58	6.2
Other	44	4.8
I am a person diagnosed with ADRD	15	1.6

9. Would you consider yourself to be or have been a caregiver for a person with Alzheimer's disease or a related dementia? (Select all that apply)*

<u>Employment Status</u>	<u>#</u>	<u>Percent</u>
Family / Friend caregiver	405	43.3
Professional caregiver	119	12.7
Both professional and family/friend caregiver	39	4.2
No	373	39.9

We define a caregiver as an individual who provides paid or unpaid care to relatives, friends, or patients to help them take care of themselves. Family or friend caregiver activities include but are not limited to food preparation, transportation, behavior management, legal and financial management, and safety. Professional caregiver occupations include but are not limited to physicians, nurses, and social workers.

10. On a scale of 1-5, with 5 being very concerned, how concerned are you about Alzheimer's disease and a related dementia causing the death or disability of you or a loved one?



11. How familiar are you with care and resources available for Alzheimer’s disease and related dementias in Tennessee?

	#	Percent
Familiar	318	34.1
Somewhat familiar	433	46.4
Not familiar at all	181	19.4

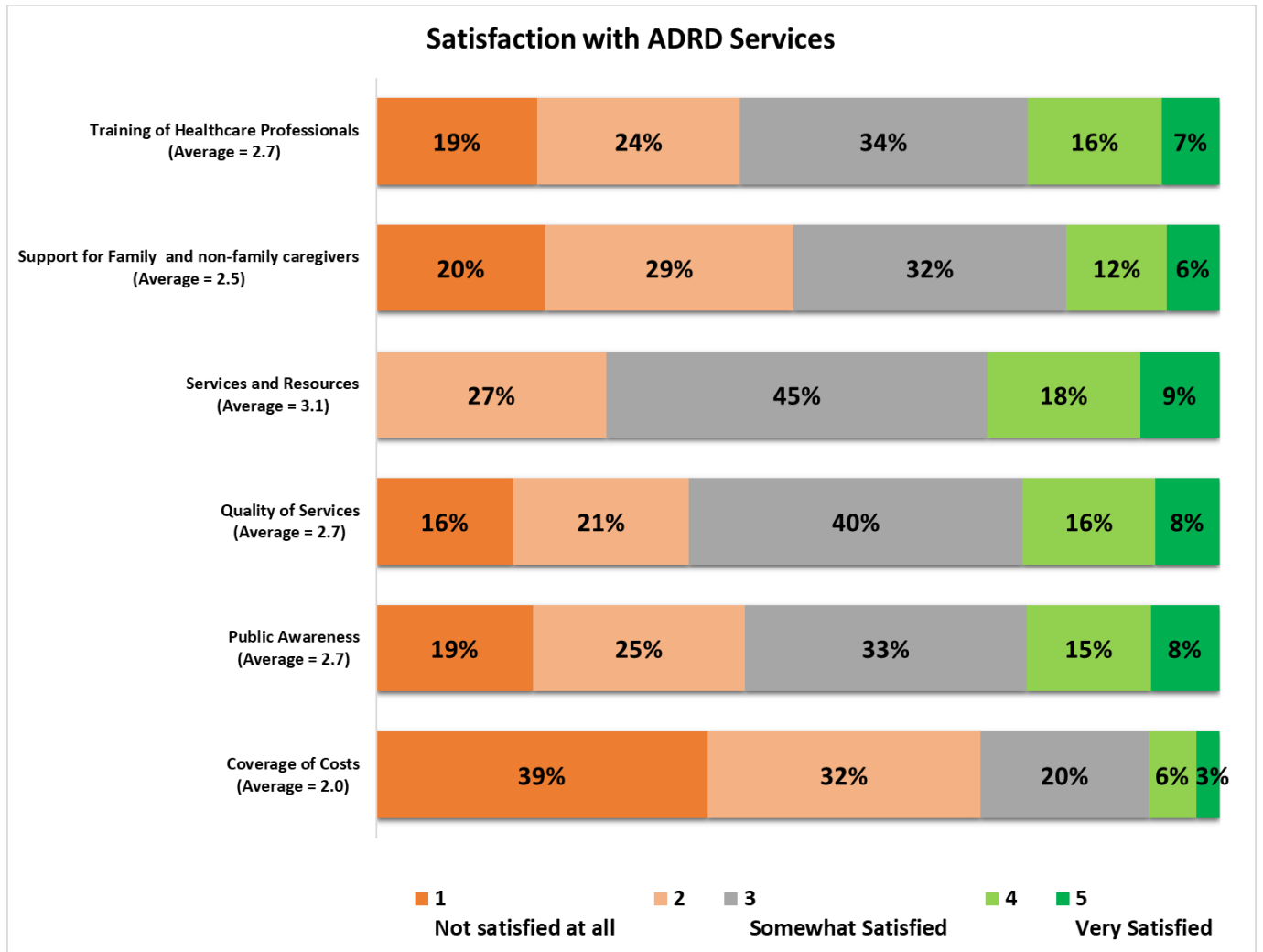
12. What do you wish you knew and/or understood better about Alzheimer’s disease and related dementias?

Individual responses not being listed due to concerns for confidentiality. Results are being deidentified and processed for further analyses.

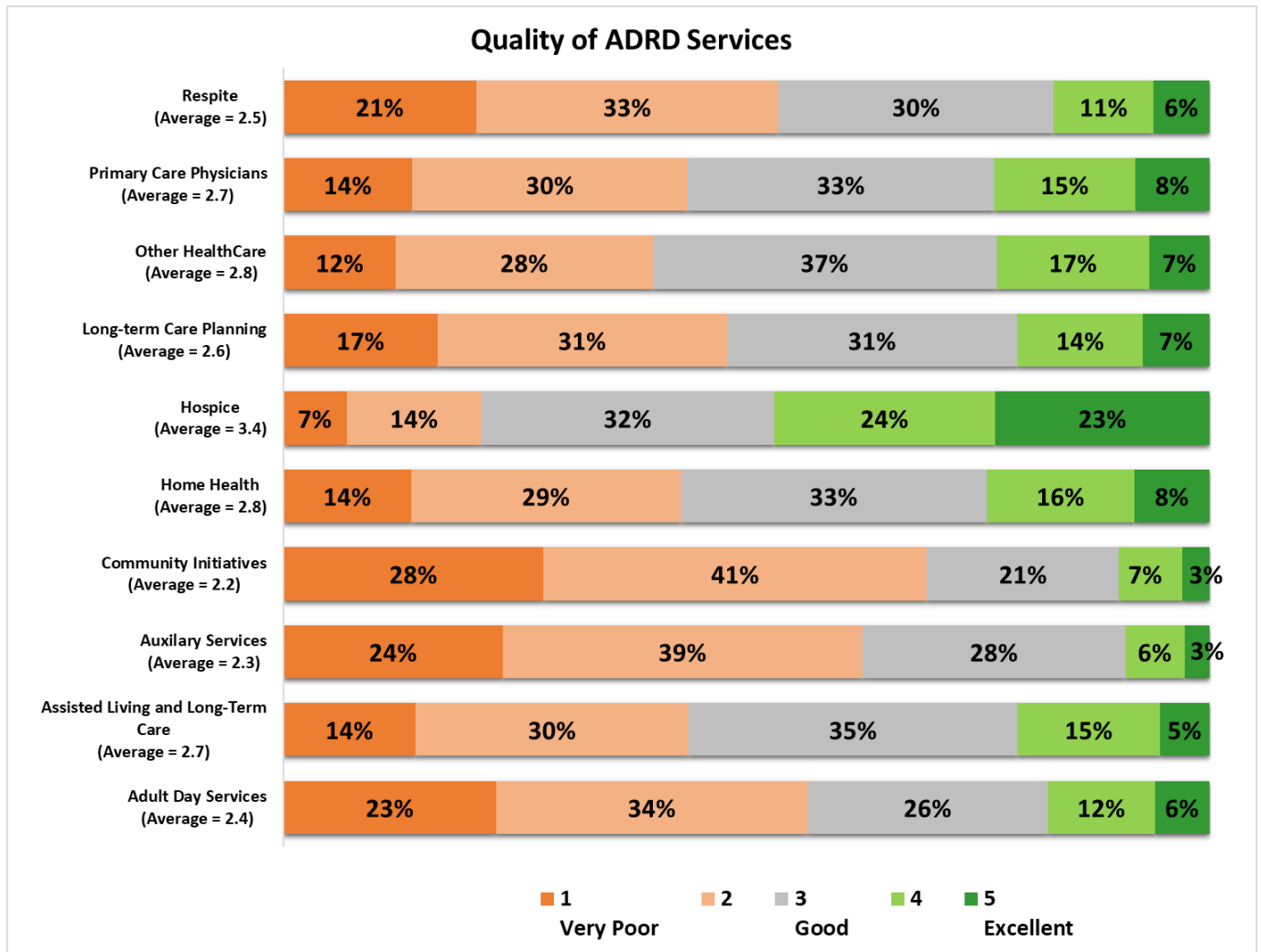
13. What are the three most pressing needs for persons in Tennessee impacted by Alzheimer’s disease or related dementias?*

“What are the three most pressing needs for persons in Tennessee impacted by Alzheimer’s disease or related dementias?”		
	#	%
Coverage of costs for services and resources	630	67.3%
Services and resources available in your area	432	46.2%
Information about services and resources upon and beyond diagnosis	421	45.0%
Community support for family and non-family caregivers	399	42.6%
Education and training of health care professionals and caregivers	355	37.9%
Quality of services and resources	348	37.2%
Public awareness of the disease	202	21.6%
Other	41	4.4%

14. On a scale of 1–5, with 5 being very satisfied, how satisfied have you been with the following aspects of Alzheimer’s disease and related dementias in Tennessee?



15. On a scale of 1–5, with 5 being excellent, how would you rate the quality of Alzheimer’s disease and related dementias care in Tennessee?



16. If you needed to seek out information related to care and resources available for Alzheimer’s disease and related dementias in Tennessee, where would you go first?

If you needed to seek out information related to care and resources available for Alzheimer’s disease and related dementias in Tennessee, where would you go first?		
	#	%
Alzheimer's Association	212	22.6%
Internet Search	156	16.7%
Physician	154	16.5%
Alzheimer's Tennessee	102	10.9%
TCAD, AAAD, or Office on Aging	54	5.8%
Other	159	17.0%
No Response or Don't Know	194	20.7%

17. What recommendations do you have for improving the experience of Tennesseans living with Alzheimer’s disease or a related dementia and their caregivers?

Individual responses not being listed due to concerns for confidentiality. Results are being deidentified and processed for further analyses.

** indicates that question is required for submission*

Appendix F

Data Proposed for Further Analyses

1. BRFSS – Subjective Cognitive Impairment and Caregiver Modules
2. CMS
 - a. Chronic conditions dataset
 - b. Healthcare expenditures dataset
 - c. Medicare Disparities dataset
3. Other Medicare / Medicaid claims data
4. TCAD Program data
5. CDC Wonder data
6. National Health and Aging Trends Study
7. National Study on Caregiving
8. Open-ended responses from online needs assessment survey=