

# Texas Council on Alzheimer's Disease and Related Disorders Biennial Report 2022 – Draft Recommendations Discussion Chart

**DRAFT**

**For discussion:** This compiled discussion chart of recommendations and strategies for the 2022 biennial report is from the biennial report work group conference call on August 11, 2021.

- As designated by Council chair Marc Diamond at the March 23, 2021, Council meeting, the DSHS convened a 4-person work group via conference call on August 11, 2021. The chair appointed himself, Eddie Patton, Vaunette Fay, and Sudha Seshadri to the work group.
- The purpose of the work group was to take the recommendations provided by the entire Council using an input form (provided individually to DSHS by email) to condense duplicate recommendations and create a list for the entire Council to review. The work group did not have a quorum of the Council and did not vote on any matter.
- Council members who responded to the assignment for input are included.
- Last names of Council members are provided with their comments.

## Recommendation 1

### 2020 Language:

*Sustain and support ongoing coordinated Alzheimer's disease (Alzheimer's) research and research into improving the lives of families and caregivers of persons with Alzheimer's or related disorders.*

### Council Input: Keep

Cordes, DeFina, Fay, Fegan-Bohm, Hu

### Council Input: Keep & Amend (in red)

(Patton) **Amend:** Sustain and support ongoing coordinated Alzheimer's disease (Alzheimer's) research and research into improving the lives of **persons with the disease, as well as the lives of** families and caregivers of persons with Alzheimer's or related disorders.

### Rationale: Keep, Amend, or Delete

(Fay) This continues to be a major need and focus of the Council.

### Questions

None

## Strategy 1 for Recommendation 1

### 2020 Language:

*Continue recognition and support of coordinated statewide research, as the Texas Legislature demonstrated in passing House Bill 1504, 76th Legislature, Regular Session, 1999 (Texas Education Code, Chapter 154), to establish the Texas Consortium of Alzheimer's Disease Centers.*

### Council Input: Keep

DeFina, Fay, Fegan-Bohm, Hu, Patton, Seshadri

### Council Input: Keep & Amend (in red)

(Cordes) **Amend:** Continue recognition and support of coordinated statewide research. ~~as the Texas Legislature demonstrated in passing House Bill 1504, 76th Legislature, Regular Session, 1999 (Texas Education Code, Chapter 154), to establish the Texas Consortium of Alzheimer's Disease Centers.~~

### Rationale: Keep, Amend, or Delete

(Seshadri) Statewide research initiatives increase the likelihood of providing answers specific for our population, patient characteristics (including race-, ethnic mix) and healthcare system needs. Improve national funding and results in higher impact publications.

### Questions

(Cordes) Not sure we need to keep the 20+ year clause.

## Strategy 2 for Recommendation 1

### 2020 Language:

Support research on Alzheimer's, both basic science research and clinical research, focusing on

- early detection,
- differentiation between Alzheimer's and related dementias,
- differentiation between diverse biological and environmental factors that contribute to cognitive dysfunction, and
- treatment and care for persons living with dementia and their caregivers.

### Council Input: Keep

Cordes, DeFina, Hu

### Council Input: Keep & Amend (in red)

(Fay) Keep – **Comment:** Feel we need to highlight and stress the clinical research component.

(Fegan-Bohm) **Add bullet point:**

- well-being of caregivers for those with Alzheimer's including physical health, mental health and financial impact

(Patton) **Add bullet point:**

- detection and understanding of the short-term and long-term cognitive effects of Covid 19 infection.

(Seshadri) **Amend:**

- Early detection and prevention
- ~~Differentiation between Alzheimer's and related dementias~~ Identifying all the contributing and modifying factors underlying each patient's dementia
- ~~Differentiation between~~ Understanding diverse biological and environmental factors (including social determinants of health) that contribute to cognitive resilience and dysfunction
- Treatment, and care, and support for persons living with dementia and their caregivers,
- Support city- state- wide dementia friendly initiatives to expand scope of contributions persons living with dementia can continue making to society

### Rationale: Keep, Amend, or Delete

(Fegan-Bohm) Add the bullet point as an additional area of ongoing research.

### Questions

None

## Strategy 3 for Recommendation 1

### 2022 Language:

*Support the incorporation of the Alzheimer's optional modules in the annual Texas Behavioral Risk Factor Surveillance System. The two Alzheimer's modules are the Caregiver Optional Module and the Cognitive Decline Optional Module.*

### Council Input: Keep

Cordes, Fay, Fegan-Bohm, Hu, Patton, Seshadri

### Council Input: Keep & Amend (in red)

(DeFina) **Amend:** Support the incorporation of the Alzheimer's optional modules in the annual Texas Behavioral Risk Factor Surveillance System. The two Alzheimer's modules are the **Alzheimer's and Related Dementia's** Caregiver Optional Module and the Cognitive Decline Optional Module.

**NOTE FROM DSHS:** We have asked about changing the BRFSS modules and learned that they are developed at a national level and are the same in all states.

### Rationale: Keep, Amend, or Delete

(DeFina) If these modules get added, the unique issues of caregiving for dementia should be focused on. The current caregiver module asks about Alzheimer's disease in its primary list and as a secondary condition which is great. The general caregiver module does not address the unique behavioral and social issues experienced by those who care give for those with dementia. However, I acknowledge that there needs to be interest in the caregiving research community to evaluate the answers.

### Questions

None

## Strategy 4 for Recommendation 1

### 2020 Language:

*Support efforts to bring to Texas one or more National Institute on Aging funded Alzheimer's Disease Research Centers, and other similar national organizations.*

### Council Input: Keep

DeFina, Fay, Fegan-Bohm, Hu, Patton, Seshadri

### Council Input: Keep & Amend (in red)

(Cordes) **Comment:** Keep and possibly emphasize in some way (i.e., Texas has the 4<sup>th</sup> highest percentage of dementia caregivers in the US, yet 21 other states have an ADRC...)

### Rationale: Keep, Amend, or Delete

None

### Questions

None

## Strategy 5 for Recommendation 1

### 2022 Language:

*Establish a statewide brain banking system.*

### Council Input: Keep

Cordes, DeFina, Fay, Fegan-Bohm, Hu, Patton

### Council Input: Keep & Amend (in red)

(Seshadri) **Amend:** Establish a statewide brain banking system, and support and grow Hispanic and other minority participation in statewide brain banking system.

### Rationale: Keep, Amend, or Delete

None

### Questions

None

## **NEW Strategies to consider for Recommendation 1 to include in the 2022 Biennial Report**

### **New Strategy**

6. Patton: Establish a research information center so that both patients and physicians can locate research efforts throughout the state.

#### **Rationale**

Patton: Increase awareness about research efforts to increase enrollment.

### **New Strategy**

7. Seshadri: Initiate surveillance for long-term sequelae of SARS-CoV-2 on brain structure and function

#### **Rationale**

Seshadri: Impact of COVID on future cognition appears likely to be significant and Hispanics, indigenous persons and African Americans may be at highest risk.



## Recommendation 2

### 2020 Language:

Continue support for quality care for persons with Alzheimer's and related dementias and their caregivers.

### Council Input: Keep

Cordes, DeFina, Fegan-Bohm, Hu

### Council Input: Keep & Amend

None

### Rationale: Keep, Amend, or Delete

None

### Questions

None

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## Strategy 1 for Recommendation 2

### 2020 Language:

*Promote interdisciplinary education of health professionals, first responders, and other essential personnel on how to interact with persons with dementia, management of behaviors (e.g., anxiety, aggression, wandering, etc.) through behavior modification, environmental modifications and medication use, and promoting dementia friendly concepts.*

- a. Work with city and county officials to promote the concept of dementia friendly cities and communities.*
- b. Support programs that center on education of police, first responders, and other essential personnel on how to deal with persons with dementia.*

### Council Input: Keep

Cordes, DeFina, Fay, Fegan-Bohm, Hu, Patton, Seshadri

### Council Input: Keep & Amend

None

### Rationale: Keep, Amend, or Delete

(Seshadri) Population is aging and there is growing emphasis on aging at home; needs higher level of awareness.

### Questions

None

## Strategy 2 for Recommendation 2

### 2020 Language:

*Support the development of quality care tailored to the needs of persons with dementia and the inclusion of family caregivers in decision making. Recognize and accommodate the needs of diverse populations including the effects of culture, language, and socioeconomic background.*

### Council Input: Keep

Cordes, DeFina, Fay, Fegan-Bohm, Hu, Patton

### Council Input: Keep & Amend

None

### Rationale: Keep, Amend, or Delete

None

### Questions

None

## Strategy 3 for Recommendation 2

### 2020 Language:

Promote the [Alzheimer's Association's 2018 Dementia Care Practice Recommendations](#). The Dementia Care Practice Recommendations outline recommendations for quality care practices based on a comprehensive review of current evidence, best practices, and expert opinions.

### Council Input: Keep

Cordes, DeFina, Fegan-Bohm, Hu, Patton

### Council Input: Keep & Amend

None

### Rationale: Keep, Amend, or Delete

None

### Questions

None

## Strategy 4 for Recommendation 2

### 2020 Language:

*Promote the Alzheimer's awareness campaign as funded by the 2020-2021 General Appropriations Act, House Bill (HB) 1, 86<sup>th</sup> Legislature, Regular Session, 2019. HB 1 allocated \$1 million in funding specifically for the development and implementation of a public awareness campaign for Alzheimer's.*

### Council Input: Keep

DeFina, Hu

### Council Input: Keep & Amend (in red)

(Cordes) Keep – **Comment:** I would like to see us advocate for increased funding.

(Fay) Keep – **Comment:** Amend to reflect the most current passage in April 2021 in 87<sup>th</sup> legislature regular session.

**NOTE FROM DSHS:** Senate Bill (SB) 1, 87<sup>th</sup> Legislature, Regular Session 2021 allocated \$1 million to continue the Alzheimer's awareness campaign over the FY22-23 biennium.

### Rationale: Keep, Amend, or Delete

None

### Questions

(Patton) Do we have access to these funds for the creation of education material?

**NOTE FROM DSHS:** These funds may only be used for the campaign.

## Strategy 5 for Recommendation 2

### 2020 Language:

*Enhance the Department of State Health Services (DSHS) Alzheimer's Disease Program website by providing additional resources specifically for health care professionals.*

### Council Input: Keep

DeFina, Fegan-Bohm, Hu, Patton,

### Council Input: Keep & Amend (in red)

(Cordes) Keep - **Comment:** Recognize that some of this work has been done.

### Rationale: Keep, Amend, or Delete

None

### Questions

None

## Recommendation 3

### 2020 Language:

*Engage in strategic collaborations.*

### Council Input: Keep

Cordes, DeFina, Fegan-Bohm, Hu

### Council Input: Keep & Amend

None

### Rationale: Keep, Amend, or Delete

None

### Questions

None

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## Strategy 1 for Recommendation 3

### 2020 Language:

*Encourage partnerships between state and county medical organizations and other stakeholders to promote research and awareness campaigns with an emphasis on geographic areas with the greatest need.*

### Council Input: Keep

Cordes, DeFina, Fegan-Bohm, Hu, Patton, Seshadri

### Council Input: Keep & Amend (in red)

(Fay) **Amend**: Encourage partnerships between state and county **medical health professional** organizations and other stakeholders to promote research and awareness campaigns with an emphasis on geographic areas with the greatest need. (See rationale)

### Rationale: Keep, Amend, or Delete

(Fay) Amend with "health professional" to make it more inter-disciplinary and inclusive.

### Questions

None



## Strategy 2 for Recommendation 3

### 2020 Language:

Promote the Alzheimer's Association and Centers for Disease Control and Prevention's [Healthy Brain Initiative, State and Local Public Health Partnerships to Address Dementia: The 2018-2023 Road Map](#), to promote brain health as a vital component of public health, and to increase the number of Texans who recognize the direct impact physical health can have on brain/cognitive health.

### Council Input: Keep

Cordes, Fay, Fegan-Bohm, Hu, Patton, Seshadri

### Council Input: Keep & Amend (in red)

(DeFina) Keep – **Amend:** Promote the Alzheimer's Association and Centers for Disease Control and Prevention's [Healthy Brain Initiative, State and Local Public Health Partnerships to Address Dementia: The 2018-2023 Road Map](#), to promote brain health as a vital component of public health, to increase the number of Texans who recognize the direct impact physical health can have on brain/cognitive health, **and to increase caregiving resources available for Texans.**

### Rationale: Keep, Amend, or Delete

None

### Questions

None

## Strategy 3 for Recommendation 3

### 2020 Language:

Support and promote the [Texas State Plan for Alzheimer's Disease 2019-2023](#) (state plan). [Texas Health and Safety Code, Section 99.001](#) directs DSHS to develop and implement a state plan for education on and treatment of Alzheimer's and other dementias. The state plan will be reviewed and modified as necessary every five years.

### Council Input: Keep

Cordes, DeFina, Fay, Fegan-Bohm, Hu, Patton, Seshadri

### Council Input: Keep & Amend

None

### Rationale: Keep, Amend, or Delete

None

### Questions

None

## Strategy 4 for Recommendation 3

### 2020 Language:

*Invite local representatives to speak at Council meetings about how they are implementing the state plan.*

### Council Input: Keep

Cordes, DeFina, Fay, Fegan-Bohm, Hu, Patton, Seshadri

### Council Input: Keep & Amend

None

### Rationale: Keep, Amend, or Delete

None

### Questions

None

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## Recommendation 4

### 2020 Language:

*Expand local caregiver services and supports.*

### Council Input: Keep

Cordes, DeFina, Fegan-Bohm, Hu

### Council Input: Keep & Amend

None

### Rationale: Keep, Amend, or Delete

None

### Questions

None

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## Strategy 1 for Recommendation 4

### 2020 Language:

*Strengthen the DSHS Alzheimer's Disease Program and its role in providing support and resources for persons living with the disease, caregivers, and health care professionals.*

### Council Input: Keep

Cordes, DeFina, Fay, Fegan-Bohm, Hu, Patton, Seshadri

### Council Input: Keep & Amend

None

### Rationale: Keep, Amend, or Delete

None

### Questions

None

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## Strategy 2 for Recommendation 4

### 2020 Language:

*Enhance the DSHS Alzheimer's Disease Program website by making it more user-friendly with links and references to Alzheimer's state and community services.*

### Council Input: Keep

Cordes, Fay, Fegan-Bohm, Hu, Patton, Seshadri

### Council Input: Keep & Amend (in red)

(DeFina) Keep - **Amend: Continue to** enhance the DSHS Alzheimer's Disease Program website by making it more user-friendly with links and references to Alzheimer's state and community services.

### Rationale: Keep, Amend, or Delete

(DeFina) This is minor, but the website is enhanced so we want it to continue to be managed and updated as needed by the science and available service.

### Questions

None

## **NEW Strategies to consider for Recommendation 4 to include in the 2022 Biennial Report**

### **New Strategy**

3. Patton: Work with DSHS to create educational material concerning the long-term cognitive effects of Covid 19 post Covid syndrome.

### **New Strategy**

4. Seshadri: Track if services are reaching most disadvantaged zip codes, persons.

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## Comments/Questions:

(DeFina) My suggestions are minor and focus on caregiving which is not my area of expertise. However, during the pandemic, it is critical to ensure that focus on Alzheimer's and Related Dementias caregiving is maintained. Additionally, I have no additions at this time as I believe that during the pandemic we should continue to ensure that the existing priorities are considered in light of the added impact of the pandemic.

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## Comments for Appendix A

(Cordes) Consider including [2021 Alzheimer's Disease Facts and Figures \(Texas\)](#) 1-pager from the Alzheimer's Association.

No other comments were provided by Council members.

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