Maximizing Respite Dollars Through Partnership and Collaboration: One Community’s Story of Caregiver Support
Learning Objectives

• Understand the importance of respite services and how the use of this resource can enhance the lives of caregivers and care recipients

• Learn about the types of partnerships/collaboration that are essential to maximize respite dollars

• Learn about the ways caregivers can work with Texas Lifespan Respite Care Program grant recipients to develop the delivery of respite services
Care Connection Aging and Disability Resource Center

- The City of Houston is the grantee agency for Older Americans Act Services for Harris County

- Harris County Area Agency on Aging (HCAAA) is part of the City of Houston Department of Health and Human Services

- Care Connection is part of HCAAA

- Care Connection covers a 13 county region
Who are Caregivers?

• Estimated 3.1 million non-family caregivers in Texas at any given time

• 5 million family caregivers provided care at some time during the year
Who are Caregivers?

Texas data:
- Average age 57
- 7% are age 74 or older
- 58% are female
- 82% provide care for a relative
- 26% have provided care for more than 5 years
- 53% have been employed at some point
Who are Caregivers?

Relationship of Care Recipient to Caregiver: Texas 2010

- Parent: 31.6%
- Parent-in-law: 17.2%
- Child: 14.1%
- Spouse: 8.0%
- Sibling: 7.8%
- Grandparent: 6.2%
- Grandchild: 4.2%
- Other Relative: 10.6%
- Non-relative: 0.3%
Who are Caregivers?

Hours of Care Provided: Texas 2010

- <=8 hours: 48%
- 9-20 hours: 21%
- 21-40 hours: 17%
- 40+ hours: 14%
Why Respite?

- 66% older persons with disabilities who receive care at home receive it exclusively from family caregivers

- 25% receive care from a combination of family and paid help

- Only 9% receive care through a paid caregiver
Why Respite?

- Estimated economic value of unpaid care = $34 billion

- Caregivers save the state $3.2 billion to $12.6 billion in Medicaid institutional spending annually
Why Respite?

- Caregiving Tasks
  - Transportation (82%)
  - Homemaking (82%)
  - Companionship or supervision (81%)
  - Healthcare assistance (74%)
  - Financial Assistance (70%)
  - Personal Care Assistance (63%)
Why Respite?

• Health Conditions of Care Recipients
  • Other physical health condition-disease (17.4%)
  • Cancer (14.6%)
  • Diabetes (10.7%)
  • Other (7.4%)
  • Other Dementia (7.2%)
  • Heart Disease (4.9%)
  • Arthritis-Rheumatism (4.0%)
  • Stroke (3.9%)
  • Alzheimer’s Disease (3.5%)
Why Respite?

• 40-70% of caregivers have clinically significant symptoms of depression

• 16% of caregivers feel emotionally strained

• More than 20% are exhausted when they go to bed at night
Why Respite?

• About one in ten caregivers report that caregiving has caused their physical health to decline

• Caregivers report chronic conditions (including heart attack/heart disease, cancer, diabetes and arthritis) at nearly twice the rate of non-caregivers

(45% vs. 24%)
Why Respite?

• 69% of working caregivers report having to rearrange their work schedule, decrease hours, or take unpaid leave

• 5% turn down a promotion, 10% take early retirement or leave work entirely

• The lost value of wages, social security and pensions due to leaving work early or giving up a promotion averages $303,880 per person
Why Respite?

Research shows that counseling and support groups, in combination with respite and other services, have positive direct effects on health behavior practices and assist caregivers in remaining in their caregiving role longer, with less stress and greater satisfaction.
Texas Lifespan Respite Care Program

- Established by Texas Legislature in 2009
- Goals:
  - Increase caregiver awareness of respite care resources
  - Make it easier for caregivers to find respite
  - Provide caregivers with training and skills
Texas Lifespan Respite Care Program

• Care Connection became a Lifespan Respite grantee in 2012

• Partners
  – HCAAA
    • Care Coordination & Caregiver Support Coordination
    • Hospital Care Transitions Program
  – Easter Seals of Greater Houston
  – ADRC Partners
  – Perry Lee Home Health
  – Texas Southern University
Funding

- FY12-13: $256,667
- FY14-15: $229,250 (Includes $10,000 for Hospital Care Transitions)
- FY16: $125,000
- FY17: Will receive: $116,500 (SGR and ACL)
Caregivers Served (2012-2016)

• Number of caregivers we have served
  – 448
• Number of caregivers caring for children
  – 210
• Number of caregivers caring for older adults
  – 238
Caregivers Served (2012-2016)

- Top five health conditions of care recipients
  - 2012: Autism, Alzheimer’s/Dementia, Stroke, Down Syndrome, ADD/ADHD
  - 2013: Autism, Alzheimer's/Dementia, Downs syndrome, Intellectual disabilities, Cerebral palsy
  - 2014: Autism, ADHD, Downs syndrome, Intellectual delay/mental, Other (Alzheimer's, Stroke, Diabetes)
  - 2015: Alzheimer's, Other (chromosomal conditions, Autism, Bi-polar disorder, seizures, legally blind)
  - 2016: Alzheimer’s/Dementia, Stroke, Diabetes, CHF, Autism

- Counties where caregivers reside: Harris, Fort Bend, Montgomery, Brazoria, Waller, Galveston, Austin
How is Funding Leveraged?

Through Collaboration & Partnership!
Collaboration & Partnership

• Harris County Area Agency on Aging’s Caregiver Support Coordination Program:
  - Serves consumers 60 years and older
  - A process of assessing the needs of a caregiver and care recipient to effectively plan, arrange, coordinate and follow-up on services which most appropriately meet the identified needs as mutually defined by the caregiver, the care recipient, and the access and assistance staff
Program Structure
Caregiver Support Coordination Program:

• Caregiver Respite Care–In-Home:
  – Temporary relief for caregivers including an array of services provided to dependent older individuals who need supervision

• Caregiver Respite Institutional/Adult Day Care:
  – Temporary relief for caregivers including an array of services provided in a congregate or residential setting (hospital, nursing home, and adult day care) to dependent older individuals who are in need of supervision
Program Structure

- Worked with partners to create program structure
- Vouchers available for up to 80 hours, to be used over a two month period
- Easter Seals manages voucher distribution
- Texas Southern University provided education
- Education and training component
  - Orientation
  - Respite and community resources discussed
  - Use of vouchers
Caregiver Education and Training Class
Program Structure

• Provided counseling to caregivers to explore respite options
  – Caregivers receiving other forms of respite not eligible for Lifespan Respite

  – Care Connection staff provided information about alternate resources to ineligible consumers

  – Caregivers of care recipients 60+ referred to HCAA

  – Care Connection staff discussed long term respite resources beyond Lifespan Respite program
Program Structure

• What happens after Lifespan Respite?
  – Discussed other service options
  – Helped caregivers apply for other respite services
  – Helped caregivers who are on waiting lists apply for respite services
  – What does your family support network look like?
Partnership Opportunities

• Caregiver Education
  – Referrals made to HCAA’s Care Coordination, Caregiver Support Coordination Programs & Conversations with Caregivers
  – Opportunity to meet other caregivers and develop natural support systems
  – Opportunity to receive in-home respite
Easter Seals
Greater Houston

• Finding services can be difficult, Easter Seals makes it easy for Caregivers to access information within the agency and through partners:
  • Information referral
  • Case Management
  • Follow ups
Easter Seals
Greater Houston

Other Respite Services offered through Easter Seals:

- **Family Day Out (FDO)**
  - Two locations Bellaire and Montgomery

- **Parent Night Out (PNO)**
  - **Bellaire**: 6:30-10:30pm for clients ages 6-24 and siblings ages 6-10.
  - **Katy**: 6-9pm for clients ages 12-21.

- **CAMPS!!!**
  - Camp Buckaroo
  - Camp Smiles
  - Camp MOST
Partnership Opportunities

- Stretching respite dollars through partnership with Easter Seals
  - Care Transitions
  - Lifespan
  - Wellness Retreat for Alzheimer’s Caregivers
  - Using respite with other services
    - Camps, FDO, and PNO
Partnership Opportunity with Easter Seals

Wellness Retreat for Alzheimer’s Caregivers
Partnership Opportunities

• Stretching respite dollars through HCTP
  – HCTP received funding for respite beginning June 2015
  – Nine caregivers utilized the service
  – Caregivers and patients were invited to participate in quarterly Conversations with Caregivers
Lifespan Respite Care Program Benefits

• Community partners learn about all forms of respite
• Expand knowledge of professionals and consumers
• Temporary relief for care recipients on long waiting lists
• Think creatively about how to serve families
• Agencies and caregivers become more resourceful
• Education and training become even more crucial with scarce resources
Why Respite?

• Taking care of a loved one can be very rewarding but it can also be challenging.

• Lifespan Respite gives caregivers another resource needed to recharge and refuel so they can continue to provide care to their loved ones.
Thank You!

Special Thanks to Joyce Pohlman from DADS for statistical data and other presentation content.

Note: Data sources are not listed but can be provided upon request.