

2023 **SPRING**
ADRC
MEETING

Best Practices for Establishing Genuine Community Partnerships to Engage Underserved Groups in ADRD Research

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South Texas Alzheimer's
Disease Research Center

May 01, 2023 Washington DC



- I have no actual conflict of interest in relation to this presentation.
- Grant Support provided by the National Institute of Aging Awards 1P30AG059305-01, 1P30AG066546-01A1, DP1AG069870, R13AG071167, R13AG066391.
- Grant Support from the Texas Alzheimer's Research and Care Consortium 2020-06-25-CR, 2020-45-25-CR.
- I have potential conflict of interest due to a financial interest with Fundaconciencia, Inc. A management plan has been created to preserve objectivity in research in accordance with UTRGV policy.
- My views are mine and do not reflect those of my employer or funders.

Concepts

Meaningful
Engagement

Multiculturalism

Documenting
Change

South Texas

Summary

Concepts

Concepts

- **Best Practices:** Set of guidelines/ethics/processes representing the most efficient or prudent course of action in a given situation.
- **Establishing:** To build, or bring into being.
- **Genuine:** it is real and exactly what it appears to be.
- **Community Partnerships:** Supportive relationships.
- **Engage:** Participate or become involved in.
- **Underserved Groups:** Do not receive the attention/care/services they need.
- **ADRD Research:** A mean to mitigate/decrease/eliminate the burden of ADRD.

Concepts

Meaningful
Engagement

Meaningful Engagement

- The conceptual model posits four broad categories or domains of measurable outcomes:
 - Strengthened partnerships and alliances
 - Expanded knowledge
 - Improved health and health care programs and policies
 - Thriving communities

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Strengthened Partnerships and Alliances

- Diversity and inclusivity → Representation, multicultural, not traditionally included
- Partnerships and opportunities → Those engaged benefit through deepened and mutually supported relationships.
- Acknowledgment, visibility, and recognition → Community participants are seen and recognized as contributors, experts, and leaders.
- Sustained relationships → Depth, longevity, not transactional, and not time-limited.
- Mutual value → Reciprocity, both sides benefits from, not only contribute to, the effort.
- Trust → Showing up authentically, being honest, following through on commitments, and committing to transparency in order to build a long-lasting and robust relationship.
- Shared power → Involved in leadership activities such as codesigning and developing the partnership's shared vision, goals, and have shared responsibilities.
- Structural supports for community engagement → Established and mutually agreed-upon compensation, requirements for equitable governing board composition, protocols to ensure integration of community partners into grant writing and management, and equitable arrangements for data-sharing.

Expanded Knowledge

New curricula, strategies, and tools



Encapsulate new knowledge and evidence in ways that allow it to be disseminated, accessed, replicated, and scaled.

Bidirectional learning



Partners can collaboratively generate new knowledge, stories, and evidence that reframe how the community is described and appreciated.
Equally values all forms of knowledge and wisdom, including stories and lived experience.

Community-ready information



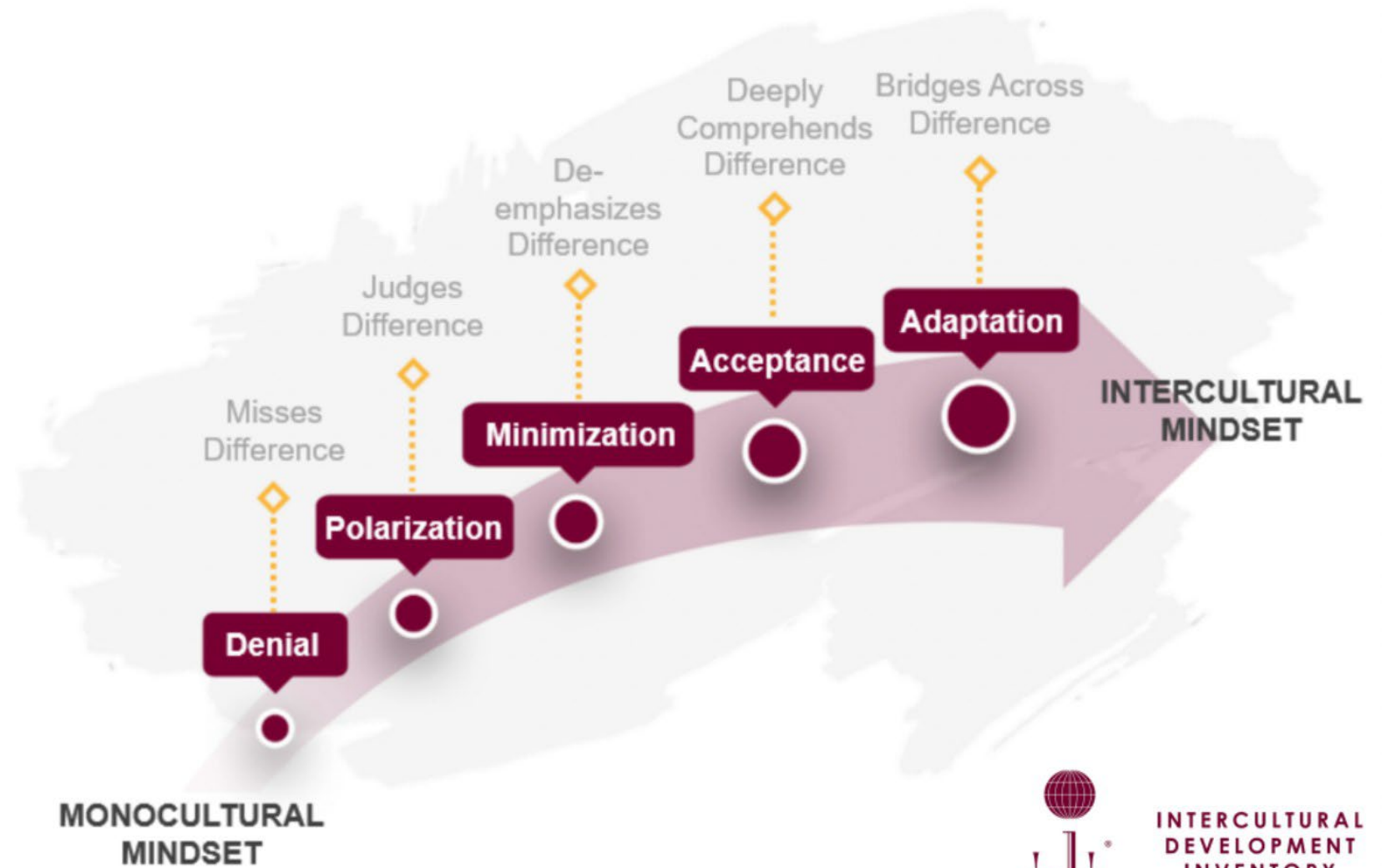
Creation of actionable findings and recommendations that are returned to the community in ways they understand, value, and can use.

Concepts

Meaningful
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Multiculturalism

Intercultural Development Continuum (IDC™)

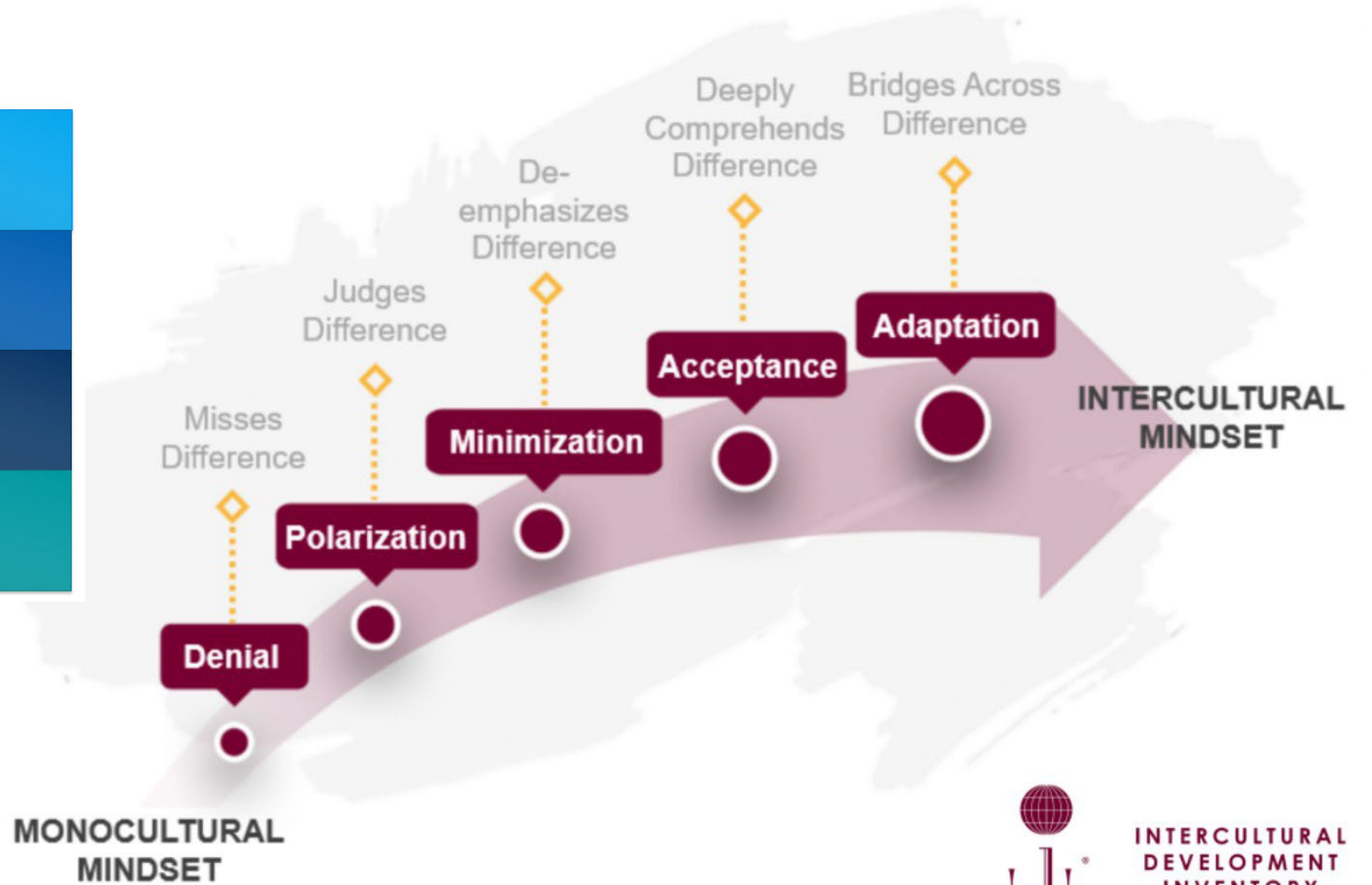
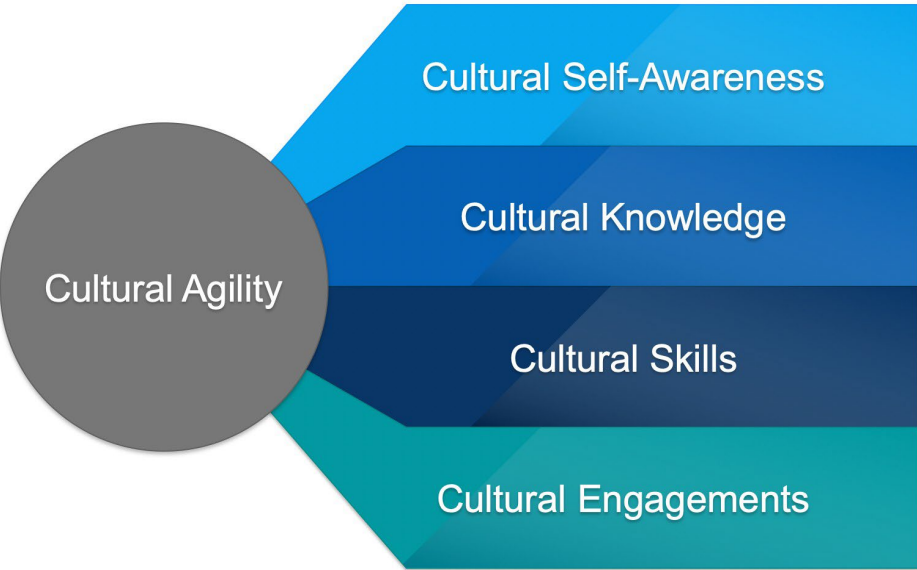


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INTERCULTURAL
DEVELOPMENT
INVENTORY

Intercultural Development Continuum (IDC™)



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INTERCULTURAL
DEVELOPMENT
INVENTORY

Multicultural
older adults
belong to
multiple
worlds and
carry those
worlds with
them.



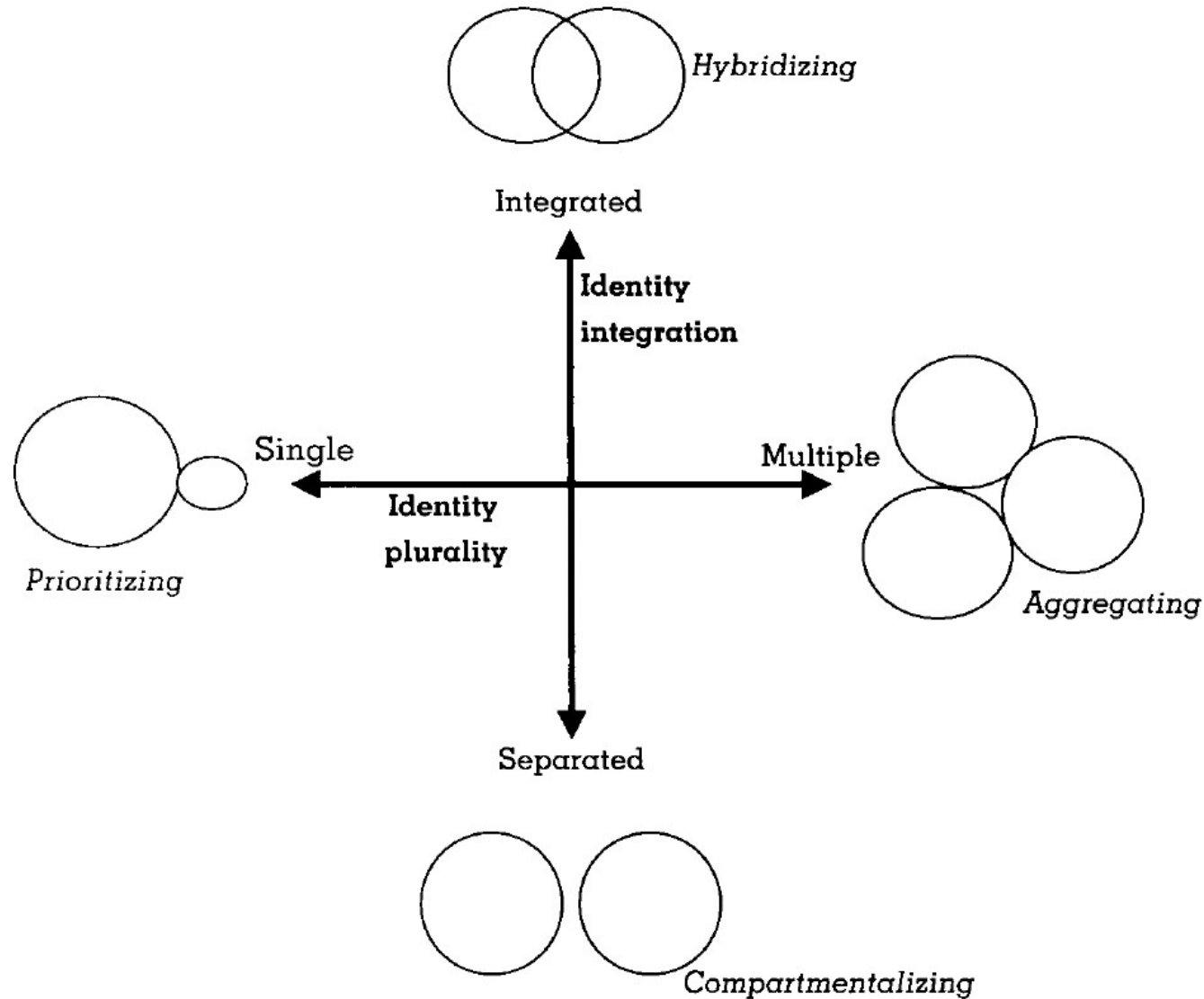


Multicultural individuals are those who identify with two or more cultures and have internalized associated cultural schemas

Not all identities are internalized

- When individuals internalize a cultural identity, they internalize the associated set of knowledge, beliefs, values, norms, habits, and domain-specific self-schemas (Markus, 1977).

Model of Multicultural Identity Dimensions



Concepts

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Documentation System Portal



South Texas Alzheimer's
Disease Research Center

Search this site

RGV AD-RCMAR Community Check Box
The Rio Grande Valley Alzheimer's Resource Center for Minority Aging Research



Announcements



Shared Documents



Calendar



Project Planning



Contacts



Discussion Board

Community
Check Box



Community Check Box

<https://checkbox.ctb.ku.edu/>

Actions to change non-participation in ADRD research



Engagement Activities to Document

- Development activities:

Actions taken to prepare or enable the group to address its goals and objectives



RESEARCH FACILITATION



TRAINING



COMMUNITY-
ACADEMIC
PARTNERSHIPS

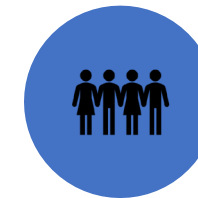
- Technical Assistance, Consultation, Mentoring, Networking, Access & Development of Resources, Workshops, etc.

- Community action:

Action to bring about a specific new or modified program, policy, or practice in the community or system.



COMMUNICATION &
DISSEMINATION



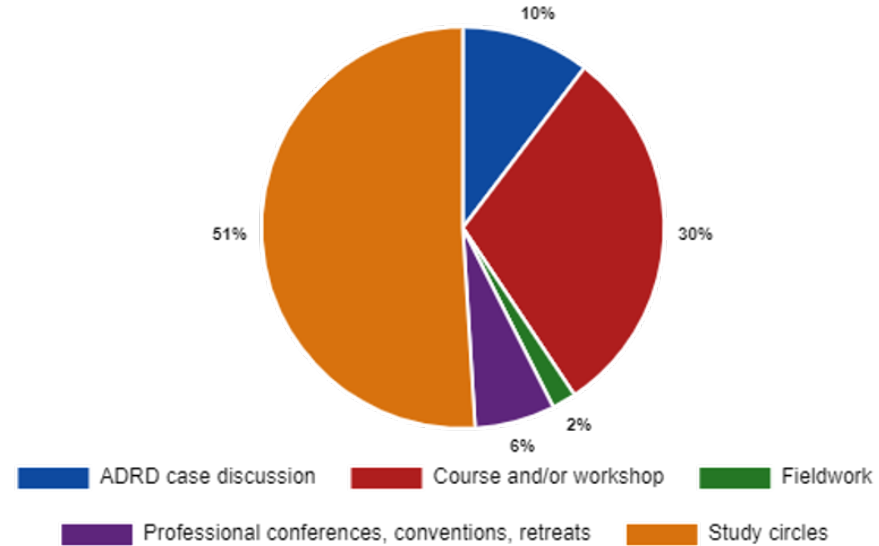
COMMUNITY-
ACADEMIC
PARTNERSHIPS

-*Listening sessions, Community forums, Community review panels.*

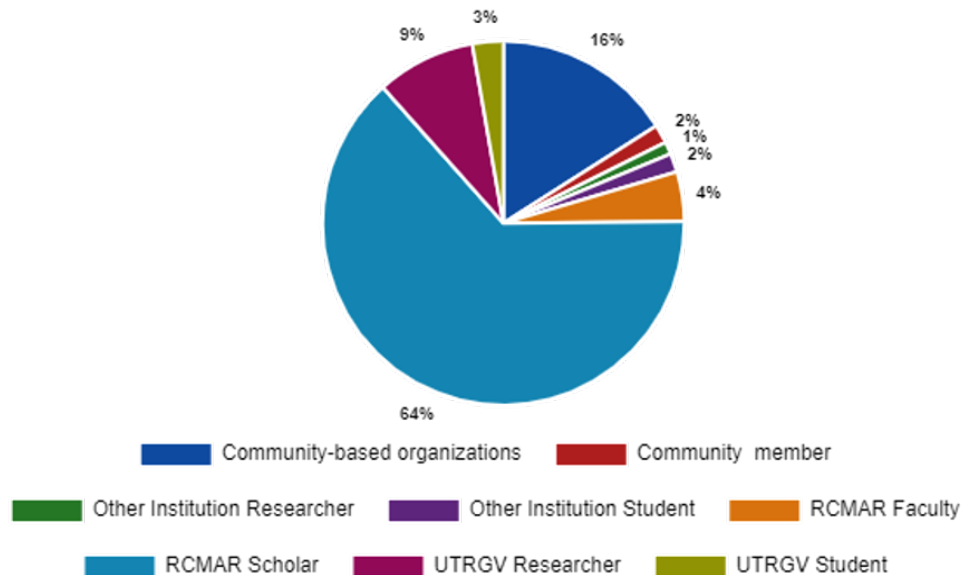
Training

51% of our trainings are study circles (Journal Clubs, research meetings)

Training Provided - Y1 to Y3



Beneficiaries of Training Opportunities
Y1 to Y3

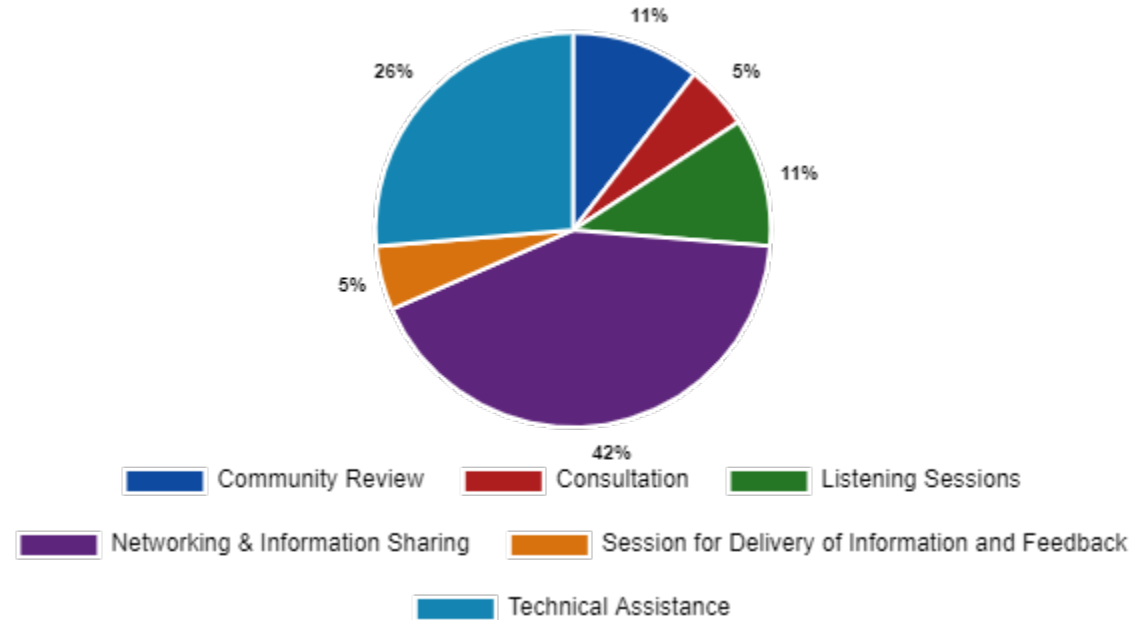


Besides RCMAR and REC Scientists (64%), we also facilitate trainings for our community partners (16%) and researchers from other Centers

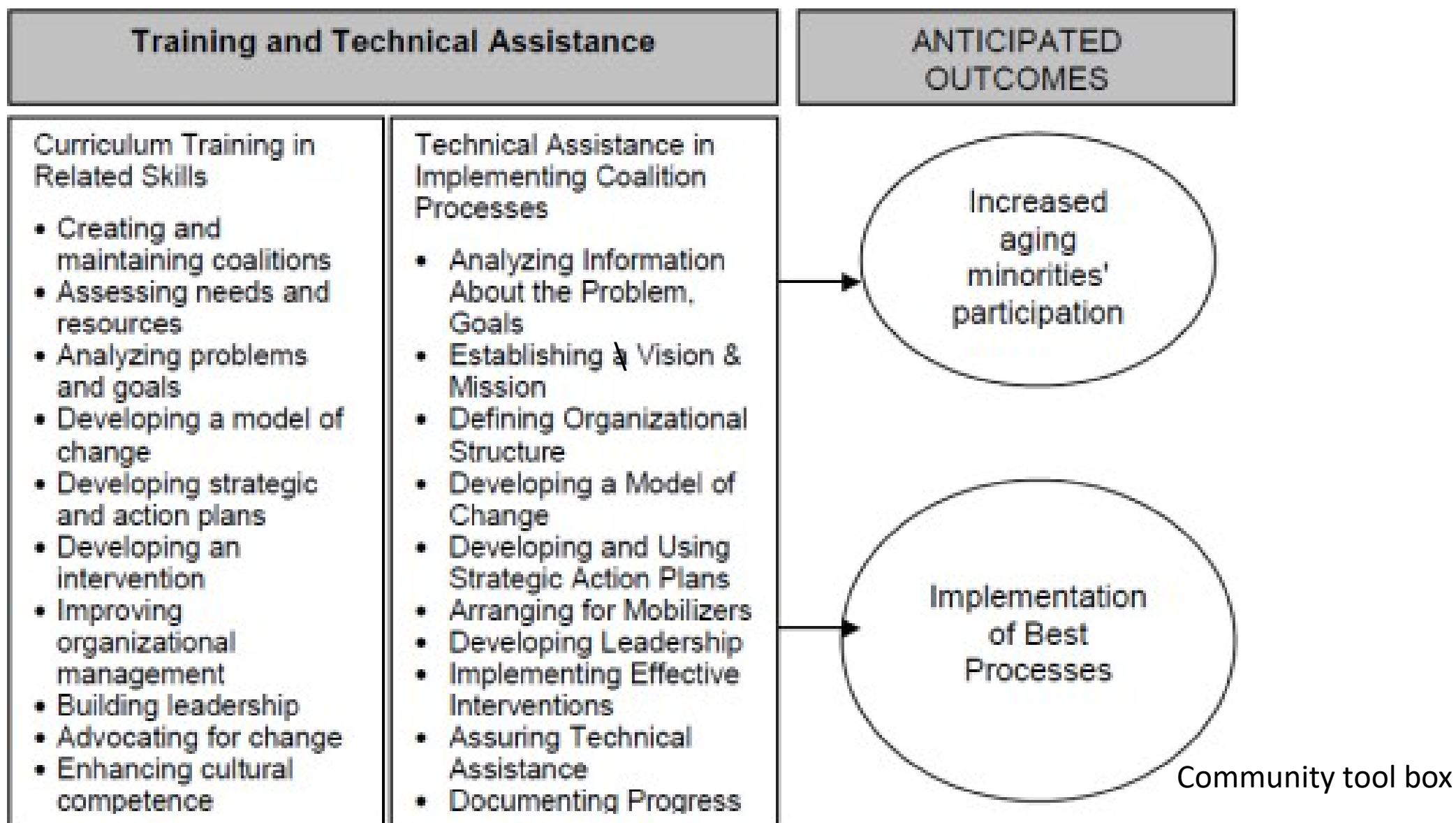
Community Academic Partnerships

Types of Support Provided to Partnerships

42% of our support are networking & information sharing activities



Community Academic Partnerships



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South Texas



Y1 Annelyn Torres-Reveron
Environmental Enrichment & Caregivers



Y1 Juan Lopez-Alvarenga
Vascular dementia & cognitive impairment



Y1 Mario Gil
Psychosocial Stressors



Y2 Romeo Escobar
Characteristics of Caregivers in the Border



Y2 Ana Leandro
Epigenetics Influences on AD Risk



Y2 Marcio Almeida
Novel Endophenotypes Predicting Risk of Dementia



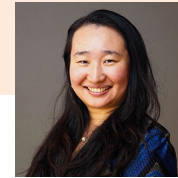
Y3 Upal Roy
Genetic Basis of AD in Hispanic Americans affected by T2D
Diabetes



Y3 Bernard Fongang
Gut microbiome and Dementia



Y4 Candace Robledo
Persistent organic pollutant exposures & mild cognitive impairment



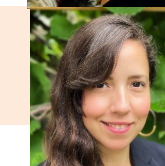
Y4 Lin Jiang
Social isolation among informal caregivers of persons with dementia



Y4 Mikko Kuokkanen
Lipidomic correlates of mild cognitive impairment



Y5 Kim Finn
Promoting Transcendence for Hispanics with AD Through Cultural Engagement



Y5 Mayra Estrella
Socioenvironmental support systems and brain health among Latino populations



Y5 Liza Talavera
Social engagement and cognitive function among Latino populations



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Environmental Enrichment & Caregivers



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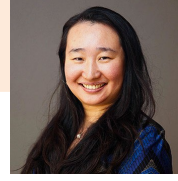
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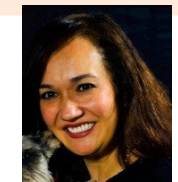
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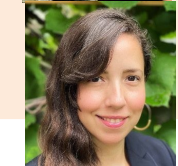
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Promoting Transcendental Meditation for Hispanics with AD Through Digital Health



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Socioenvironmental support systems and brain health among older adults

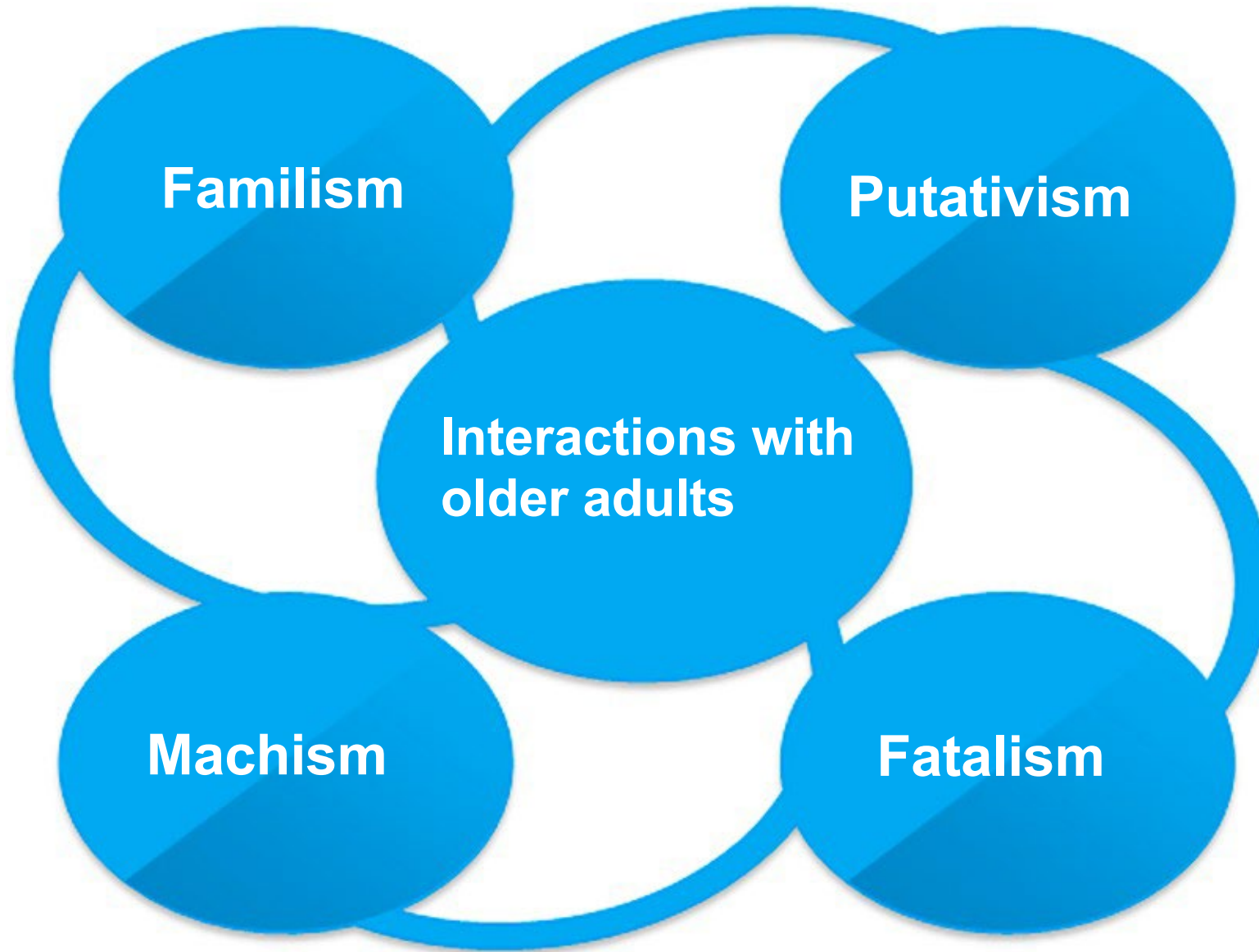


Y5 Liza Talavera
Social engagement and cognitive function among Latino older adults

Social roles in the Hispanic family



Social roles in the Hispanic family



Community Engagement and Outreach Events

Essentials of Caregiving monthly classes

Memory Cafes

Gentle Yoga

Music & Arts

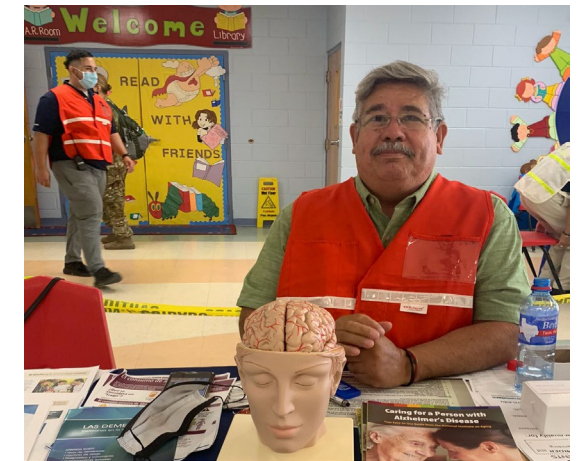
Health Fairs

Alzheimer Walks (SA, RGV)

Dialogue on Dementia series

Community talk requests
(churches, ALS Assn TX, etc)

“24/7” Caregiving Podcast
underwriter



Aim 1. Systematically assess community priorities, needs, barriers to, and interests in AD and related disorders (ADRD) research

Progress to Date

Focus Groups

- February 26, 2022
- March through May – additional focus groups

Semi-Structured Interviews with Key Informants (n=16)

- Health and social agencies, CBOs, participants from focus groups

Surveys with Mexican American adults (n=600)

- Participation in, knowledge of, expectations for, and barriers to participation in biomedical research

Training Activities

- UTRGV Neuroscience Research Seminars
- Interdisciplinary hospice and home health teams on caring for persons with dementia and assisting to identify resources for families
- Training with promotoras (CHW training school, ECHO program)
- Medical students, residents in family medicine and geriatric and palliative care fellows
- IPE projects in dementia care with health professions students



UTRGV | UT Health Rio Grande Valley | RCI | TAR | JANUARY 2022

COMMUNITY BRIEF
COMMUNITY HEALTH PROFILE: CAMERON COUNTY, TEXAS

This community profile focuses on Cameron County, Texas, which is located in the Lower Rio Grande Valley (LRGV) of Texas. The Lower Rio Grande Valley is comprised of four different counties. Cameron County covers 1,276 square miles and is home to 17 cities and towns as well as unincorporated land that are historically underserved and underpopulated. The county is bordered by the Gulf of Mexico to the east and by the Rio Grande River, the border with Mexico, on the south. To the north, Cameron County is Willacy County and Hidalgo County. Its unique location makes Cameron County an important player both regionally and internationally.

To better understand our target population, a demographic analysis was performed using data from 2016 and 2019. This report highlights the change faced by the local community that is addressed in future public health initiatives. This information may be helpful to demographers and researchers to seek to understand and improve the health of the community.

POPULATION

Cameron has a population of 423,163 people with estimates adding 36,000 unincorporated immigrants that also called the county their home. The county represents 30.72% of the population of the LRGV making it the second largest population in the LRGV.

Over the last ten years (2010-2020), the population of older adults (adults 65 years and older) has grown from 44,891 people to 61,138. In 2020, older adults made up 14.4% of the population, and it is estimated that the population will continue to grow over the next 30 years. By 2050, older adults are estimated to make up 22.25% of the county population. In 2050, the older adult population is estimated to be 91,914 which is 26,892 people that currently live in the county. Older adults have unique needs and needs that differ from the rest of the community. With their population increasing, there are different challenges and opportunities in the county.

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COMMUNITY BRIEF
HEALTH PROFILE: SENIORS IN HIDALGO COUNTY, TEXAS

This community brief focuses on Hidalgo County, Texas, which is located in the Rio Grande Valley (RGV) region. The purpose of this profile is to describe population demographics as well as factors related to seniors that may impact health and well-being, such as neighborhood characteristics. The information gathered from community leaders describe the current situation and, in turn, advocate for and utilize resources to create new programs or services to improve seniors' health. This information can also be useful to have these profiles as the community over time to see whether the efforts have created positive change.

Hidalgo County was named in 1885 after Manuel de Zavala, a famous Mexican priest who was a hero of the Mexican War of Independence. Hidalgo County, which is 1,583 mi², is home to 22 cities and towns, and is bordered on the south by the Rio Grande international boundary with Mexico. The population of Hidalgo County is 870,366. The population will represent 67.59% of the Lower Rio Grande Valley (LRGV).

POPULATION

The population of adults over age 50 in Hidalgo County has increased by 30% in the past 30 years. However, it has been estimated that the population of seniors will increase 55% for the period between 2015 and 2050.

Hidalgo will have 27% more adults who are 50 years or older in the next 30 years. Hidalgo County will have the highest increase for adults over 50 years in the RGV. Particularly, the number of adults who are 65 or older will grow more rapidly. Hidalgo's proportion of older adults is greater than the corresponding group in the entire state of Texas from 2040 onwards. In 2015, the population of adults 65 and older is greater than that of those aged 50-64. Between 2015 and 2050, the 50- to 64-year age group will increase by 25%, but the one and older will increase by 93%.

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COMMUNITY BRIEF
Our architecture, our health, and our life: Rio Grande Valley

Architectural features of the buildings and streets influence people's perceptions of the environment. Almost without knowing, urbanism and architecture are involved in our life every day when we walk, when we drive, and as the day unfolds in our daily activities. It is important that we gain a better understanding of the effects that different architectural features surrounding us have in our well-being. Knowledge about how these effects could be predicted as early as during the creation of a two-dimensional development plan, and should be of utmost importance for urban planners, decision-makers and all residents. To this end, this brief explores the main architectural features of buildings and streets in Cameron County, Texas.

History of Architecture in Cameron County

The architecture of South Texas reflects the influence of the different cultures in the region. During a long period of colonization, people of different nationalities enriched the architecture and culture with customs and tastes rooted in their social past.


- Indian or pre-colonial:** The earliest residents in the south of Texas were nomadic peoples. No permanent structures were predominant among the tribes. This architecture was made of animal hides, wood, and grasses. The earliest tribe in the south of Texas was the Coahuiltecan, they lived in camps, with wickiups, which were framed huts covered with brush or reeds.
- Spanish colonial-Mexican (1682-1835):** In the beginning, a lot of residents in this area were soldiers and missionaries, for that we can find construction techniques very particular to defense. In this architecture, we can see a number of churches, convents, apartments, and various service structures.
- Republic-antebellum (1835-61):** During this period, the Anglo-Americans and European immigrants both seeking land and opportunities contributed to the enrichment of architecture and established other buildings as farms and houses with other materials of construction. One of the characteristics that the people in this period contributed to the architecture was the porch roofs in front of the house, providing shade and protected space.

Alzheimer's Talks at the University of Texas Rio Grande Valley

Alzheimer's Disease Prevention:


Can changes in our lifestyle and behavior make a difference?

Invited Speaker: Darren Gitelman, MD



Editor: Gladys E. Maestre MD, PhD

UTRGV | UT Health Rio Grande Valley



A Caregiver Guide to Dementia

Neuroarchitecture:
 Redesigning bathrooms for people living with dementia.



5TH AGING HEALTHY IN RGV SUMMIT
 May 26, 2022+
 Brownsville Event Center, 1 Event Center, Brownsville, TX 78526



Please
Look but
DON'T
TOUCH
Thank you!
Please
look but
DON'T
TOUCH
Thank you!



PHARMA

Please
Look but
DON'T
TOUCH
Thank you!



Please
Look but
DON'T
TOUCH
Thank you!



Ongoing Dissemination to Support OREC Aims

Community Education

- Essentials of Caregiving for family caregivers
- Learning Skills Together, complex care intervention
- Dialogues on Dementia
- Training interdisciplinary hospice and home health teams on caring for persons with dementia and assisting to identify resources for families

Community Engagement

- Bilingual Memory Cafe; Memory Café Network
- ONWARD program – yoga, arts and music (collaboration with symphony, Grace Notes Community Choir)

Support for Community Academic Partners

- Listening sessions, technical assistance and consultation to our community-academic partners

Dissemination to Communities

- Town Hall, October 2018 - Dementia Friendly America March 2019
- Proclamation by City of San Antonio, September 2021
- Participation in community forums, CAPs internal meetings, community fairs
- PCORI-sponsored conferences with communities (June 2019, September 2020, February 2021)
- Presence in local newspapers, TV channels
- Presentations to different community groups including faith-based groups

Ongoing Activities Integrated with OREC Aims

Promotora Training

- Brain Health ECHO program for CHWs (2021)
- Training sessions provided to promotora training sites about mental health and aging

Translation of Evidence-Based Programs

- COPE intervention for family caregivers
- CARINOS En Su CASA – Care for you at home – home based primary and supportive care for persons with dementia and families

Primary care teams training

- Training primary care teams within UT Health and in the community on caring for persons with dementia
- Training for advance care planning for persons with dementia

Training future workforce

- Training medical students, residents in family medicine and geriatric and palliative care fellows
- IPE projects in dementia care with health professions students
- UTRGV Neuroscience Research Seminars

Presentations to Scientific Community

- STAC Conferences 2019, 2020, 2023

The end point of community engagement is to mitigate ADRD burden, and research is one mechanism.

Community change requires academic-community partnerships through supportive, authentic relations

Valuing multiculturalism decrease psychological toll of collaborations and increase social capital

¡Seamos amigos! Let's leverage our strengths and accelerate discoveries!



Gladys Maestre,
MD, PhD



Neela Patel, MD,
MPH



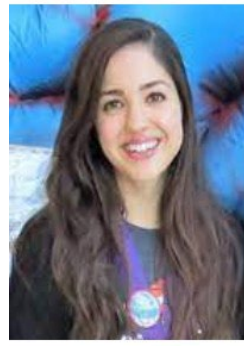
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MPH, PhD



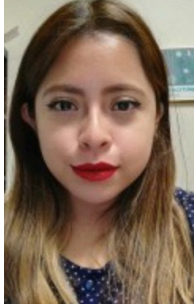
Melissa Flores,
LPC



Ney Alliey-
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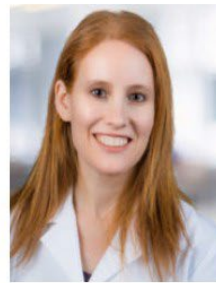
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Cynthia Parker,
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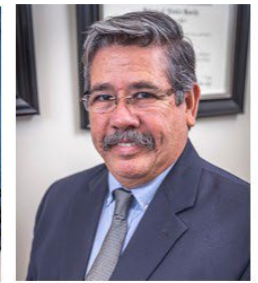
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Amy Saklad, MA



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Gracias!
Tack!
Thanks!
Asante!

