

**KRONKOSKY CHARITABLE FOUNDATION
ROUNDTABLE DISCUSSIONS**

TOPIC: Respite Care
DATE: February 12, 2004
PREPARED BY: Lauren Gulbas, Intern

PARTICIPANTS

Invited Agency Representatives

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| • Mary Barsalou | ALS Association |
| • Sharon Baughman | Christian Senior Citizens |
| • Allisa Butler | Community Care Net |
| • Laura Csinero | City of San Antonio |
| • Bert Pfeister | Respite Care of San Antonio |
| • Nancy Rheams | Alzheimer's Association |
| • Steve Saldana | Catholic Charities |
| • Carol Zernial | Bexar County Area Agency on Aging |

Foundation Staff

Eusebio Diaz	Grant Manager
Lauren Gulbas	Graduate Student Intern

PURPOSE

The purpose of this meeting is to discuss the respite care needs for individuals living throughout San Antonio. Specifically, the purpose is to define the current state of respite care; the needs of both caregivers and individuals in need of respite care; and barriers or challenges in gaining access to respite care.

BRIEF OVERVIEW OF RESPITE CARE SERVICES

ALS Association

- Provides services to individuals suffering from Amyotrophic Lateral Sclerosis (ALS) and offers support services to families with individuals with ALS

Christian Senior Services

- Provides services to individuals over the age of 60 years, including Meals on Wheels, Seniors Companion Program, and Grace Place

- Meals on Wheels, which serves the homebound elderly population, currently provides over 2,000 daily meals
- Seniors Companion Program provides respite care to elderly individuals for short periods of time
- Grace Place provides respite to individuals caring for someone with Alzheimers

Community Care Net

- Provides services to elderly individuals, including a nursing home and respite care

City of San Antonio

- Provide numerous services to residents of San Antonio, including assistance with cancer treatment and kidney dialysis and home care

Respite Care of San Antonio

- Provide respite for families caring for children with disabilities
- At the Davidson Respite House, care is provided for an extended time

Alzheimer's Association

- Offer numerous services and support individuals and families with individuals who have Alzheimer's

Catholic Charities

- Provide services to elderly populations living in East, West, and South San Antonio
- Caregivers Day Out provides respite to elderly caregivers

Bexar County Area Agency on Aging

- Provide respite for elderly caregivers over the age of 60 years
- Voucher program allows family and/or individual to choose care provider

OVERVIEW OF THE POPULATION NEEDING AFFORDABLE RESPITE CARE

- Families most in need of affordable respite care usually have too many resources to qualify for federally subsidized programs, such as Medicaid
- However, they do not have enough resources to pay for private respite care
- The growing elderly population presents numerous challenges associated with respite care:
 1. The fastest growing segment of the American population is individuals 85 years and older
 2. Currently, there are 100,000 seniors over the age of 100 years
 3. Ten percent of the elderly population is 65 years old, while nearly 48 percent is over the age of 85 years
 4. The elderly population is susceptible to developing cognitive disabilities and nearly half of the elderly population over 85 years will be diagnosed with dementia, increasing the need for respite care
 5. Because seniors are living longer, there is an increased risk of developing Alzheimer's
 6. Individuals with Alzheimer's are living longer (five to seven years) due to advances in medical technology and thus require longer periods of care

7. Because the elderly population tends to be on a fixed income and are at an increased likelihood for incurring debt, affordable respite care is key; for example, providing care to an individual with Alzheimer's costs nearly \$40,000 per year
8. The average caregiver is female, between the ages of 40 and 60
9. The average caregiver is employed, increasing the need for respite care

NEEDS OF INDIVIDUAL CAREGIVERS AND PATIENTS

- Patient needs are dependent upon the characteristics of the disorder and/or disease, including the cognitive and/or physical manifestations of the disease and care needed due to problems associated with the aging process
- Both in-home and out-of-home care is needed for patients who are not confined to bed
- As such, the caregiver can receive the much needed mental break, either by relaxing in her/his home or by going on personal outings
- Furthermore, for those patients who do not have a significant physical disability, going outside the home provides physical and/or social stimulation
- Because many caregivers are grandparents and grandchildren have underlying emotional disturbances, it is difficult to find qualified and skilled respite caregivers
- The network for family caregivers is shrinking: in 1990, there were 11 potential caregivers per patient, whereas today the ratio is shrinking due to the fact that families tend to be smaller and more dispersed
- Depending on the area being served, 30 to 70 percent of caregivers have stress related disorders due to care-giving responsibilities
- Respite care should be consistent (two to three times per week) in order to best benefit recipients
- Employers do not often understand the needs of caregivers, and over \$29 billion per year is lost by businesses due to the care-giving responsibilities of employees

BARRIERS TO OBTAINING AFFORDABLE RESPITE CARE

- Because many activity centers are not equipped to handle individuals with certain disabilities, out-of-home care is sometimes not an option
- Transportation prohibits access to out-of-home respite care programs, especially for an individual with severe physical disabilities
- There is an extensive need for long-term respite care
- Individuals with Down's Syndrome develop Alzheimer's much earlier; but because they are young, they do not qualify for nursing home programs

BARRIERS TO PROVIDING AFFORDABLE RESPITE CARE

- The cost of insurance prohibits effective in-home respite care
- There are not enough funding resources, and the cost of operating a respite care program is expensive
- In programs like the Seniors Companion Program, lack of transportation hinders potential care-giving companions from traveling to the client

- The stigma associated with the phrase *day care* may hinder individuals from seeking help
- Many people do not understand what *respite* means and, therefore, are unaware of the services provided by respite care programs
- Many people confuse respite care with hospice care
- Many individuals wait too long to seek respite care, when the stress of care-giving has become too great
- Caregivers perceive care-giving as a familial duty and are, therefore, reluctant to relinquish care to a provider, especially within Hispanic and African American communities
- Caregivers feel guilty for relinquishing care to a provider
- Caregivers and clients may distrust outside care providers
- The elderly population, who are disabled due to problems associated with aging and living alone, are underserved with regards to respite care

SUGGESTIONS TO IMPROVING AWARENESS AND ACCESS TO RESPITE CARE PROGRAMS

- *Assessment*: proper assessment is needed to make sure the caregiver and patient are getting the services he/she needs
- *Collaboration*: the medical community should become more attentive to the needs of caregivers to see if care-giving is causing undue stress; the doctor could then provide resources for respite care
- *Counseling*: counseling services not only help families deal with the guilt and grief in dealing with relinquishing care to a care provider, but also may help to smooth the transition to institutionalized care
- *Transportation*: transportation proves to be a major barrier, but unfortunately few agencies provide assistance with transportation; it may be beneficial to assess how volunteer transportation programs operate in other areas to determine if such programs could operate in San Antonio
- *Education*: a prime way to educate the community about available resources for respite care is to collaborate with churches and other religious institutions or develop neighborhood initiatives and/or caregiver alliances, in which individuals who participate in respite care programs educate other community members about available resources
- *Communication*: increased dialogue is needed between recipients of respite care and providers to ensure needs are being met
- *Sliding Scale Fee*: allows the client to partake in an active role – “hand up not a hand out”
- *Referral System*: let caregivers and patients choose or recommend a respite care provider in order to build rapport