

HHSC: Texas Council on Alzheimer's Disease and Related Disorders, June 4th, 2020



The <u>Texas Council on Alzheimer's Disease and Related Disorders</u> advises DSHS and recommends needed action for the benefit of people with Alzheimer's disease and related disorders and for their caregivers.

The Texas Council on Alzheimer's Disease and Related Disorders (Council) was established in 1987 by (Health and Safety Code, Subtitle E., Chapter 101 (HB1066, 70R). Members are appointed by the Governor, Lieutenant Governor, and Speaker of the House. The Council shall:

- Advise the department and recommend needed action for the benefit of persons with Alzheimer's disease and related disorders and for their caregivers
- Coordinate public and private family support networking systems for primary family caregivers
- Disseminate information on services and related activities for persons with Alzheimer's disease and related disorders to the medical and health care community, the academic community, primary family caregivers, advocacy associations, and the public
- Coordinate a volunteer assistance program primarily for in-home and respite care services
- Encourage research to benefit persons with Alzheimer's disease and related disorders
- Recommend to the Department disbursement of grants and funds available for the Council
- Facilitate coordination of state agency services and activities relating to persons with Alzheimer's disease and related disorders



Members include:

Byron Cordes, LCSW, C-ASWCM	Laura DeFina, MD
San Antonio	Dallas
Marc Diamond, MD, Chair	Joe A. Evans, Jr.
Dallas	Beaumont
Vaunette Fay, PhD	Sudha Seshadri, MD, DM
Houston	San Antonio
Ana Guerrero Gore	Angela Turner
Galveston	Normangee
Char Hu, PhD	Eddie Patton, Jr., MD, Vice-Chair
Dallas	Sugar Land
Mary Quiceno, MD	Terrence Sommers
Dallas	Amarillo
Valerie J. Krueger	Michael Gayle, PT, DPT, MA, OCS
Texas Health and Human	Texas Health and Human
Services Commission	Services Commission
Jessica R. Hyde, MS, CHES	Staff
Texas Department of	Lynda Taylor, MSW
State Health Services	Texas Department of
	State Health Services

Call to Order, Logistics, and Roll Call and Introductions. The meeting was convened by Marc Diamond, Chair. He reported that the meeting was being conducted remotely. A quorum was established.

Council Action on October 28, 2019, Meeting Minutes. The minutes were approved as written.

Council Action on Council's 2020 Biennial Report to the Governor, Lieutenant Governor, Speaker of The House, and Legislature. The purpose of this item is to discuss the biennial report. The Chair stated that the Council submits a report to the leadership every even numbered year, due by September 1_{st}. The report is the opportunity to suggest to



leadership the top priorities of the council related to Alzheimer's Disease and associated conditions. A workgroup was formed to consolidate recommendations from the council. The workgroup submitted the consolidated chart to the Council. A draft version of the report has been compiled, but without recommendations and strategies.

The recommendations and strategies presented below include unimplemented recommendations and strategies from the 2018 report as well as suggested changes and edits to include on the 2020 report.

Recommendation 1	
2018 Language:	
Sustain and support ongoing coordinated A	Alzheimer's disease (Alzheimer's) research.
Council Input: Keep	Council Input: Keep & Amend
Cordes, Diamond, Guerrero Gore, Hyde,	Sustain and support ongoing coordinated
Quiceno, Seshadri, Turner	Alzheimer's disease (Alzheimer's) research
	"and/including (Fay) research into
	improving the lives of families and
	caregivers of those with Alzheimer's or
	related disorders". (Patton)

Strategy 1 for Recommendation 1 2018 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	Council Input: Keep & Amend
Cordes, Diamond, Fay, Guerrero Gore,	Comment from Dr. Seshadri was moved to
Hyde, Patton, Quiceno, Seshadri, Turner	PROPOSED Strategies for Recommendation 1.

Strategy 2 for Recommendation 1 2018 Language:

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

- early detection
- differentiation between Alzheimer's and other related disorders, and <u>cognitive</u> <u>dysfunction</u>
- treatment and care.

Council Input: Keep	Council Input: Keep & Amend
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Diamond, Guerrero Gore, Hyde, Patton, Turner	 Support research on Alzheimer's disease, both basic science research and clinical research, focusing on early detection differentiation between Alzheimer's and other related disorders and understanding all the various biologies that contribute to the burden of dementia in Texas including vascular, head injury and other neurodegenerative etiologies (Seshadri), and treatment and care for persons living with dementia and their family caregivers. (Quiceno, Fay, Cordes)
	The Chair proposed the following addition amending the suggestion above: "Understanding of the diverse biological and environmental factors that contribute to cognitive dysfunction" Treatment and care for persons living with dementia and their caregivers

Strategy 3 for Recommendation 1

2018 Language:

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

Council Input: Keep	Council Input: Keep & Amend
Cordes, Fay, Guerrero Gore, Hyde, Patton,	Quiceno, Seshadri, Turner

PROPOSED Strategy 4 for Recommendation 1 (Seshadri) 2020 Language:

Support efforts to get one or more National Institute on Aging (NIA) funded Alzheimer's Disease Research Centers (ADRCs) into Texas.

Council Input: Keep	Council Input: Keep & Amend
	The Chair asked if this is something requiring
	legislative and executive involvement.



Dr. Seshadri stated that they would seek additional funds
Mentioning funding needs in the report would be important, and that would bring awareness to the issue. The funding should be more general and not limit it to NIA.
"National Funding" would be more inclusive because there are more federal sources out there.
There was consensus to broaden the language.

PROPOSED Strategy 5 for Recommendation 1 (Seshadri)2020 Language:Establish a state-wide brain banking system such as the Florida Brain Bank

(http://elderaffairs.state.fl.us/doea/BrainBank/howto.php) with a focus on ethnic minorities.

Council Input: Keep	Council Input: Keep & Amend
	Consensus was to keep it general "A
	statewide brain banking system"

PROPOSED Strategy 6 for Recommendation 1 (Seshadri)2020 Language:Create a state-wide registry of persons interested in clinical trials.	
Council Input: Keep	Council Input: Keep & Amend
	There are many ways to get information and it might not be worth the time and effort to recreate already existing resources.
	It is hard to argue with a registry.

MOTION: *Approve recommendation 1 with noted changes – prevailed*. (Staff will edit final recommendation and strategies.)

Recommendation 2	
2018 Language:	
Continue support for quality care.	
Council Input: Keep	Council Input: Keep & Amend



Guerrero Gore, Hyde, Patton, Turner	Add: Continue support for quality care for
	persons with Alzheimer's and related
	dementias and their family caregivers.
	(Cordes, Fay)

Strategy 1 for Recommendation 2 2018 Language:

Promote interdisciplinary education of health professionals and first responders on management of behaviors (e.g., anxiety, aggression, wandering, etc.) through behavior modification, environmental modifications and medication use, and promoting dementia friendly concepts.

Council Input: Keep	Council Input: Keep & Amend
Cordes, Fay, Guerrero Gore, Hyde, Turner,	 Promote interdisciplinary education of health professionals and first responders on management of behaviors (e.g., anxiety, aggression, wandering, etc.) through behavior modification, environmental modifications and medication use, and promoting dementia friendly concepts. Work with city and county officials to promote the concept of dementia friendly cities and communities. (Patton) Support programs that center on education of police and first responders on how to deal with patients persons with dementia. (Patton)

Strategy 2 for Recommendation 2 2018 Language: Support the development of quality care tailored to the needs of persons with dementia and the inclusion of family caregivers in decision making. Council Input: Keep Council Input: Keep & Amend Cordes, Fay, Guerrero Gore, Hyde, Patton 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 culture,



language, and economic background.
(Turner)

Strategy 3 for Recommendation 2

2018 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	Council Input: Keep & Amend
Cordes, Diamond, Fay, Guerrero Gore, Hyde,	Patton, Turner

PROPOSED Strategy 4 for Recommendation 2 (Cordes)

2020 Language:

Promote the Alzheimer's awareness campaign as funded by the 86th Texas Legislature in House Bill (HB) 1 for the FY20-FY21 biennium. HB 1 allocated \$1 million in funding specifically for the development and implementation of a public awareness campaign for Alzheimer's disease.

Council Input: Keep	Council Input: Keep & Amend
	This is to show support for the awareness campaign. Reminding the legislature that they did this.
	Propose to move to strategy two.

PROPOSED Strategy 5 for Recommendation 2 (Hyde)

2020 Language:

Enhance the DSHS Alzheimer's Disease Program website by providing additional resources specifically for healthcare professionals.

Council Input: Keep	Council Input: Keep & Amend
	A proposal was made to move this to strategy 2 also.
	Include language related to all first responders

MOTION: *Approve recommendation 2 with noted changes - prevailed*. (Staff will edit final recommendation and strategies based on recordings from the meeting.)

Recommendation 3	
2018 Language:	



Engage in strategic collaborations.

Council Input: Keep

Council Input: Keep & Amend

Council Input: Keep & Amend

Cordes, Fay, Guerrero Gore, Hyde, Quiceno, Turner

Strategy 1 for Recommendation 3

2018 Language:

Partner with state and county medical organizations and other stakeholders to promote research and awareness campaigns.

Council Input: Keep	Council Input: Keep & Amend
Hyde, Patton, Quiceno, Turner	Encourage partnerships between Partner
	with (Cordes), (Fay) state and county
	medical organizations and other
	stakeholders to promote research and
	awareness campaigns with an emphasis on
	geographic areas with the greatest need.
	(Guerrero Gore)
	Consensus was in support of this change

Strategy 2 for Recommendation 3

2018 Language:

Promote the Centers for Disease Control and Prevention's (CDC) Healthy Brain Initiative: Public Health 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, Diamond, Fay, Guerrero Gore, Hyde, Patton, Quiceno, Turner

Strategy 3 for Recommendation 3

2018 Language:

Through stakeholder input, continue to develop a state plan to address Alzheimer's every five years.

Council Input: Keep	Council Input: Keep & Amend
Diamond, Fay, Guerrero Gore, Hyde, Patton,	(Cordes) Support and promote the Texas
Quiceno, Turner	State Plan for Alzheimer's Disease 2019-
	2023.
	Health and Safety Code, Section 99.001
	directs the Department of State Health



Services (DSHS) to develop and implement
a state plan for education on and treatment
of Alzheimer's disease and other dementias.
The state plan will be reviewed and
modified as necessary every five years.
This statute is already in place and a plan exists. This simply supports the fact that this exists.
The consensus was to replace the 2018 language with this

PROPOSED Strategy 4 for Recommendation 3 (Quiceno) 2020 Language:

Invite local representatives to speak at Council meetings about how they are implementing the Texas State Plan for Alzheimer's Disease 2019-2023.

Council Input: Keep	Council Input: Keep & Amend
	The Council can always invite speakers.
	Roll into strategy three
	It is not our job to monitor the progress

MOTION: *Approve recommendation 3 with noted changes – prevailed*. (Staff will edit final recommendation and strategies based on recordings from the meeting.)

Recommendation 4	
2018 Language:	
Expand local caregiver services and supports.	
Council Input: Keep	Council Input: Keep & Amend
Fay, Guerrero Gore, Hyde, Patton, Turner	

Strategy 1 for Recommendation 42018 Language:Strengthen the Department of State Health Services' (DSHS) Alzheimer's Disease Programand its role in providing support and resources for persons living with the disease,caregivers, and healthcare professionals.Council Input: KeepCouncil Input: Keep

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Cordes, Fay, Guerrero Gore, Patton, Turner	(Quiceno) Keep and mention the new state plan and funding.
	Consensus to strike the whole thing

Strategy 2 for Recommendation 4 2018 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. Include a portal with information and resources for healthcare professionals.

Council Input: Keep	Council Input: Keep & Amend
Cordes, Fay, Patton, Turner	(Hyde) Enhance the DSHS Alzheimer's Disease Program website by making it more user-friendly for family caregivers, with links and references to Alzheimer's state and community services. Include a portal with information and resources for healthcare professionals.
	(Guerrero Gore) Enhance the DSHS Alzheimer's Disease Program website by making it more user-friendly for seniors, with links and references to Alzheimer's state and community services. Include a portal with information and resources for healthcare professionals. Include virtual assistance where possible.
	The website is already under review for improvement. Perhaps say "make it more user friendly", keeping it general.
	Consensus to include with changes.

PROPOSED Strategy 3 for Recommendation 4 (Seshadri)

2020 Language:

Create a state-wide web-based compilation of resources for persons living with dementia and their caregivers.

Council Input: Keep

Council Input: Keep & Amend



It could be hard to keep up and maintain such a website. The Alzheimer's Association has this already.
Consensus - to not include.

PROPOSED Strategy 4 for Recommendation 4 (Quiceno) 2020 Language: Invite local representatives to speak at Council metings about how they are implementing the Texas State Plan for Alzheimer's Disease 2019-2023. Council Input: Keep & Amend We have seen this before. We can't have it on both recommendations. Consensus is to strike it here because it is included above.

MOTION: *Approve recommendation 4 with noted changes - prevailed*. (Staff will edit final recommendation and strategies based on recordings from the meeting.)

Report contents and format is included below.



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MOTION: Accept the report that is written in the required template format with the above approved recommendations - prevailed.

Public Comment.

(Speaker did not state full name.) Stated that people need action on the six charges of the council. (See above.) The council spends a lot of time on research. The other five charges should be equally addressed.

Announcements. Members of the council were afforded the opportunity to make an announcement. There were no announcements.



Adjourn. There being no further business, the meeting was adjourned.

This summary contains supplemental information from third-party sources where that information provides clarity to the issues being discussed. Not every comment or statement from the speakers in these summaries is an exact transcription. For the purpose of brevity, their statements are often paraphrased. These documents should not be viewed as a word-for-word account of every meeting or hearing, but a summary. Every effort has been made to ensure the accuracy of these summaries. The information contained in this publication is the property of Texas Insight and is considered confidential and may contain proprietary information. It is meant solely for the intended recipient. Access to this published information by anyone else is unauthorized unless Texas Insight grants permission. If you are not the intended recipient, any disclosure, copying, distribution or any action taken or omitted in reliance on this is prohibited. The views expressed in this publication are, unless otherwise stated, those of the author and not those of Texas Insight or its management.