



# Different Journeys, One Unhealthy Road: Health Implications for Racially/Ethnically Diverse Family Caregivers of Persons with IDD or Alzheimer's Disease/Dementia

Judith S. Rocha, MSW, LCSW  
Sandy Magaña, PhD, MSW  
University of Illinois at Chicago

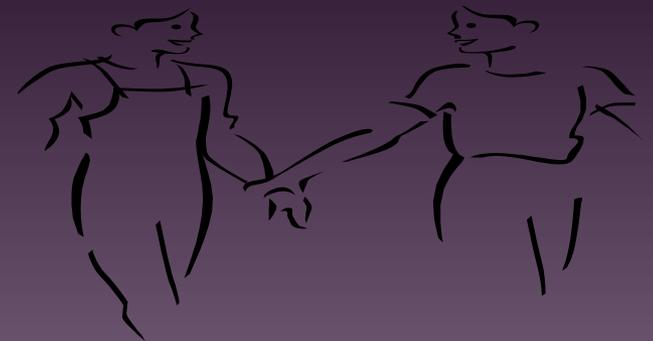
# Overview of Presentation

- Introduction
- Health among African American and Latina mothers of children/adults with IDD
- Health among Latino caregivers of family members with Alzheimer's disease (AD)
- A culturally responsive intervention focused on the caregiver's health and well-being
- Using research as a tool to inform policy
- How do we become better advocates, allies, and companions in their journey



# Families of Adults with IDD

- More than half of adults with developmental disabilities (DD) live with their families
- African American and Latino persons with DD are more likely to live with their families
- Parents are often involved with the care for as long as they are able





# People of Color: Unique Experiences

- People of color experience environmental contexts, ecological circumstances and structural oppressions that are not shared by Whites
- Chronic exposure to many stressors
- Health disparities – especially chronic conditions



# Research on Racially/Ethnically Diverse Caregivers

- Studies on African American caregivers
  - Report less burden, similar levels of depression compared to White caregivers
  - Religion an important coping resource
- Studies on Latino caregivers
  - Experience burden and depression at higher levels than their White counterparts
  - Family support and family well-being important for maternal well-being
- Both groups have been found to be severely disadvantaged (low education, income and poor health).

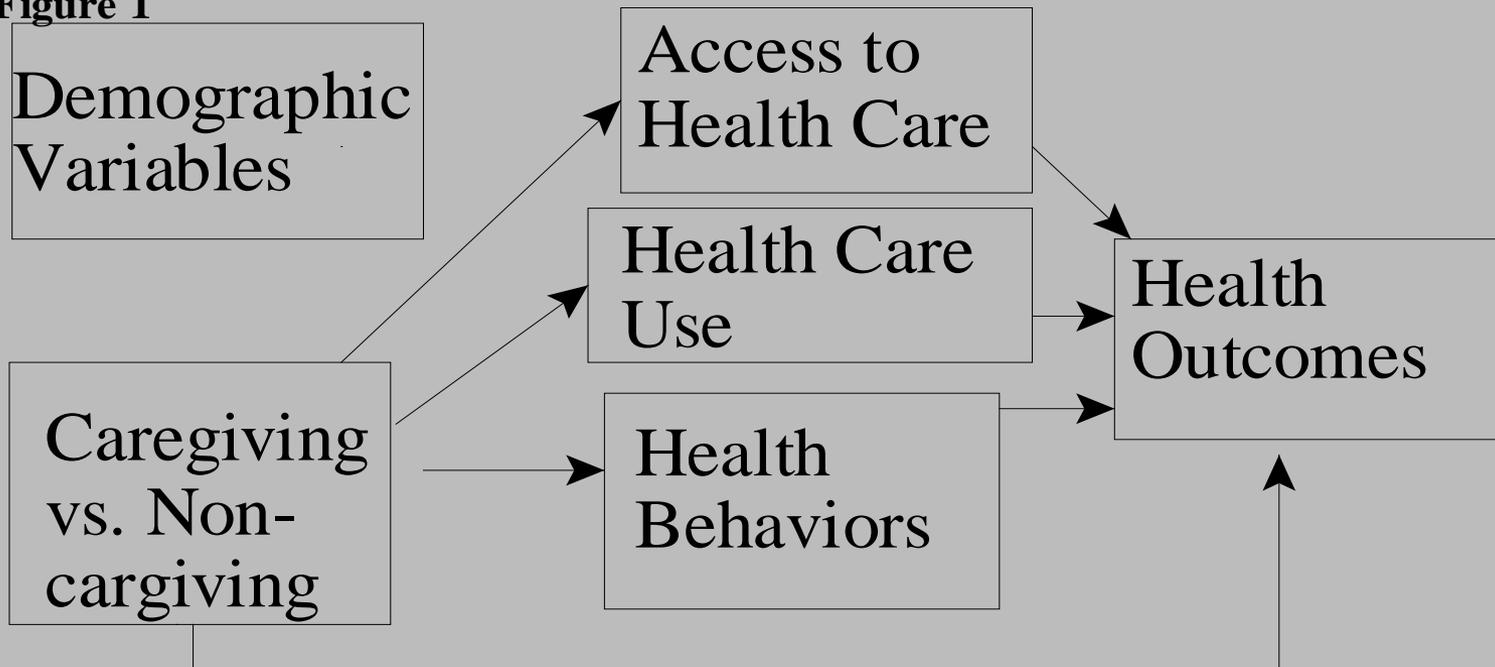


# Current Study

- Used a representative sample from which both comparison groups are drawn
- Examined similar issues within each group of African American and Latino caregivers
  - physical and mental health outcomes
  - health behaviors, healthcare use and access

# Conceptual Framework

Figure 1





# Sample

- National Health Interview Survey (NHIS)
  - Multi-purpose health survey conducted by the National Center for Health Statistics (NCHS), Center for Disease Control and Prevention (CDC)
  - Over-sampled both African American and Latino populations
  - Used 3 years of the NHIS combined to ensure large enough DD minority sample

# Sample

- 79 Black American and 83 Latina mothers who were 40 and older and co-resided with a child with a DD
- Mean age of the persons with DD was 17.9 (SD = 11.3)
- 59.4% of care recipients were male
- Majority identified as having mental retardation, or other developmental disability
- Comparison- 1087 Black, 1667 Latina

# Findings: Health Outcomes

- Outcome measures:



- Diagnosed with hypertension, heart problems, asthma, diabetes
- Conditions that limit activity: arthritis, hypertension, diabetes
- 5 depressive symptom items





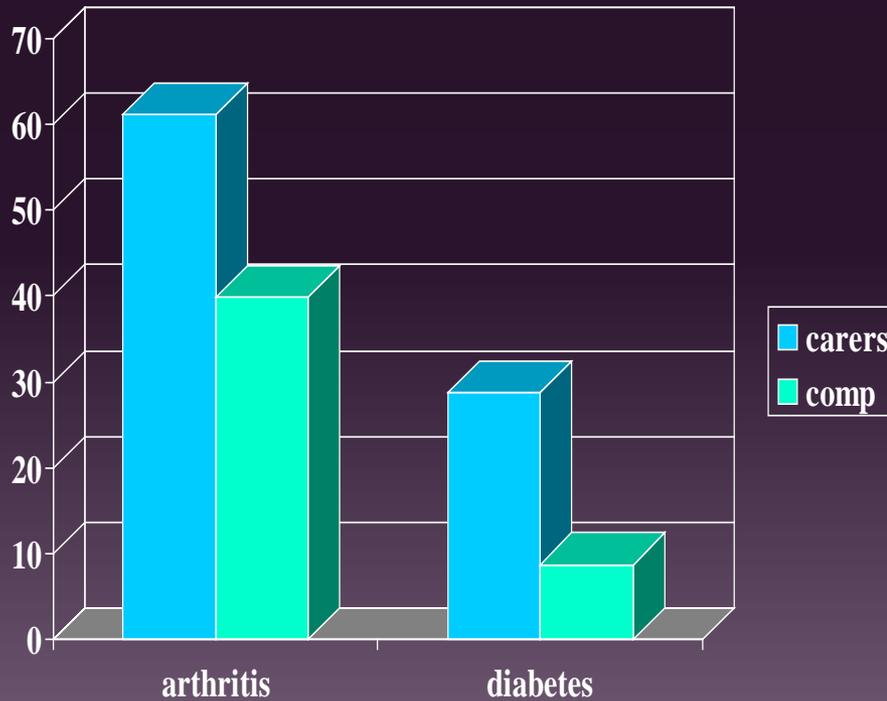
## Findings: Health Behaviors, Healthcare Use and Access

- Health behaviors: smoking, drinking, exercise, obesity
- Healthcare use: have seen mental health professional, general practitioner, OT or PT
- Access: can't afford MH care or prescription meds, have insurance

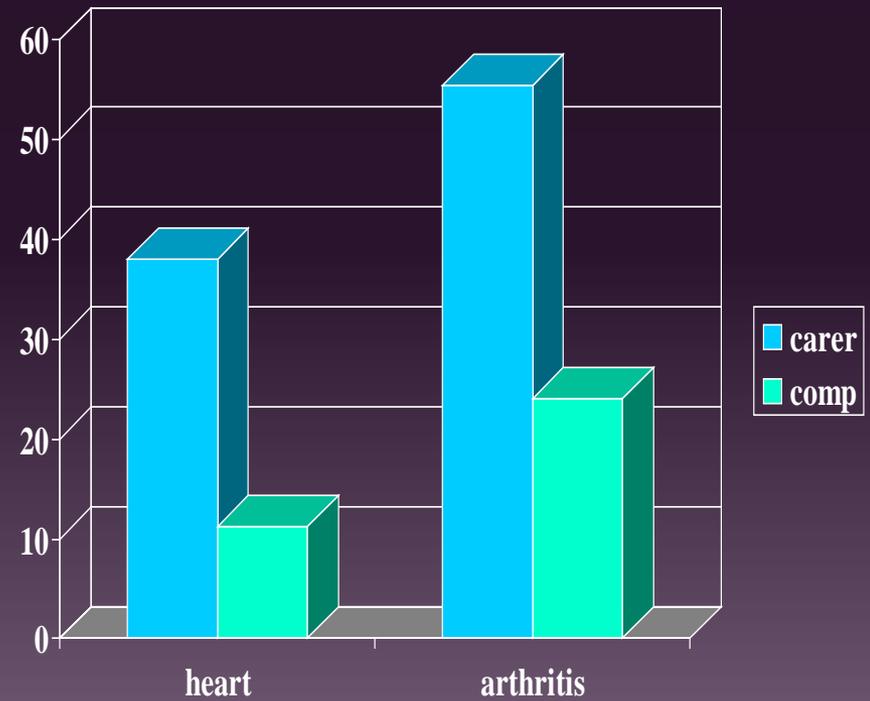


# Physical Health

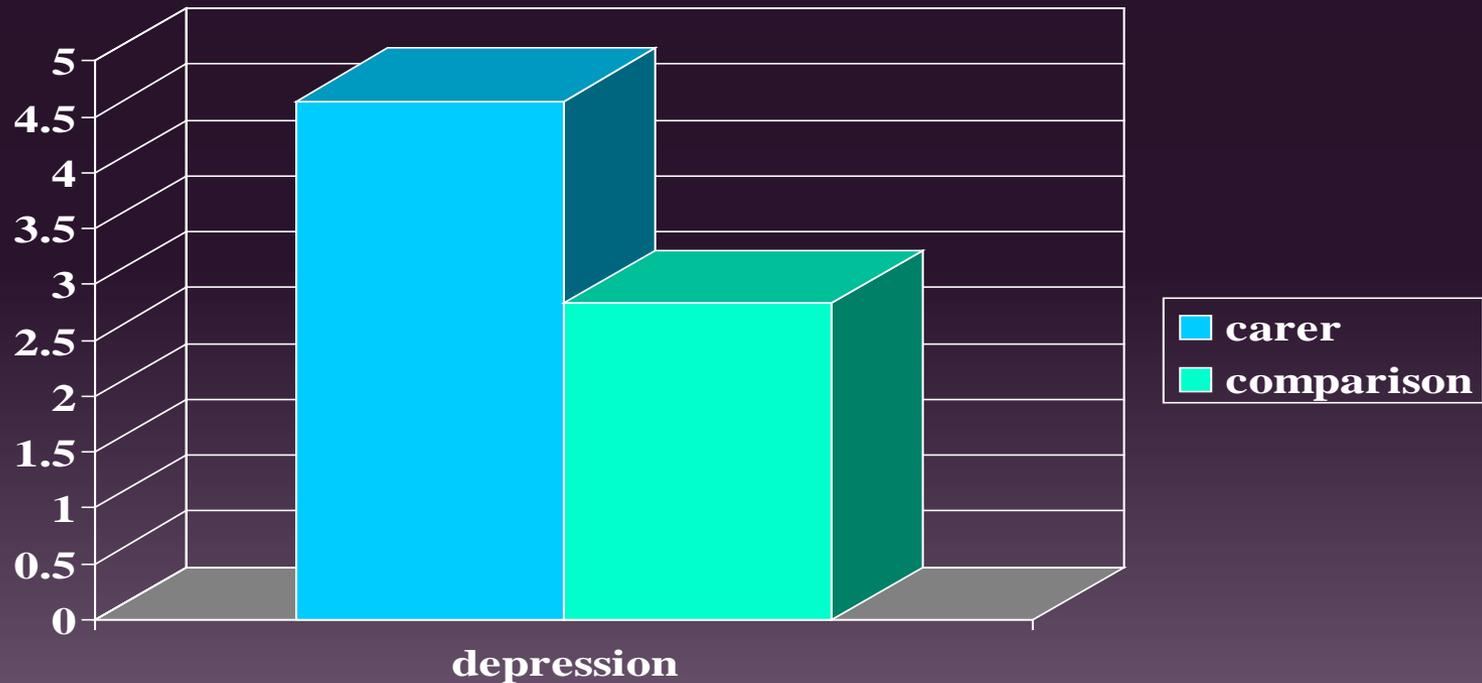
## Older Black American Women



## Older Latinas

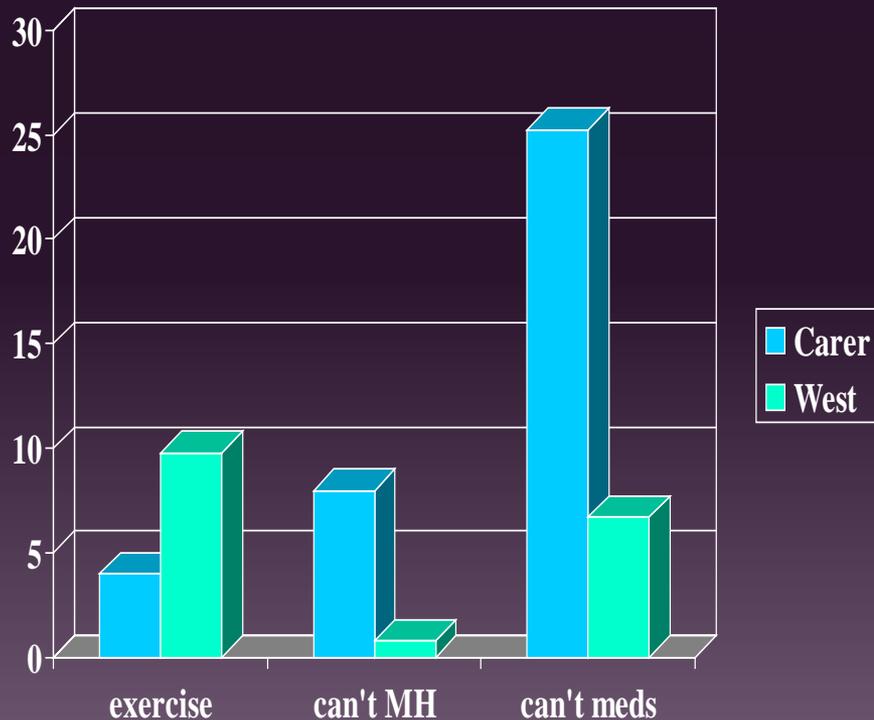


# Midlife Latinas: Mental Health

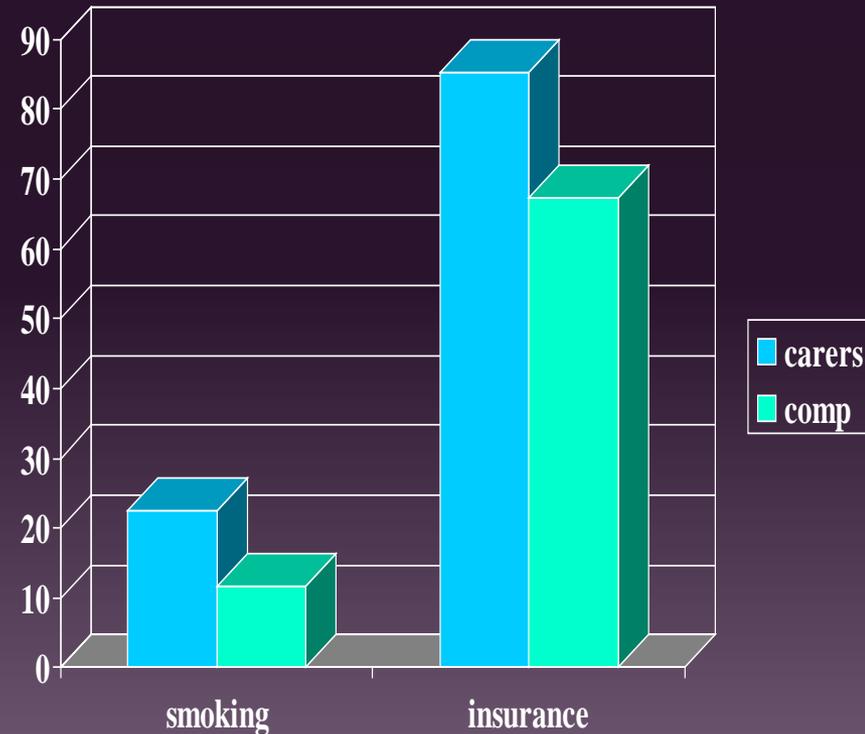


# Health Behaviors and Healthcare Access

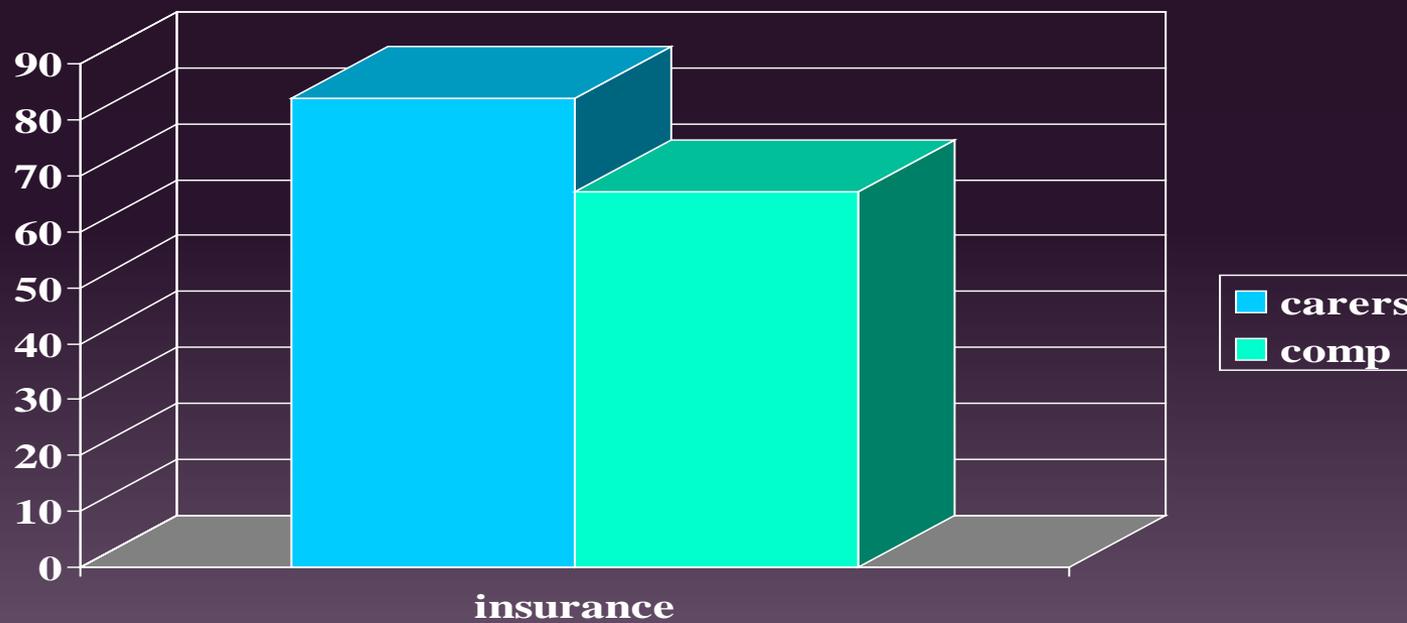
## Black American Women



## Midlife Latinas

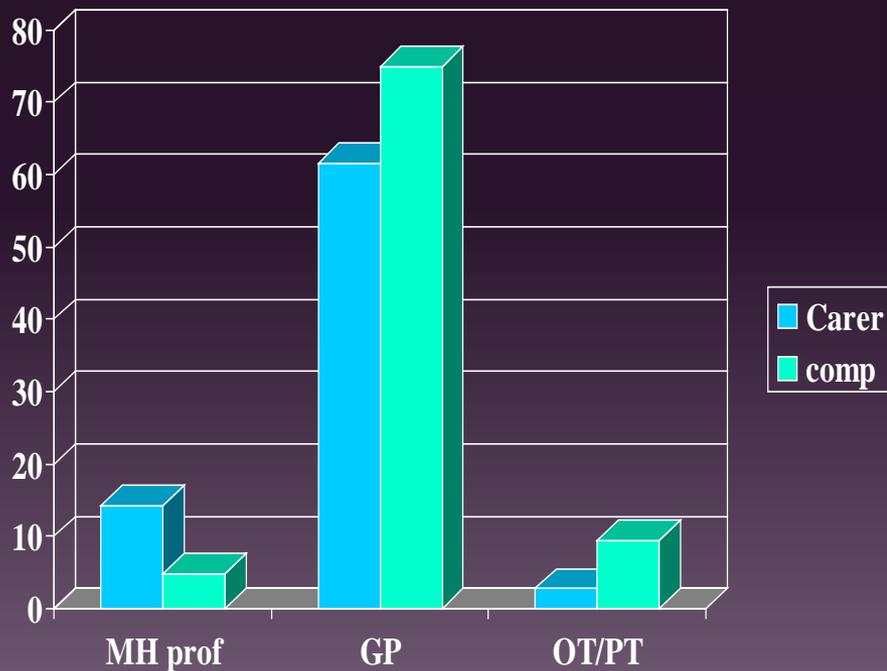


# Foreign born Latinas



# Healthcare Utilization

## Black American Women



## Older Latinas





## Summary of findings

- Older caregivers were more likely to report having physical health problems than non-caregivers
- Caregiving was associated with more depressive symptoms for Latinas
- Caregivers less likely to see doctor
- Black caregivers less likely to afford prescriptions and mental health care and less likely to exercise
- Latina caregivers more likely to have insurance and to smoke

# The Health of Latino Alzheimer's Family Caregivers

- Latino caregivers are affected by higher levels of caregiver burden and lower general health as compared to non-Latino Alzheimer's caregivers
  - More bodily pain and somatic symptoms
  - Worsened health and physical strain
  - Diminished cognitive function
  - Obesity in Latinas
  - More depression and higher levels of caregiver burden



# Caring for Myself



Care giving  
role as  
primary  
responsibility



Support  
services  
aimed at  
child, little  
for care  
givers

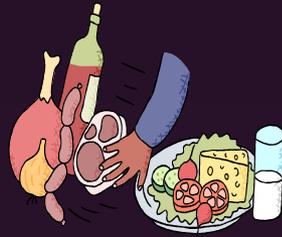


Need for  
culturally  
appropriate  
intervention  
focused on  
health of Latina  
mothers



# Caring for Myself

- A culturally responsive intervention focused on the caregivers health and well-being
- Use of the *Promotora de Salud* peer educator model
- Original intervention focused on IDD caregivers but adaptation for AD in progress



# Caring for Myself

- Eight week health education program – group or home-based

- **Session One:** Taking care of oneself & pre-test
- **Session Two:** Health care
- **Session Three:** Well-being activity
- **Session Four:** Nutrition
- **Session Five:** Exercise
- **Session Six:** Stress & depression
- **Session Seven:** Including others
- **Session Eight:** How to sustain growth & post-test

# Caring of Caregivers Organically (CoCO)

- Adaption for family caregivers of persons with Alzheimer's disease or related dementia (ADRD)
- Focus groups have occurred with Latina family caregivers as well as service providers and content area experts
- Adaptation of manual in progress



# Caring of Caregivers Organically (CoCO)

- Rather than *Promotoras* the intervention will be administered in a group by *Compañeras*
- A session will be added that talks about the condition, trajectory of care and some helpful tips for caring for a person with AD or dementia
- Pilot with 20 Latina family caregivers - 10 randomized into the intervention group and 10 into a control group

# Research to Inform Policy

July 2006

## Disability Research Brief IDHD

### Institute on Disability and Human Development

#### Health Outcomes of Midlife and Older Adult Latina and Black American Mothers of Children with Disabilities

UIC Department of Disability and Human Development  
UNIVERSITY OF CHICAGO COLLEGE OF APPLIED HEALTH SCIENCES

#### Racial and Ethnic Disparities in Developmental Disabilities



Disability

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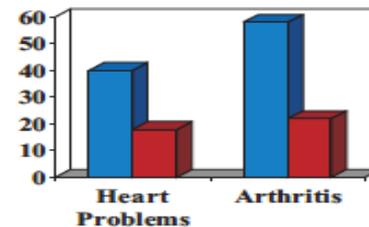
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Nearly 5 million families cope with the developmental disability of a relative, with a large majority of these families providing care for this individual. Although the impact of caring on the well-being of parents of children with developmental disabilities has received much attention among European Americans families, this impact is not well understood among families of color. Families of color often experience differences in resources and socioeconomic status that make their responses to the challenges of caregiving unique from those of European Americans.

#### Differences in Specific Health Problems among Caregiving and Non-Caregiving Women

##### Older Latina Caregivers



#### Findings:

Older Latina caregivers were more likely than older non-caregivers to report:

- being diagnosed with heart problems
- arthritis as a condition that limits their physical activity

As a result, this study reports on cultural, social, and educational health intervention for Latina mothers who care for youth and adults with

test. Repeated-measures analysis of covariance was used to examine

Bandura (2007), this is a prerequisite to actual

For this databrief we looked at the sibling role in long-term care for their family member with intellectual and developmental disabilities (IDD). Our purpose was to assess the choice and control measures for sibling caregivers and their respective family member with IDD to see if

Overview





# Advocates, Allies, and Companions

- Understand that the caregiver and their family are the experts of their journey and they should be made to feel that way with regards to direct service practices, research and policies
- Join existing and/or create coalitions to address gaps that are evident



# Advocates, Allies, and Companions

- Become very visible to your legislators/policy makers and mobilize efforts to present research findings, personal testimonies that give a face to your cause, and strategies that address structural change and best practice models
- Identify (legislative & funding) champions and keep them well informed and close

# In Congress Currently

- **Family and Medical Insurance Leave Act or the FAMILY Act - [H.R. 947](#) and [S. 337](#)**

Provides paid family and medical leave for up to 12 weeks for workers to care for a newborn or adopted child, a seriously ill family member, or their own serious health condition.

*Sponsor:* Representative Rosa L. DeLauro (D-CT); Senator Kirsten E. Gillibrand (D-NY)

# In Congress Currently

- **Social Security Caregiver Credit Act - [H.R. 3377](#) and [S. 2721](#)**

Provides a social security credit to be added to a person's total career earnings for a maximum of 5 years and used to calculate future social security benefits. This would benefit caregivers who spend at least 80 hours a month providing unpaid care. This includes caregivers of a parent, aunt, uncle, grandchild, niece, nephew, spouse, or domestic partner.

*Sponsor:* Representative Nita Lowey (D-NY); Senator Chris Murphy (D-CT)

# Social Security Credits

- In 2017, for every \$1,300 of worked earnings, one credit is earned
- Maximum of 4 credits per year can be earned and in 2017 one would need to earn at least \$5,200 ( $\$1,300 \times 4$ ) to get the 4 credits for the year
- Need 40 credits (10 years) to qualify for retirement benefits
- An average indexed monthly earnings (AIME) amount is calculated using the worker's highest 35 years worth of earnings. If you did not have 35 years of earning then zeros are added to those years with no earnings and an average is taken from 35 years. Adding zeros to divide by the 35 years would thus lower the AIME so that is where being deemed an earnings credit for up to 5 years of caregiving would help an individual that has not been working during that time.

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