

Supporting Better Outcomes:

The Role of the Family Caregiver and the Aging Network in the Chronic Care Model

Session Overview

- **Introduction of Panel**
- **Session Overview**

THE IMPORTANCE OF CAREGIVING FROM A PHILANTHROPIC PERSPECTIVE

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THE IMPORTANCE OF CAREGIVING FROM A PHILANTHROPIC PERSPECTIVE

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THE IMPORTANCE OF CAREGIVING FROM A HEALTHCARE PERSPECTIVE

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CAREGIVING FROM THE HEALTH CARE PERSPECTIVE

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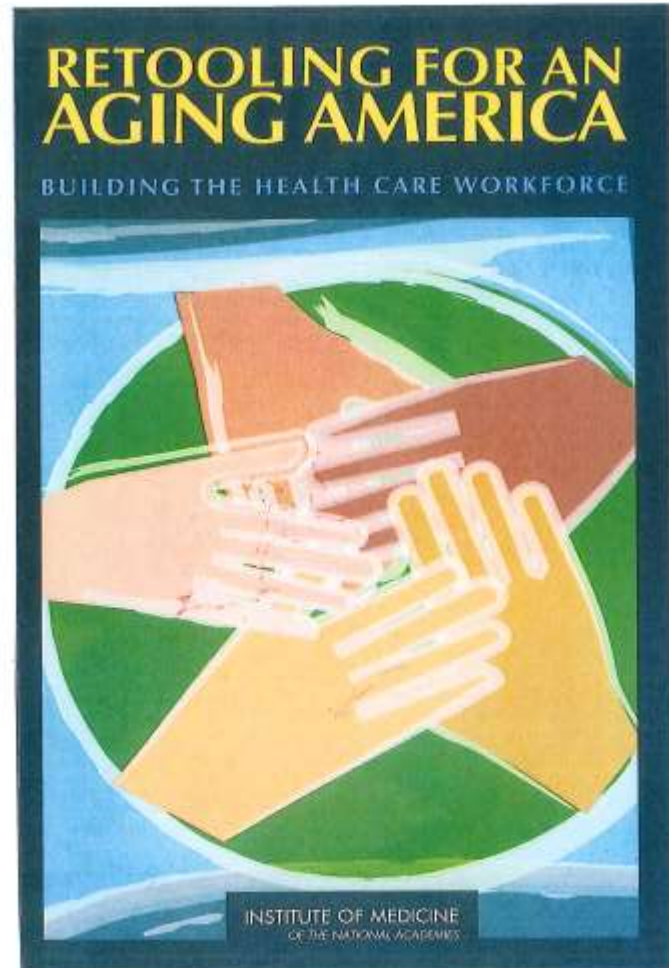
THE “INVISIBLE WORKFORCE”

More than 43 million Americans are family caregivers for adults age 50 and older with chronic and acute illnesses.

Approximately 35 million Americans are family caregivers for adults age 65 and older with chronic and acute illnesses.

THE “INVISIBLE WORKFORCE”

“... family members, friends and other unpaid caregivers provide the backbone for much of the care that is received by older adults...”



THE “INVISIBLE WORKFORCE”

“Ultimately, any plan for enabling informal caregivers and patients to become more capable members of the health care team is likely to require increased training along with support from and integration with the formal health care system.”

Family Matters in Health Care Delivery

Jennifer L. Wolff, PhD

THE RELEVANCE OF FAMILY, BROADLY DEFINED AS encompassing blood relatives as well as trusted friends and partners, influences health and health care across the life span. The considerable economic value conferred by families to patients and the health system is also widely acknowledged. According to a Congressional Budget Office report, "The value of donated care probably exceeds that of any other category of long-term care financing but is difficult to quantify in dollar terms."¹ According to an Institute of Medicine report entitled *Retooling for an Aging America*, "the entire health care workforce, including both formal and informal caregivers need to have the requisite data, knowledge, and tools to provide high-quality care."²

Although conceptually embraced by policy makers and professional societies, the health care system's orientation toward family is often an afterthought. Barriers to systematic and explicit acknowledgment and support of families include the bioethical emphasis on patient autonomy, legal concerns surrounding patient privacy and confidentiality, and the prevailing health insurance model grounded in individual coverage. Reimbursement systems predicated on 15-minute medical encounters limit physicians' ability to engage family members when they are present. It is therefore not surprising that anecdotal reports describe the family-clinician relationship as tense and sometimes adversarial, resulting in costly outcomes that are inconsistent with patient preferences.³ With rare exception, health system policies and infrastructure to support the patient-family-clinician partnership are absent.

This Viewpoint suggests that more explicit acknowledgment and support of family in health care processes could advance the triple aim of better health, higher-quality care, and reduced costs for patients who are vulnerable and whose care is most costly. Family members now serve as a largely hidden workforce at the intersection of medical and long-term care delivery. Within the medical system, patients' family members engage in varied activities that pertain to medical decision making, ongoing monitoring and adherence to prescribed treatments, and coordination and management of health information across clinicians and health care delivery settings.³ In the realm of long-term care, ongoing fam-

ily involvement and provision of hands-on help with personal care and household activities is often pivotal for continued community residence of those who are vulnerable and disabled.

The absence of systematic ascertainment of family participation in health care impedes credible accounting of the value conferred by the efforts of family members, knowledge of how their involvement influences clinical care and quality, or an understanding of benefits that might result from a stronger patient-family-clinician partnership. In view of recent endeavors to promulgate health system transparency, accountability, and efficiency in the delivery of care, the time is ripe for change. Uptake of electronic health records affords better capture of patient health care encounters and raises the possibility of incorporating both patient-reported as well as external (eg, family)-reported measures in public reporting and clinical care. Accreditation activities related to the Patient-Centered Medical Home and Accountable Care Organizations involve documentation of core elements of quality care processes, with commensurate measurement opportunities. That person- and family-centered care has been embraced as 1 of 6 major initiatives in the National Priorities Partnership of the National Quality Forum,⁴ and that caregivers are explicitly mentioned in the mission of the recently established Patient-Centered Outcomes Research Institute suggest an appreciation of family relevance in health reform and quality improvement efforts.

More explicit and systematic documentation of patients' authorized preferences for family member access to personal medical information would enhance patient-centeredness of health care delivery. In a survey of 18 471 veterans, 79% of respondents expressed an interest in designating shared access to their My HealthVet personal health record—most often to a spouse (62%) or other relative (38%), followed by other health care practitioners (25%).⁵ Facilitating broader access to patients' medical information in accordance with patient-expressed wishes could help to clarify and streamline delegation of logistical and management activities when desired, improve coordi-

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FAMILY MATTERS IN HEALTH CARE DELIVERY

“This Viewpoint suggests that more explicit acknowledgement and support of family in health care processes could advance the triple aim of better health, higher-quality care, and reduced costs for patients who are vulnerable and whose care is most costly.”

Jennifer Wolff, PhD, JAMA 2012

OCTOBER 2012



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HOME ALONE:

*Family Caregivers Providing
Complex Chronic Care*



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funded by



MEDICAL/NURSING TASKS

Almost half (46%) of family caregivers performed medical/nursing tasks for care recipients with multiple chronic physical and cognitive conditions.

MEDICATION MANAGEMENT

Three out of four (78%) caregivers who provided medical/nursing tasks were managing medications, including administering intravenous fluids and injections.

WOUND CARE

More than a third (35%) of caregivers who provided medical/nursing tasks reported doing wound care.

CARE COORDINATION

More than half (53%) of caregivers who performed medical/nursing tasks coordinated medical care.

INSTITUTIONALIZATION

Most family caregivers who provided help with five or more medical/nursing tasks believed they were helping their family member avoid institutionalization.

RECOMMENDATIONS

Individual health care professionals must fundamentally reassess and restructure the way they interact with family caregivers in daily practice.

RECOMMENDATIONS

Health care organizations must support health care professionals in their efforts through adequate resources and strong leadership.

RECOMMENDATIONS

Researchers should conduct further studies to understand medical/nursing tasks performed by different types of family caregivers and their needs for training and support.

PROGRAM OBJECTIVES

Compile an inventory of existing resources, programs and organizations whose efforts touch low-income older adults and their family caregivers.

PROGRAM OBJECTIVES

Identify gaps in service delivery and referral linkages and facilitate the development of resources to fill the gaps.

PROGRAM OBJECTIVES

Convene stakeholders and facilitate structured, purposeful, and continuous interactions, supported by technology, that strengthen linkages to and across resources, programs, and service providers serving family caregivers.

PROGRAM OBJECTIVES

Identify at-risk caregivers as early as possible and facilitate appropriate service use through information technologies that follow the principle of “no wrong door.”

BRIDGE TO HOME

A **HEALTH BUDDY** is a person chosen by a patient who will provide extra support when he or she leaves the hospital.

A **HEALTH BUDDY** will be educated by hospital staff and be a partner in health.

“Sometimes, it’s just as simple as having a **familiar face** help arrange a ride or assist in getting prescriptions picked up.”



Health Buddy Agreement

Being discharged from the hospital can be very challenging for patients

A Health Buddy can help

PROGRAM OBJECTIVES

Engage in public and service delivery provider awareness campaign efforts to increase knowledge of available resources.

PROGRAM OBJECTIVES

Improve coordination of care and communication between health care providers and family caregivers, and provide systematic support and appropriate referrals to services.

There are only four kinds of people
in the world:
Those who have been caregivers,
Those who are currently caregivers,
Those who will be caregivers,
And those who will need caregivers.

Rosalynn Carter

BRINGING TOGETHER PHILANTHROPY, HEALTHCARE, AND THE AGING NETWORK

Carol Zernial, MA

Executive Director

WellMed Charitable Foundation

The Background

- One in four US adults are caregivers caring for an adult family member, partner or friend with chronic conditions or disabilities.
- The average caregiver is a 49 year old working woman who provides 20 hours per week in care.
- The presence of a family caregiver during physician visits has been shown to facilitate communication and increase patient satisfaction.

Medical or Health Care Home

The medical home, in reality, is the home of the person with chronic care needs cared for by a family caregiver

L Feinberg, SC Reinhard, A Houser, and R. Choula, *Valuing the Invaluable, 2011 Update – the Growing contributions and costs of Family Caregiving*, AARP Public Policy Institute INSIGHT on the Issues (Washington, DC: AARP, 2011)

Home Alone: Family Caregivers Providing Complex Chronic Care

- A new study from the United Hospital Fund and the AARP Public Policy Institute released in October 2012
- 46% of caregivers perform “medical” or “nursing” tasks

Medication Management

- **78% managed many different kinds of medications**
 - 5-9 prescriptions each day
 - Intravenous fluids and injections
- **60% learned how to manage at least some of these on their own**
- **47% never received any training of any kind**
- **Caregivers are afraid of making a mistake and harming their family member**

Wound Care

- **35% of caregivers provide wound care**
 - **Ostomy care**
 - **Pressure sores**
 - **Application of ointments and bandages for skin care**
- **66% found this very hard**
- **47% were afraid of making a mistake**
- **36% received some training, usually from home health organization**

Heavy Medical Burden

- Those caregivers who performed 5 or more medical tasks were more likely to feel depressed
- They believe they are helping their family member avoid being placed in a nursing home.
- 57% felt they had no choice

“How has doing these medical/nursing tasks affected your own quality of life?”

Caregiver Responses:

“In the last year and a half, I have developed high blood pressure, diabetes, and weight gain so now I have sleep apnea.”

“What life?”

Chronic Care Model

The Chronic Care Model

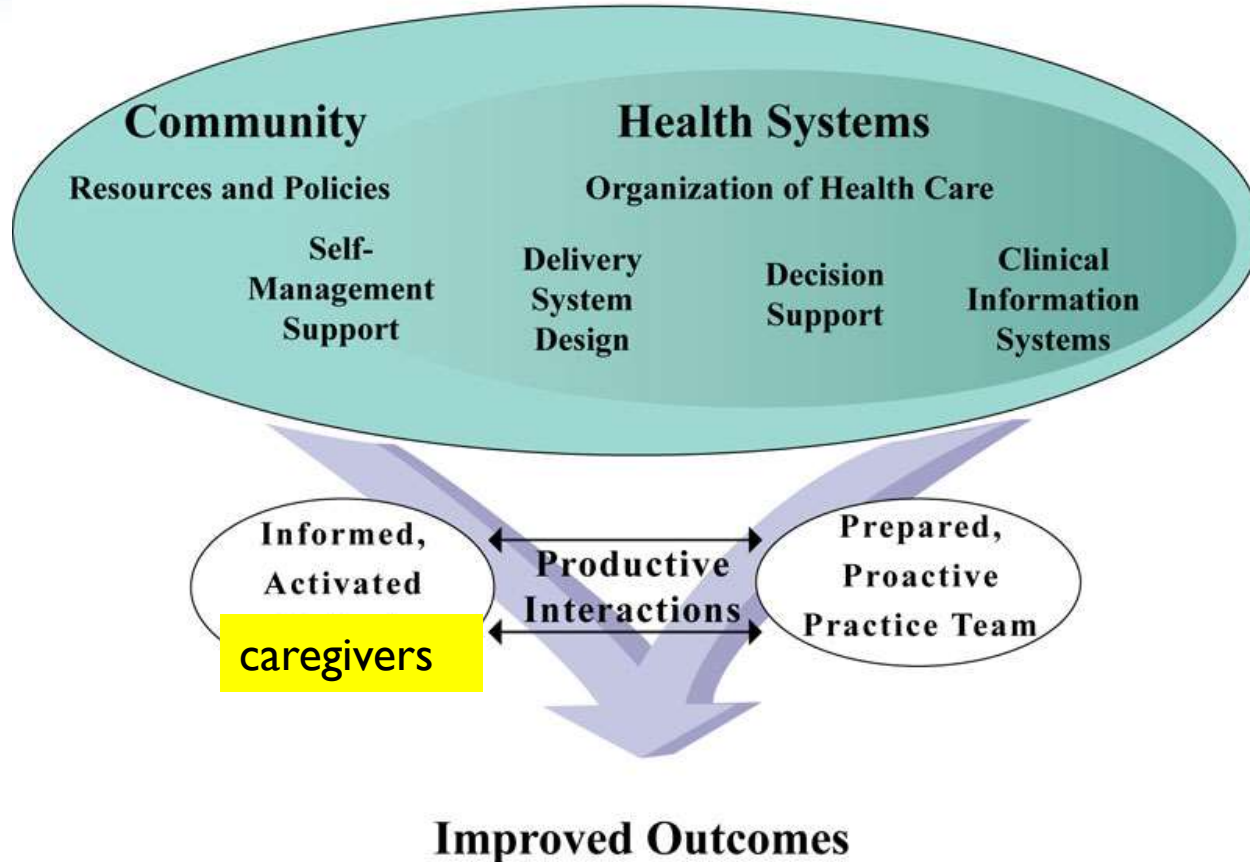


Care Transitions

- High levels of caregiver burden and/or depression are associated with problematic discharges.
- Risk of re-hospitalizations occurs when the family caregiver feels unprepared for care in the home.
- Between 40 and 50 percent of readmissions are linked to social problems and lack of community resources.

Chronic Care Model for Caregivers

The Chronic Care Model



Positive Interventions

- **Involving family caregivers in discharge planning during care transitions may improve quality of care and lessen risk of readmission.**
- **Goals:**
 - **Understand instructions for medication and self care**
 - **Recognize symptoms that signify complications**
 - **Make and keep follow-up appointments**
 - **Engaged and activated caregivers as members of the health care team**

Person/Family Centered Approaches

- In 2008, the American College of Physicians endorsed ethical guidance to physicians emphasizing the importance of the patient-caregiver-physician relationship.
- United Hospital Fund initiative to improve quality of care by regularly recognizing, training, and supporting family caregivers.
- Programs with a combination of education, skills training, coping techniques, and counseling show positive results.

The Costs of Doing Nothing

- **17-35% of caregivers have significant chronic health issues, such as heart disease, diabetes, sleep problems, and increased use of psychotropic drugs.**
- **Caregivers of persons with dementia were more likely to have an emergency room visit or hospitalization.**

Involving family caregivers in a meaningful and practical way, and supporting their own health care needs, should be a key component in all new models of care to promote better care, improve the experience of care, and reduce costs.



EXAMPLES OF RESEARCH AND EVIDENCE-BASED CAREGIVING PROGRAMS

Stress-Busting Program for Family Caregivers

- **Multi-component program in a support group setting**
- **9 weeks**
- **1 ½ hours/week**
- **Led by 2 group facilitators**



Session 1

Getting Started

- **Introductions to the program**
- **Hearing the caregivers' stories and building support**



Stress Management Technique

Relaxation Breathing

- **A simple and most effective way to stop the stress response:
Relaxation (abdominal) breathing**



Session 2

Stress: Effects on Mind, Body, and Spirit

- **General concepts of stress**
- **Negative effects on physical and emotional health**



Principle Underlying Stress Management

- You may not be able to change the stressors in your life
- But *you can choose* how you react or respond to them



Stress Management Technique

Meditation

- **A state of**
 - **Thoughtless awareness**
 - **Profound, deep peace that occurs when the mind is calm and silent, yet completely alert**



Session 3

Caregiver Stress and Relaxation

- **Stress related to being a caregiver**
- **Creating a relaxation environment**



Stress Management Technique

Imagery

- **Use of one's mind to generate images that have a calming effect on the body**



Session 4

Challenging Behaviors of People with Dementia

- **Common behavioral problems of patient with dementia and ways to deal with them**



Stress Management Technique

Journaling

- **Allows an individual to express self in writing**
- **Ask caregivers to write about the positive aspects of caregiving**



Session 5

Grief, Loss, and Depression

- **Losses related to Alzheimer's disease**
- **Ongoing grief**
- **Resulting depression**



Stress Management Technique

Massage

- **Works well for relaxation of caregiver**
- **Hand massage also helps dementia patients who are agitated**



Session 6

Coping with Stress

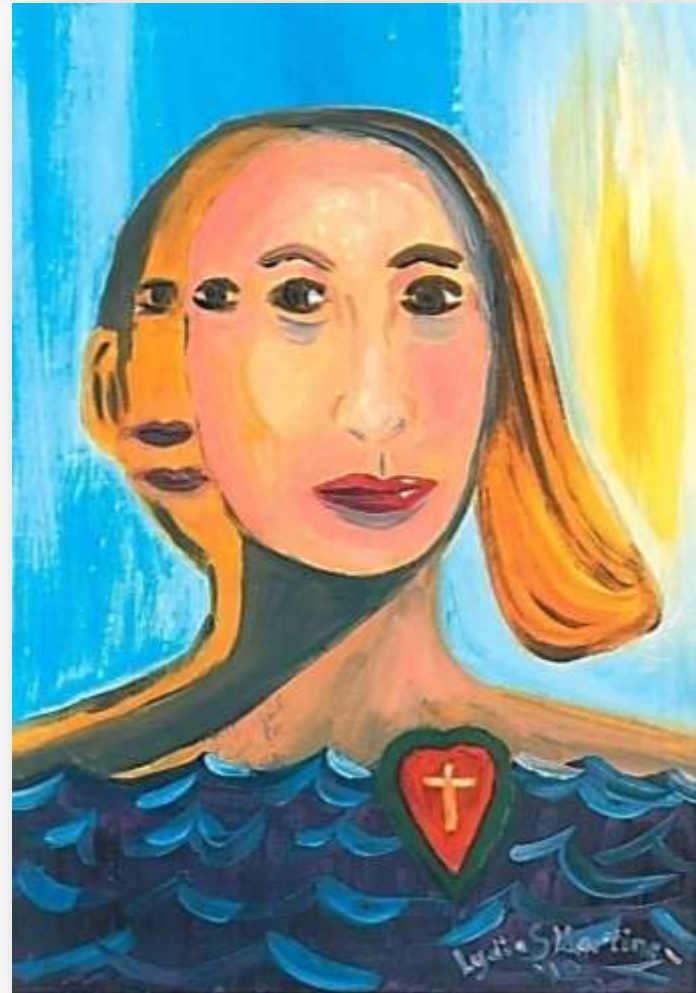
- **Changing family relationships**
- **Using coping strategies**
- **Humor**



Stress Management Technique

Art

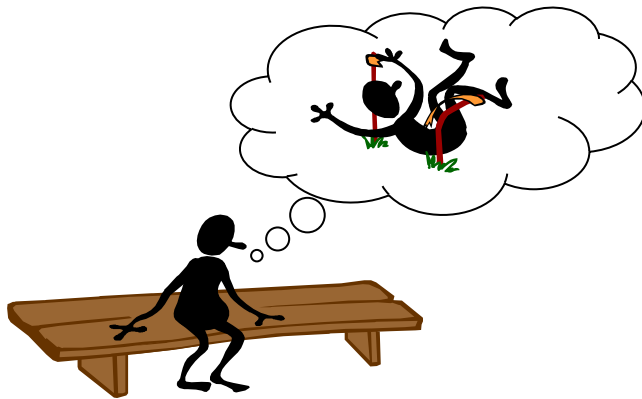
- **Allows a person to nonverbally express and communicate feelings, emotions, and thoughts**



Session 7

Positive Thinking

- **For some caregivers just thinking about the positive aspects can “reframe” their role and help it seem more manageable**



Stress Management Technique

Aromatherapy

- **Use of essential oils for the beneficial effects on the mind, body, and spirit**



Session 8

Taking Care of Yourself: Healthy Living

- **Caregivers frequently devote themselves totally to their loved one**
- **In the process, neglect their own needs**



Session 8

Taking Care of Yourself: Healthy Living

Exercise



Nutrition



Sleep



Hobbies



Stress Management Technique

Music

- **Music can help achieve a relaxed state**



Session 9

Choosing a Path of Wellness

- **Putting it all together**
- **Setting goals**



Stress-Busting Program

Why is it Effective?

Cornerstones

- **Facilitators**
- **Nurturing of caregivers**
- **Program content**

Stress-Busting Program for Family Caregivers

- **Evidenced-based program at the highest level of criteria**



Stress-Busting Program

Master Trainers

- **Training (2 days)**
- **Responsibilities**
 - **Recruit caregiver participants**
 - **Co-facilitate groups**
 - **Train group facilitators (lay leaders)**

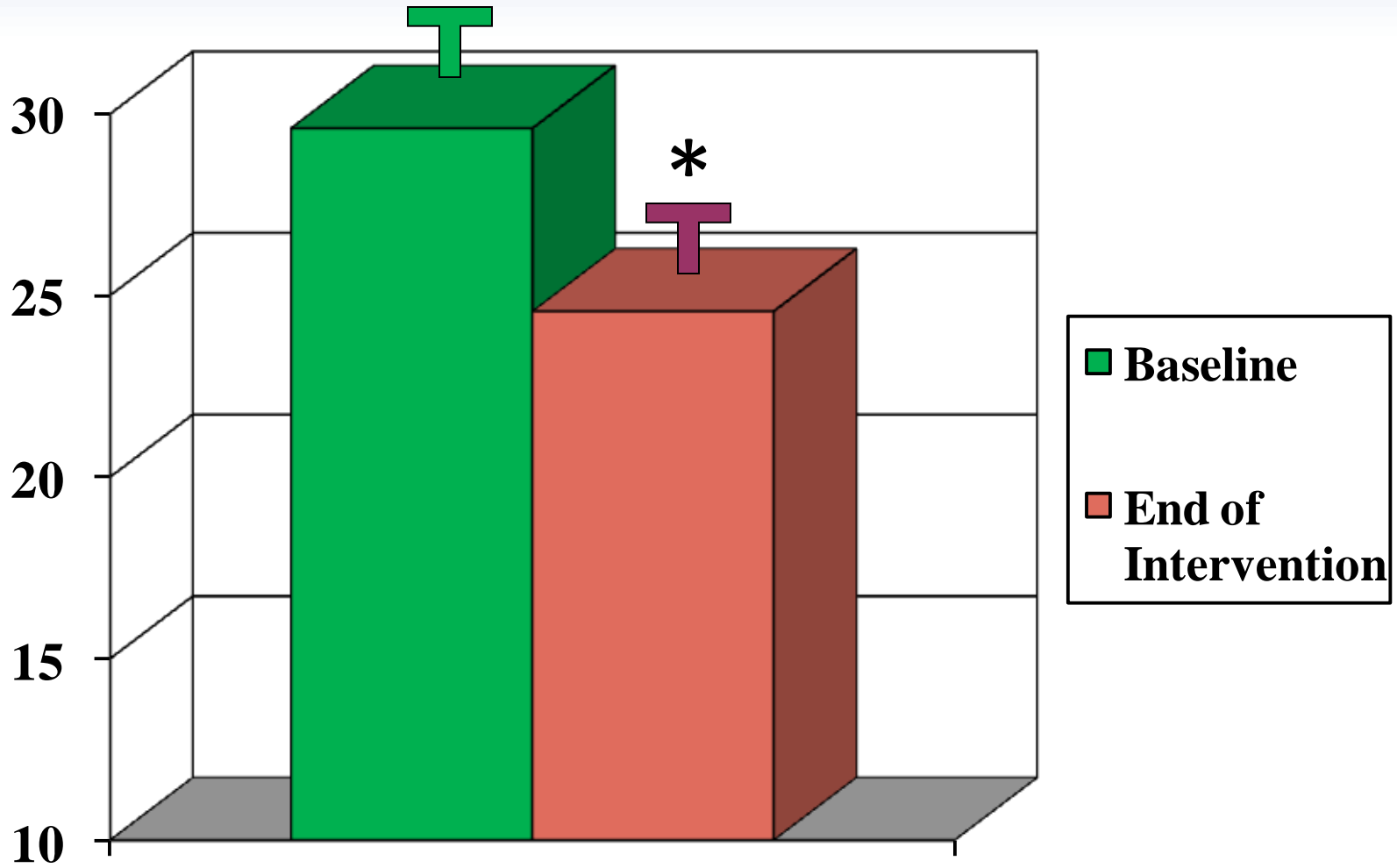
Stress-Busting Program

Group (Lay) Facilitators

- **Training (2 days)**
- **Responsibilities**
 - **Co-facilitate groups**
 - **Assist in recruiting caregiver participants**

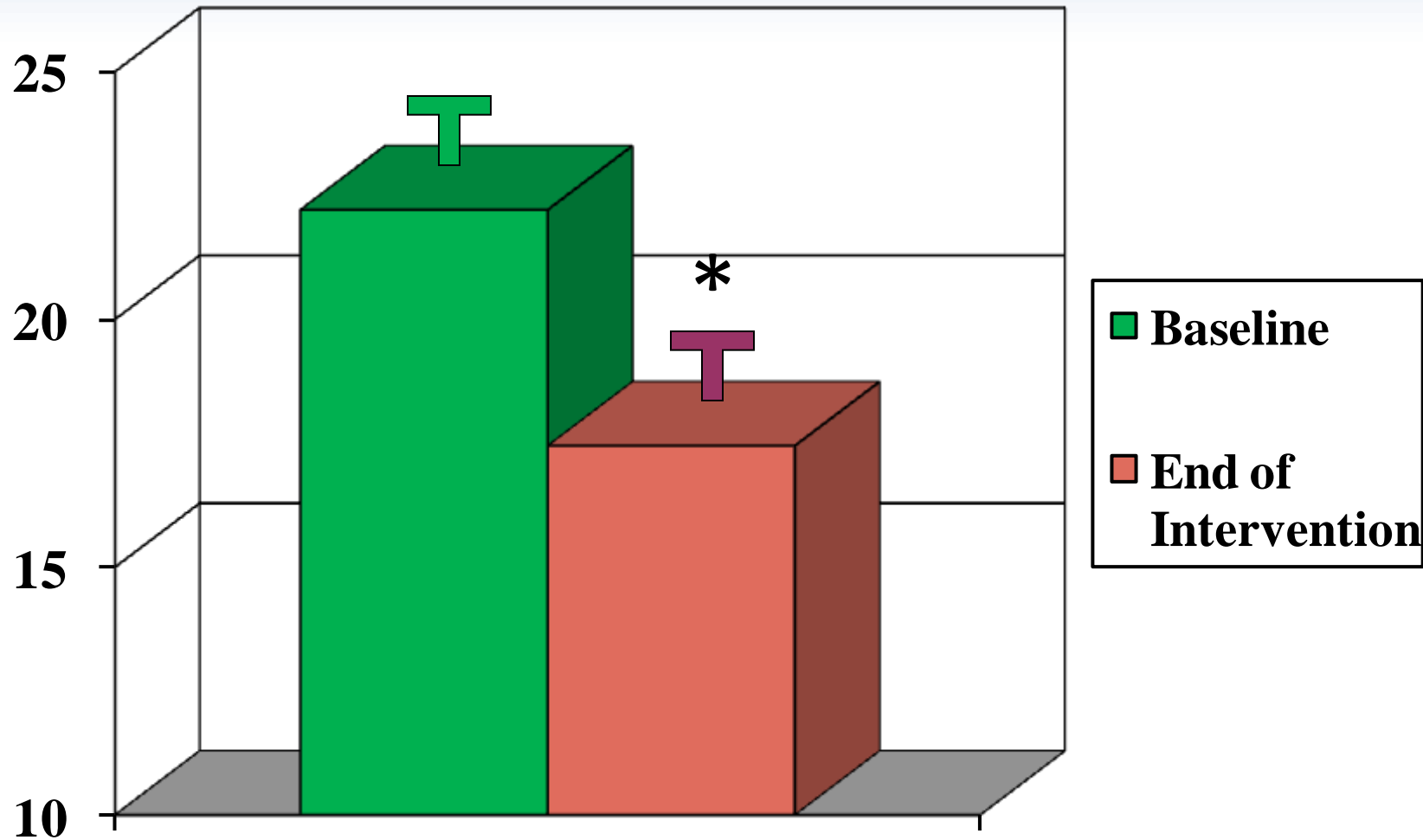
Stress

All Caregivers



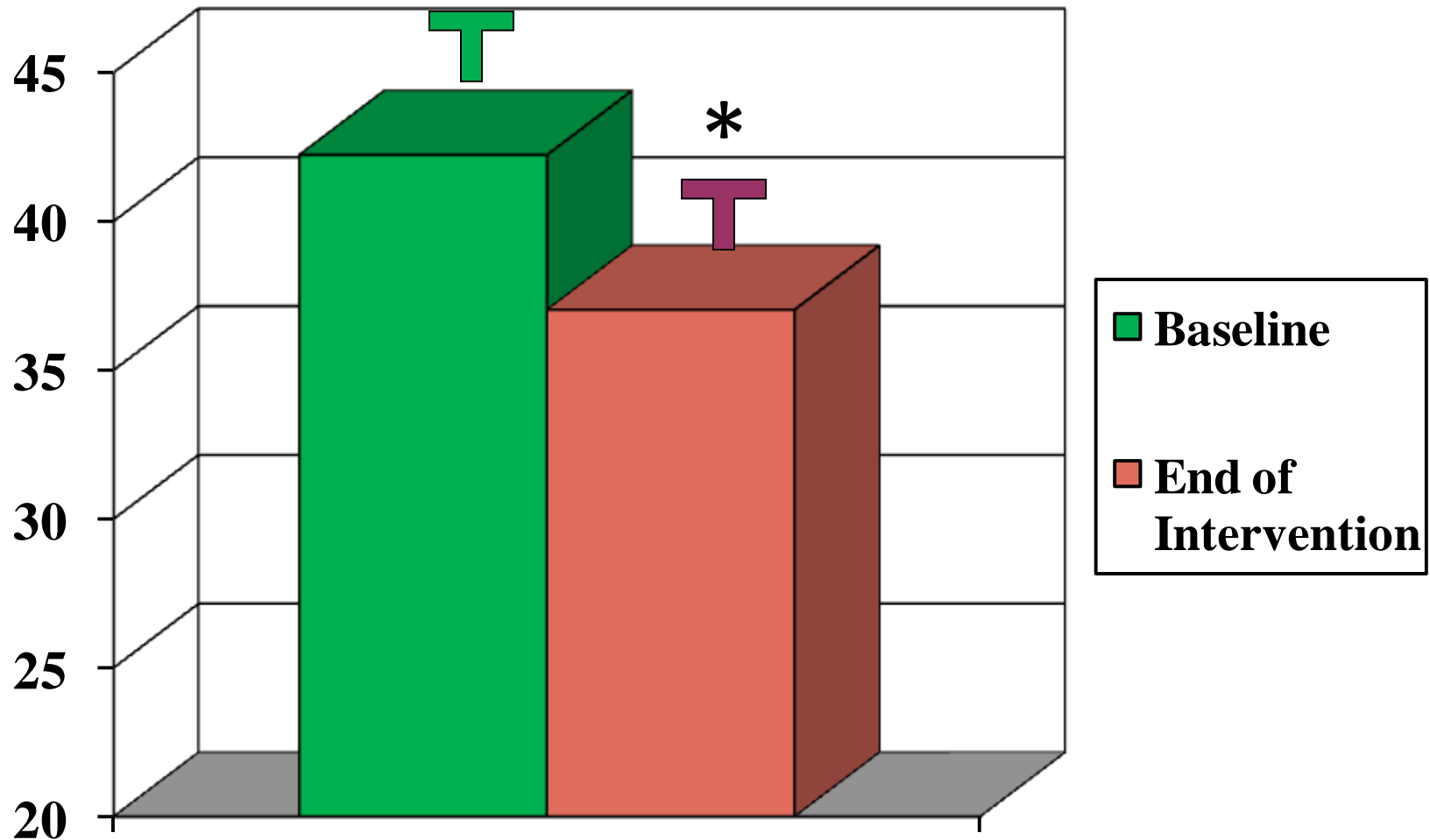
Depression

All Caregivers



Caregiver Burden - Subjective

All Caregivers



Stress-Busting Program

Summary of Results

Decreases in	Improvements in
<ul style="list-style-type: none">• Stress• Depression• Caregiver burden	<ul style="list-style-type: none">• Quality of life• Sense of control

Why Should You Be Interested in the Stress-Busting Program?

- **It is an evidenced-based program for your agency to expand its outreach to family caregivers**
- **It has a program structure that is readily reproducible in community settings**
- **Ultimately the program can be self-sustaining in your community**

How Can I Implement this Program?

- SBP has been adopted by organizations in Florida, Alabama, Arkansas, Oklahoma, and Kentucky, in addition to Texas
- The program is currently licensed through the WellMed Charitable Foundation

How Can I Implement this Program?

- Program has adapted to a Master Trainer/Facilitator model
- Master Training is available in San Antonio, TX or off-site
- Check the website www.caregiverstressbusters.org for more information



**Cutting Edge Approaches in Response
to Emerging Caregiver Needs**

What is Tele-Learning?

- **One-hour sessions on the telephone**
 - **Topic experts present a 40 minute educational program**
 - **20 -30 minute discussion among caregivers**
- **It is a free, safe and confidential program where caregivers can interact with others**
 - **Don't have to get dressed**
 - **No transportation required**
 - **Don't need respite**

Tele-learning sessions

- **Caregiving 101: What does it mean to be a caregiver**
- **At the End of My Rope: Warning signs for caregiver burnout**
- **How do I Spell Relief: Caregiver Stress Management**
- **Why Do I Feel Guilty**
- **I'm not the Same Person Anymore: Coping with role changes**
- **The Top Five Ways to Thrive as a Family Caregiver**
- **When is enough, enough: Setting personal boundaries**

Testimonials

- ***“It's an interesting concept for sharing information to caregivers who are so stressed for time and may be unable to get out of the home due to their caregiving responsibilities. I think it's very valuable to them and therapeutically beneficial to be able to do so and participate in a group format.”***

-Kelley, caregiver and first time participant

- ***“I enjoyed the tele-learning session experience which offered a comfortable, open and inviting environment, especially when able to punch in from the comfort of the couch. The tele-learning session allowed me to want to learn and perhaps I will be able to ask more questions along the way. It's helpful to see others in the question/answer session as to what they are going through that assists with my own personal experiences.***

-David, caregiver and first time participant



- **Free monthly e-newsletter with resources for caregivers**
- **Distributed to over 6,000 caregivers statewide and outside of Texas**
- **Call Toll-Free 866-390-6491 to be added to the list**

Caregiver SOS On Air

- National podcast for family caregivers available at www.caregiversos.org
- Guests:
 - Harvard Medical School
 - Mayo Clinic
 - United Hospital Fund
 - Adler Aphasia Center
 - Book Authors
 - Caregivers



The Role of the Family Caregiver and Aging Network in the Chronic Care Model

September 17, 2014

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“A test of a people is how it behaves
toward the old.”

Abraham Joshua Heschel



The Harry and Jeanette Weinberg Foundation

Mission:

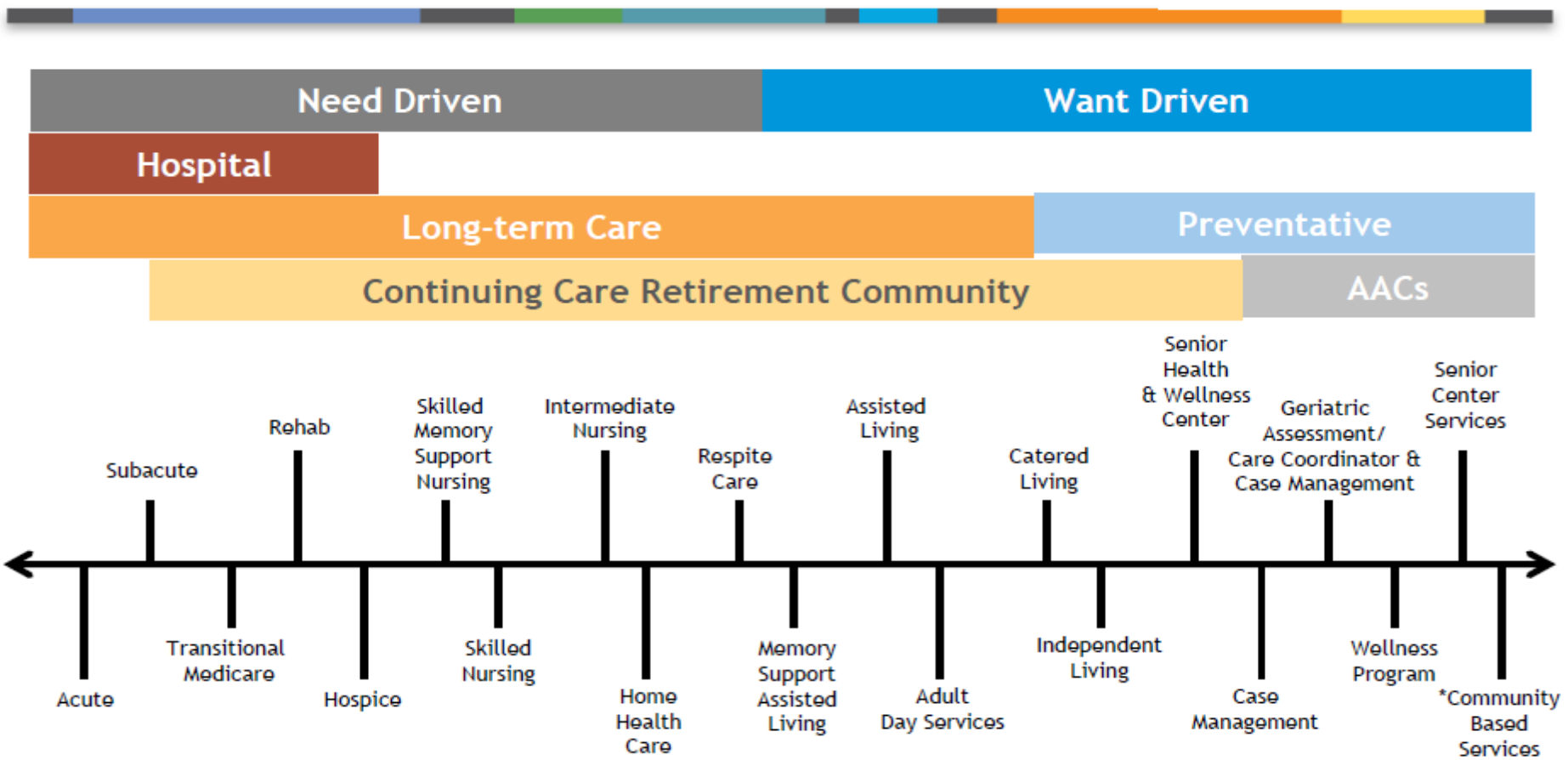
To help low-income and vulnerable individuals and families by providing grants to nonprofits that provide direct services.

“While others are finding the cures for all the ills of the world, someone will be hungry, someone will be cold. That’s our job.”

Older Adults

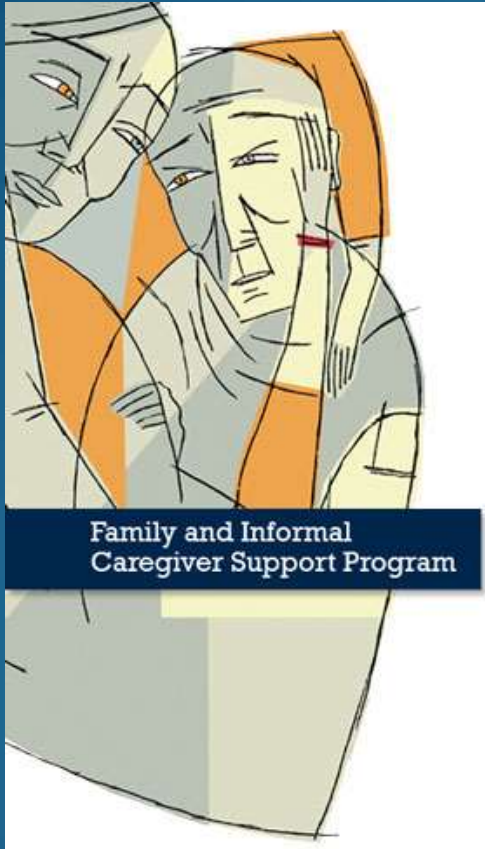
- No other American foundation of similar size has emphasized care for poor older adults to the extent demonstrated by The Weinberg Foundation. The Foundation is the #1 funder in the field of Aging at \$38-40 million a year.
- Seven foci:
 1. Community based services - Supportive Communities and Elder Abuse*
 2. Caregiver supports and services – Making Maryland the Best Place to Grow Old*
 3. Workforce Development for paid caregivers to older adults
 4. Elder Economic Security
 5. Affordable Housing with Services*
 6. Culture change long-term care residences
 7. Community Based Centers formerly known as Senior Centers

The Spectrum of Care



*Transportation; Information/Referral; Counseling; Meals-on-Wheels; Integrated Day Care; Homemaker/Chore/Housekeeping; and Emergency Response System

The Harry & Jeanette Weinberg Foundation, Inc



Family and Informal Caregiver Initiative

Michael Marcus

Caregiver Initiative Goals

- Provide direct services to low to moderate income caregivers most at risk for deteriorating health, financial security and quality of life.
- Develop innovative and evidence-based approaches to support family and informal caregivers
- Build capacity to provide comprehensive, culturally competent, and coordinated services through development of collaborative partnerships.

Grant Characteristics

- Collaborations of 2 to nearly 25 partners
- Held together by MOA's – “hot referrals”
- Governed by an active steering committee including caregivers
- With the endorsement of a local senior elected official
- Connection to the local area agency on aging
- Unfettered access to low/moderate income caregivers
- Local evaluator responsible for applying the universal assessment tool and local evaluation

Initiative Specifics

- HJWF made a commitment of up to \$9 M over 3 years
- RFP sent to 35,000 distinct e-mail addresses
- Received over 350 LOI's
- 20 expert reader/advisors and principal evaluator reviewed 250
- Invited 51 proposals
- Made 14 grants in 9 states totaling about \$8.2 M in grants matched by about \$7.7 M in local resources.

No Wrong Door

- Caregiver assessments to determine care needs
- Case management ensuring comprehensive and coordinated services
- Homecare by volunteers and paid home care aides
- Respite care
- Home modification
- Transportation
- Meal preparation
- Shopping
- Care consultation (including on-the-spot expert advice to address specific issues such as behavioral problems)
- Support groups led by professionals and experienced caregivers
- Face-to-face as well as telephone evidence-based caregiver training sessions
- Legal and financial planning

Making Maryland the Best Place to Grow Old

- Built on the Foundation's 3 year, \$8.4 m (plus \$8 m matching) national Family and Informal Caregiver Initiative, 14 sites in 9 states. Every one continues to operation. Over 400,000 caregivers received services. 2400 participants in the project assessment. Services to these participants saved over \$38 m in public expenditures.
- 4 part, 5 to 7 year initiative, beginning in Baltimore and reaching out.
 - Replicating 12 core services and supports for caregivers.
 - Developing 3 additional services: Urgent alert; wheelchair transportation; durable medical equipment lending.
 - Enhanced paid caregiver training, support and supervision.
 - No wrong door access.

Five Grants Made Thus Far

- Civic Works -- Cities for All Ages
- Benefits Data Trust – Maryland Outreach Project
- Johns Hopkins Bayview – Strengthening Caregiver Partnerships
- SAGE – SAGECAP (Caregiver Action Program)
- National Council on Aging – Elder Security Initiative/Economic CheckUp
- PHI – Pilot in NYC regarding paid caregiver training; MD environmental scan
- ASA Training

Leading Issues

- **A shortage of professional Caregivers:** Currently 2.5 million, the US will need 4 million by 2020. We need more older adult caregivers than K-12 teachers.
- **Caregiving Industry:** poor pay, high turnover, little oversight, and almost no consistency in training standards.
- **Volunteer (Informal) Caregivers:** Currently, an estimated 30-70 million Americans provide support to roughly 13 million people over 65 at a value estimated at over \$400 billion a year.

Thanks For All You Do!

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