



Forging a Trail to the Top:

Strategic Planning for Respite Care in Texas

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- Background to the development of the strategic plan
 - Gathering caregiver data in Texas
 - State legislative direction and funding
 - Federal Lifespan Respite Grants direction and funding
 - Texas Respite Coalition composition and activities

- Drafting of the strategic plan
 - Process
 - Respite summit and focus groups
 - Plan elements
- Post-plan activities
 - Texas Health and Human Services transformation

Background: Caregivers in Texas

- The first step in strategic planning for respite is to gather data to understand:
 - How many caregivers are there in our state?
 - Who are they?
 - Where are they?
 - What are their needs?
 - Where is the greatest need?

Background: Caregivers in Texas

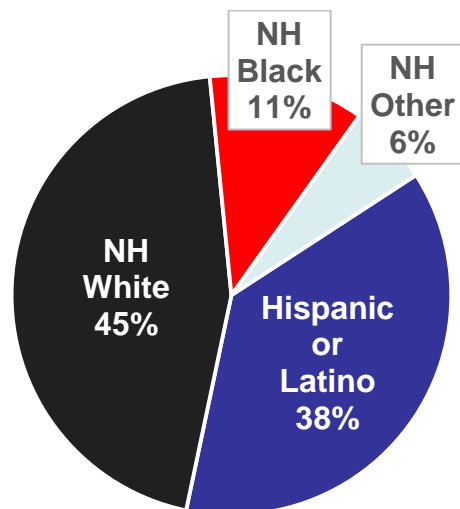
- Obtain overview of state demographics
- Literature review
- State government actions to gather data:
 - Behavioral Risk Factor Surveillance System (BRFSS) Data
 - Interviews with individuals calling in to Area Agencies on Aging (AAAs) and Aging and Disability Resource Centers (ADRCs)

Background: Caregivers in Texas

Total Estimated Population by County, Texas, 2015

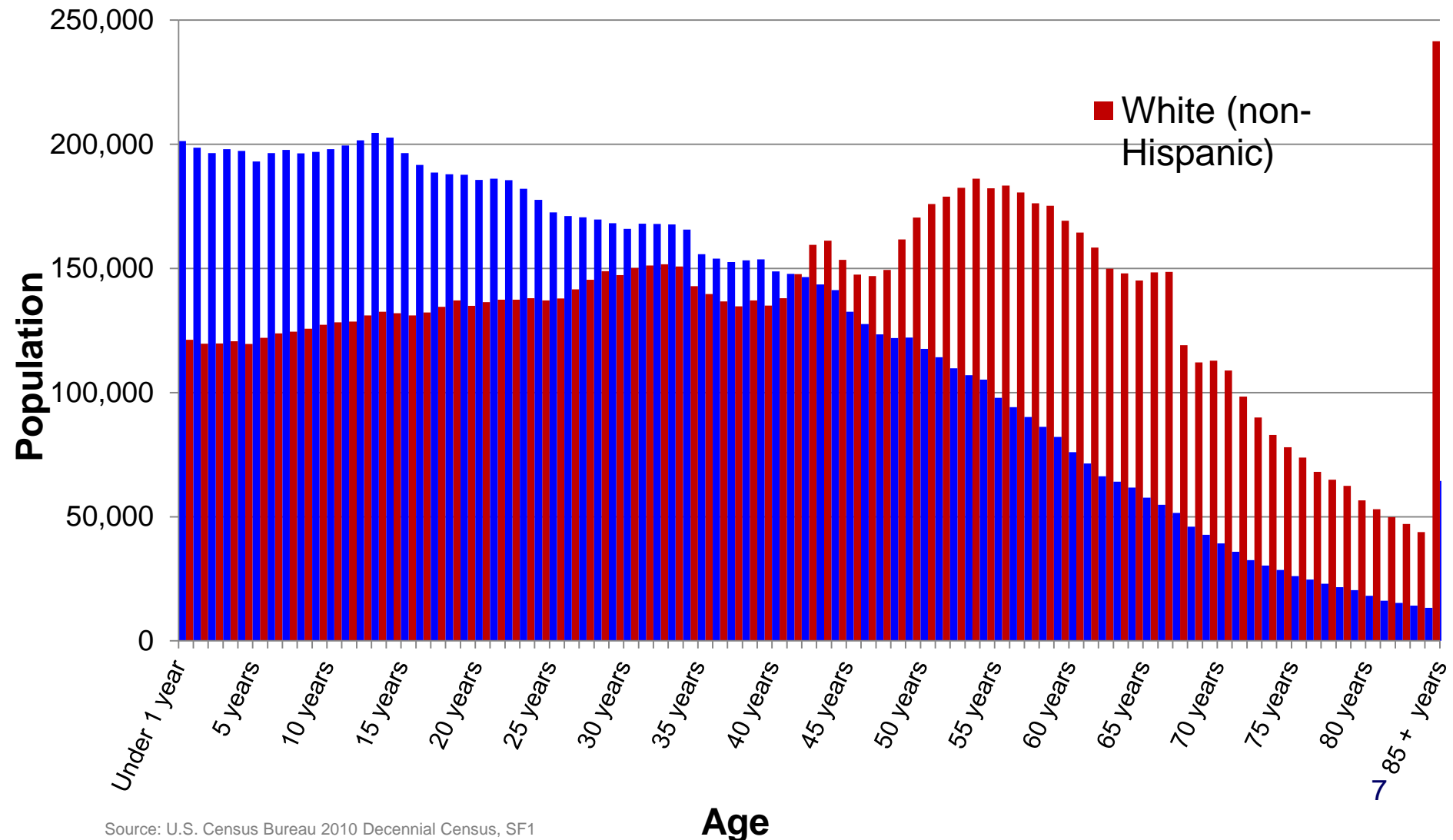
Total Population 2015 = 27,695,284

500,001 - 4,538,028



Background: Caregivers in Texas

Texas White (non-Hispanic) and Hispanic Populations by Age, 2014



Background: Caregivers in Texas



Estimated number in 2013: 3.4 million

Background: Caregivers in Texas



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Estimated number in 2013: 3.4 million

Background: Caregivers in Texas



Background: Caregivers in Texas

Texas caregivers provide an estimated 3.1 billion hours of uncompensated care annually – an estimated economic value of \$36 billion.





Background: Caregivers in Texas

**Data from the 2010
Behavioral Risk Factor
Surveillance System
Survey: 18% of adults
identified as caregivers**

Background: Caregivers in Texas

Gender

| | |
|--------|-----|
| Female | 58% |
| Male | 42% |

Age

| | |
|----------|-----|
| 18 to 29 | 12% |
| 30 to 44 | 31% |
| 45 to 64 | 41% |
| 65+ | 16% |

Race/Ethnicity

| | |
|--------------------|-----|
| White | 65% |
| Hispanic | 23% |
| Black | 8% |
| Other non-Hispanic | 4% |
| | |
| | |



Background: Caregivers in Texas

| Care recipient | Percent |
|----------------|---------|
| Parent | 32% |
| Spouse | 14% |
| Parent-in law | 11% |
| Grandparent | 8% |
| Child | 8% |
| Sibling | 4% |
| Grandchild | >1% |
| Other relative | 6% |
| Non-relative | 17% |



Background: Caregivers in Texas

| Income \leq \$25,000 yr | Percent |
|---------------------------|---------|
| Black | 45% |
| Hispanic | 40% |
| White | 20% |
| ----- | ----- |
| <i>Female</i> | 30% |
| <i>Male</i> | 23% |
| Income \geq \$75,000 yr | Percent |
| White | 48% |
| Hispanic | 19% |
| Black | 10% |
| ----- | ----- |
| <i>Male</i> | 46% |
| <i>Female</i> | 33% |



Background: Caregivers in Texas

| Indicator | Income < or = \$25,000 | Income \$25,001- <\$50,000 | Income \$50,001- <\$75,000 | Income > or = \$75,000 |
|--|------------------------------|----------------------------------|----------------------------------|------------------------------|
| Physical health fair/poor | 45% | 14% | 10% | 6% |
| Life is limited due to physical, mental, or emotional problems | 39% | 29% | 20% | 17% |
| Physical health not good five or more of past 30 days | 44% | 25% | 17% | 7% |
| Mental health not good five or more of past 30 days | 54% | 34% | 22% | 20% |
| Physical or mental problems kept caregiver from usual activities | 33% | 16% | 7% | 7% |
| | | | | |

Background: Caregivers in Texas

| Indicator | White | Hispanic | Black |
|--|-------|----------|-------|
| Physical health good/ very good | 56% | 40% | 27% |
| Physical or mental problems prevented usual activities | 14% | 14% | 25% |



Background: Caregivers in Texas

| Number of Hours per Week Providing Care | % Caregivers |
|---|--------------|
| 1 to 9 hours | 42% |
| 10 to 19 hours | 13% |
| 20 to 29 hours | 12% |
| 30 to 39 hours | 4% |
| 40 to 49 hours | 5% |
| 50 hours or more | 11% |
| Unspecified | 13% |
| Total | 100% |



| Number of Hours per Week Providing Care | % Male | % Female |
|---|--------|----------|
| 1 to 9 hours | 53% | 35% |
| 10+ hours | 38% | 50% |
| Unspecified | 9% | 15% |

Background: Caregivers in Texas

| Indicator | % Male | % Female |
|--|--------|----------|
| Greatest caregiving difficulty is stress | 19% | 28% |
| Greatest caregiving difficulty: detrimental effect upon family relationships | 7% | 3% |
| Mental health fair or poor | 23% | 37% |



Background: Caregivers in Texas

| Indicator | % Male | % Female |
|--|--------|----------|
| Greatest caregiving difficulty is stress | 19% | 28% |
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| Mental health fair or poor | 23% | 37% |



Background: Caregivers in Texas



Over two-thirds of caregivers interviewed indicated they did not understand the meaning or purpose of respite.

Background: Caregivers in Texas



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Background: Caregivers in Texas



67% of Texas
caregivers calling
Area Agencies on
Aging for
information were
not aware of
caregiver support
services.

Background: Caregivers in Texas

The majority of Texas caregivers calling social service agencies over a two year period stated:

- They found caregiving to be stressful, with a significant number reporting high stress.
- Almost half stated that they believed the person they cared for was at risk of institutionalization.

Background: State Legislative Direction

2009 Texas legislative direction and funding:

- HB 802 – mandated the creation of a lifespan respite services program.
- SB 271 – mandated:
 - Identification of caregivers of individuals who are interested in accessing Medicaid programs operated by DADS.
 - Use of standardized assessment instrument during intake to evaluate the needs of caregivers, and to collect data on state caregivers in order to improve existing programs and develop new services.
 - Coordination and expansion of outreach to caregivers about services and supports.
 - Creation of an inventory of respite services available statewide.

Respite in Texas



Texas Health and Human Service Commission oversees the Texas Lifespan Respite Care Program (TLRCP) which supports informal caregivers (such as family members) by increasing awareness and the availability of respite services.

Overview TLRCF Funding

General Ongoing Funding:

State General Revenue funding \$500,000 per year.

- First authorized in 2009 for funding to begin in 2010.
- Funding must be reauthorized each biennium by the Texas Legislature.

Federal Grants, as available.

- Texas received funding for various projects and initiatives since founding the TLRCF.

TLRCP Funding & Accomplishments

July 2009, Texas Respite Coordination Center

- Compiled and updated the Texas Inventory of Respite Services;
- Created media and best practices toolkits for respite providers and a training toolkit for caregivers; and
- Hosted a series of respite care forums throughout the state.

TLRCP Funding & Accomplishments

August 2010, the TLRCP awarded funds to three pilot projects to:

- Increase the availability of and facilitate access to, respite services for caregivers;
- Fund respite services for individuals who were not eligible for respite services through other programs; and
- Place special emphasis reaching isolated caregivers living in very rural areas and conducting culturally sensitive outreach and awareness activities.

Texas LRCP Funding & Accomplishments

February 2012

- New program logo
- Media campaign
- TakeTimeTexas Website
- Texas Inventory of Respite Services



Background: Texas Respite Coalition

Vision:

All Texas families caring for an older adult or an individual with a special need or disability will have convenient access to affordable planned and emergency respite options.

Mission:

To improve the coordination and availability of quality, affordable respite care for all Texas families that provide care for older adults and people with disabilities.

Background: Texas Respite Coalition

- Comprised of 27 agencies and organizations including:
 - State branches of national advocacy and service organizations
 - Local advocacy and service organizations
 - Local respite organizations
 - State agencies

- Purpose is to assist with developing a sustainable respite care system that addresses the needs of caregivers by developing strategies to:
 - Reduce barriers in accessing respite
 - Improve the quality of respite services
 - Reach underserved populations with respite services
 - Provide training, education, and support to family caregivers

Background: Texas Respite Coalition

- Quarterly meetings to:
 - Review caregiver-related data and literature
 - Identify and discuss respite-related issues
 - Decide on TRC priorities
 - Plan for and contribute to respite-related actions
 - Create a strategic plan for respite
- Assist and advise DADS on respite-related actions and events:
 - Texas Respite Summit
 - Focus groups held across the state

Survey of Texas LRCP Partners

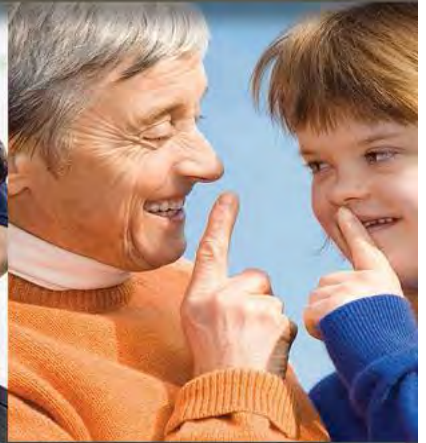
December 2013 – May 2014, HHSC Strategic Decision Support surveyed representatives of partner groups to the Texas LRCP

Partner ideas about the priority issues for caregivers were organized into categories based on the topics they addressed:

- Funding for respite
- More/improved resources besides respite
- Caregivers connected to existing resources
- More communication between organizations doing pro-respite work
- Changes to policy or law besides increased funding for respite

2014 Texas Respite Summit

2014 Texas Respite Summit



BUILDING THE FOUNDATION OF A STRATEGIC
PLAN FOR RESPITE IN TEXAS

June 12, 2014 | 9 a.m.-4 p.m.

San Marcos, Texas

2014 Texas Respite Summit

105 people registered

- Of those who reported their affiliation:
 - 42 percent were caregivers
 - 31 percent were government employees
 - 19 percent were advocates
 - 8 percent were TRC members
- Participants included:
 - Disability advocates
 - Caregivers
 - State and federal agencies that provide respite
 - Private respite providers
 - Faith-based organizations

2014 Texas Respite Summit

Presentations included:

- Panel of family caregivers
- Opening remarks by Former State Representative John Davis
- Remarks by the HHSC Deputy Executive Commissioner
- Information on resources for respite in Texas
- Presentation by Administration on Community Living officials

2014 Texas Respite Summit

Breakout Session #1

- What are your priorities for respite care in Texas? What do we need to improve the current system?
- What services should the Lifespan Respite Program provide to overcome obstacles or build on strengths?

Breakout Session #2

- What should a Lifespan Respite system in Texas look like?
- What should the role of the Texas Respite Coalition be in the Lifespan Respite Program?
- Who else needs to be a part of or partner with the Texas Respite Coalition to ensure all family caregivers are served regardless of age or disability?

2014 Texas Respite Summit

Major Themes from Summit Feedback

- Outreach and awareness about respite
- One stop shop for information on respite
- Funding to make respite more affordable
- Quality, skills, and pay of paid care providers (training)
- Medicaid funded respite and waivers
- Family/person centered respite
- More available respite
- Best practices and alternative models for respite
- Family and community collaboration

2014 Texas Respite Summit

Post-Summit Activities

Texas Respite Coalition (TRC) meetings

- Review input from breakout sessions
- Review major themes
- Preliminary prioritization of themes



Texas Respite Coalition

1. Outreach and awareness about respite

- Public awareness campaign like “Don’t mess with Texas”
- Make respite stories, “front and center”
- De-mystify the term “respite”
- Brand respite, like “Kleenex”
- Let caregivers know it is okay to take time for themselves
- Community outreach

Texas Respite Coalition

Theme 1: Outreach and awareness about respite

- Culturally sensitive approaches to reach caregivers of different backgrounds
 - Address cultural barriers
 - More literature in more languages
 - Difficult for Hispanic culture to understand respite
 - Messaging to hearing impaired

Texas Respite Coalition

Theme 2: Make respite more affordable

- Increase the availability of free and low-cost respite
- Address need for affordable respite for people who do not qualify for waiver programs
- No limitations to programs (age, income, etc.)
- Buy-in from leaders and consumers

Texas Respite Coalition

Theme 3: Make respite more available

- Increase respite across the lifespan
 - Focus on filling gap in services for persons age 22-59
 - Increase volunteer and faith-based programs
- Increase respite for persons with Behavioral Health Needs
 - Partner with Alzheimer's Association and Local Mental Health Authorities to provide training for caregivers
- Increase Emergency and Crisis Respite
 - Develop emergency respite pool
 - Reduce paperwork that slows down the delivery of respite care
- Increase Respite Availability in Rural Areas

Respite Forums

Three forums conducted:

- El Paso - November 13, 2014
- Arlington - December 8, 2014
- Longview - December 9, 2014



Respite Forums

Input from Forums

Top priorities:

- Increase outreach and awareness around respite
- Make respite more affordable
- Make respite more available
- Improve quality, skills and pay of paid care providers

Respite Forums

Input from Forums (continued)

Other Comments:

- Need for respite care among undocumented Texas residents
- Ability to do outreach is limited by the lack of respite services
- Use volunteers and collaborate with faith-based organizations
- Address inconsistencies among Medicaid respite programs
- Conduct outreach to medical providers

Strategic Planning Steps

Steps involved in creation of Strategic Plan included:

- Reviewing caregiver data
- Reviewing data gathered from the Texas Respite Summit and focus groups
- Identifying underserved caregivers and discussing how they might be better served
- Identifying and prioritizing goals

Strategic Planning Steps Cont.

- Examining strategic plans developed in other states
- Assigning a subcommittee to draft the plan
- Having the full TRC review and edit the draft plan
- Having the full TRC review and approve final plan
- Having the agency Commissioner review and approve final plan

Strategic Plan: Priority Goals

- **Goal 1: Increase Outreach and Awareness of Respite Care**
- **Goal 2: Respite Care is Readily Available and Affordable**

Strategic Plan: Priority Goals

Goal 1: Increase Outreach and Awareness of Respite Care

- **Objective 1: Increase public knowledge about how to find respite**
 - *Provide information on available respite to partner agencies.*
 - *Maintain Texas Inventory of Respite Services.*
 - *Augment Texas Inventory of Respite Services with new providers.*
 - *Use Take Time Texas to disseminate information on programs that offer free or low-cost respite.*

Strategic Plan: Priority Goals

Goal 1: Increase Outreach and Awareness of Respite Care

- **Objective 2: Increase public understanding of respite**
 - *Develop public awareness campaign to increase understanding of the term “respite,” the need for respite, and the value of respite.*
 - *Identify and recruit partners/potential partners in disseminating the messages.*
 - *Evaluate effectiveness of outreach materials and methods.*

Strategic Plan: Priority Goals

Goal 2: Respite Care is Readily Available and Affordable

- **Objective 1: Increase availability of respite for caregivers of individuals of all ages throughout the state**
 - *Research and disseminate information on existing models for respite nationwide which are replicable/sustainable models for respite care.*
 - *Promote additional volunteer/faith-based programs.*
 - *Identify funding streams for respite services.*
 - *Provide a fact sheet on ‘creative alternatives’ when respite is not available.*
 - *Promote increased coordination among programs that offer respite.*

Strategic Plan: Priority Goals

Goal 2: Respite Care is Readily Available and Affordable

- **Objective 2: Explore alternative funding for making respite more affordable**
 - *Research and provide information on sliding scale fee models for respite.*
 - *Research and provide information on using vouchers for respite.*
 - *Promote volunteer and faith-based respite programs.*

Strategic Plan: Priority Goals

Goal 2: Respite Care is Readily Available and Affordable

- **Objective 3: Address critical gaps in respite care services for caregivers ...**
 - *of individuals with behavioral health needs.*
 - *of individuals age 22-59.*
 - *in underserved areas of the state.*
 - *who need emergency and crisis respite services.*

Strategic Plan: Priority Goals

Advocacy Subcommittee Objectives:

- **Increase advocacy in support of respite.**
 - *Establish opportunities to support legislative efforts to promote respite across the lifespan.*
 - *Pursue increased state funding for respite care with the goal of making available across counties, age groups, and disabilities.*
 - *Educate community (caregivers, advocates, and faith-based community) via 'How To' links on the Take Time Texas website.*

Strategic Plan: Priority Goals

Advocacy Subcommittee Objectives:

- **Promote quality measures for respite across the spectrum.**
 - *Develop quality measures for respite across the board, based on national standards.*
 - *Inform policy makers and key stakeholders about inequities in pay rates for care providers across the spectrum.*

Post Strategic Plan Activities

- Re-formation of the TRC into the Texas Respite Advisory Committee
- Transformation of Texas Health and Human Services System
- Development of the operational plan from the strategic plan
- Acquisition of Federal grants to further plan goals

Thoughts on Group Planning

- Facilitate group discussions
- Ensure voices are heard, allow for participants to write their ideas prior to voicing them
- Strengths, Weaknesses, Opportunities and Threat analysis (SWOT)
- SMART Goals

Questions ?

Thank You !



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