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# Supporting Latino Caregiving Families

El Portal: Latino Alzheimer's Project  
A Dementia Care Network

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## PROGRAM DEVELOPMENT AND EVALUATION TEAM

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Project Director (1996-2002)

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California State University - Los Angeles  
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# PRE-PROJECT ENVIRONMENT

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- No specialized dementia care programs/services targeting Latinos
  - 1 of 7 Alzheimer's Day Programs had Latino participants
- Only a handful of clients that could be identified in the greater east and southeast areas.
- No care management staff with dementia expertise.
- No caregiver support groups.
  - 1 of 66 caregiver support groups had Latinos participants
- View that families were taking care of their own.
- No published work existed describing a dementia program model geared specifically for U.S. Latinos.

# El Portal:

## Latino Alzheimer's Project

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- In 1992, the El Portal Latino Alzheimer's Project was created as an ethnic-sensitive, consortium services model bringing together mainstream agencies with ethnic agencies to provide an array of coordinated services to Latino dementia-affected families.

*Funded in part by the Administration on Aging - Alzheimer's Disease Demonstration Grant to States*

# SERVICE AREA

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- Los Angeles county's population reflects the California's cultural, linguistic, and ethnic diversity.
  - Other than English, Spanish is the most common language spoken at home.
  - Latinos represent 36% of the total population of Los Angeles county, 54% of the state's Latino population and nearly a fifth of the Hispanics in the United States.
  - The county's Latino population aged 60+ comprises 42% of California's elderly Latinos.
- The original El Portal's service delivery area consisted of east and southeast areas of Los Angeles county.

# LATINO CAREGIVERS

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- Older U.S. Latinos are expected to quadruple between 1990 and 2020
- The largest growth in the U.S. older Latino population will be in the state of California.
- Los Angeles County is home to the largest number of Latino older adults in the mainland U.S.
- U.S. Latino caregivers have historically underutilized dementia-specific care services.
- Latino caregivers are more likely to be younger, poorer, less educated, underemployed, and in significantly worse mental and physical health than their white counterparts

# ACCESS BARRIERS

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- Limited or no health insurance
- Low literacy
- Lack of formal/informal support networks
- Discrimination
- Trust
- Language differences
- Hidden cost of "free" services.
- Lack of awareness of services to dementia-affected adults.
- Inadequacy of Existing Services - Language, cultural perceptions, and within group difference regarding dementing illnesses may affect the provision of services if misunderstood by the service provider.

# GOALS, PRINCIPLES AND CONSIDERATIONS

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## **GOALS**

- Community Outreach, Networking and Awareness
- Coordination of Services and Service Delivery
- Program Expansion and Development
- Materials Evaluation, Development and Dissemination
- Monitoring, Evaluation and Quality Assurance

## **PRINCIPLES**

- Community Organizing
- Community Empowerment
- Capacity Building
- Mutuality/Reciprocity

## **CONSIDERATIONS**

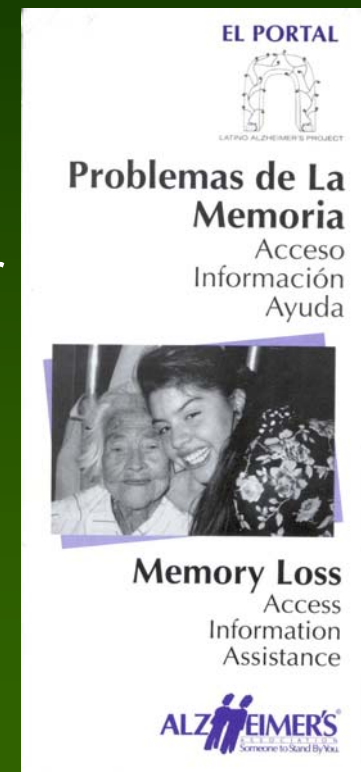
- Broad Support and Commitment
- Partnership and building of new relationships = time and flexibility
- Reciprocity and open communication
- Recognize the pervasive nature of culture

# STRUCTURE



# OUTREACH AND MARKETING

- The project name "El Portal" (the doorway or entrance) symbolize the goal of promoting access and entry to dementia care services.
- Spanish and English Helplines
- Bilingual print and electronic media advertising
- Marketing presentations to consumer and provider groups
- Media campaign through sponsorships
- Street outreach
- Advisory councils provided community input and increased awareness of the project by word of mouth.
- SAMPLE OUTCOMES:
  - Spanish-language Helpline calls increased by 50% from the pre-program period.
  - Nearly 90% of all callers identified themselves as Latino and caring for someone with memory loss.



# CONSUMERS

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## HELP-LINE CALLERS

- Female (Adult Child & Spouses)
- Primary Caregiver
- Prefer to Speak English
- First Time Caller
- Report No Services Used Prior to Contact

## CARE MANAGEMENT CLIENTS

- US Born, Female, Under 65 and Married
- More Fluent in English
- High School or Less
- Live With Elder
- 5 Years Caregiving
- Report Increased Nervousness & Depression

## ELDERS

- Under Doctor's Care
- Female, Age 75, U.S. Born Hispanic
- Spanish-Speaking
- Have Memory Problems
- Most Did Not Have AD Diagnosis

# SERVICE COMPONENTS

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- **Outreach** -- Community education and health promotion activities, marketing, and consumer recruitment.
- **Help-line** -- Toll free telephone information and referral services.
- **Care Management** – Screening, assessment, and care planning services, care coordination, service brokerage, family education and counseling, advocacy, and translations.
- **Legal Services** -- Services provided by an elder law specialist to assist with long-term care/legal issues.
- **Respite Care Services** -- Respite services provided by local adult day care programs or financial subsidies provided to families for purchase of respite care services in the home.
- **Support Groups** -- Family caregiver support groups provided in community settings.
- **Purchase of Services** – An array of services and/or products made available based on need, e.g., diagnostic evaluations, environmental modifications, counseling services, medical equipment, etc.

# OUTCOMES

Creating an environment that supports change!

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- Outreach to more than 50,000 Angelenos
- 5 Social Day Care Programs
- 4 Support Groups
- Services provided to more than 6,000 Latino families
- Provided skills building training to Latino professionals on serving dementia-affected adults and to dementia experts providing culturally competent care

## IN THE LITERATURE NOW !

- Aranda, MP; Villa, VM; Trejo, L; Ramirez, R; and Ranney, M. El Portal Latino Alzheimer's Project: Model Program for Latino Caregivers of Alzheimer's Disease-Affected People. *Social Work*, Vol. 48(2) April 2003.
- Montgomery, RJV (Ed.) A New Look at Community-Based Respite Programs: Utilization, Satisfaction and Development. NY: The Haworth Press (2002). Co-published as *Home Health Care Services Quarterly* Vol. 21(3/4) 2002.

# THE FUTURE

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## REPLICATION

### California

- African-American Families Dementia Care Network (Los Angeles), 1997
- Asian and Pacific Islander Projects – Japanese, Korean and Chinese (Los Angeles, Orange, San Francisco), 2000
- El Portal Dementia Care Network (Greater East Los Angeles and San Fernando Valley, San Diego), 1992

### Other replication sites:

- Milwaukee
- Seattle

## A CATALYST FOR CHANGE

- Opening of the Greater East Los Angeles office of the Alzheimer's Association
  - *The first health charity in Los Angeles County history to open a field office in a predominately ethnic minority community*

# BEYOND OUR BORDERS

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- Findings have been presented at professional and scientific meetings
  - El Salvador, Guatemala, Cuba, New Zealand, Argentina, Mexico and Korea
- Consultation and Training
  - Mexico, El Salvador, Guatemala, and Puerto Rico
- Replication
  - Grupo Hermita – Guatemala City, Guatemala, 1996
  - Puerto Rico - under discussion
  - Australia – under discussion