## Resourceful-U Family Caregivers Support Group™ ...<u>in Context & in Action</u>



## A SC/MLA 68<sup>th</sup> Annual Meeting <u>Contributed Paper</u>... from the Executive Team @ <u>Transforming Lives and More Inc.</u>

A 501 c3 Special Library & Information Service, Tamarac, FL <u>TLM Network Library's Website:</u> <u>https://www.tlmnetwork.org</u>

## Toward a..." Sociology of Caregiving"

Library, Healthcare, & Human Support Services are sought by Family Caregivers for The Loved Ones in Their Care One Key Caregiving Role: Navigators & Consumers of Health Information

The <u>Person's Quality of Life & Well-being</u> (QOL) (Key Outcome)

#### "Informal, Unpaid Family Caregivers" Are a Growing Client Population f or Library, Healthcare, & Human Services Professionals" through 2050

A <u>Substantive Body of Multi-disciplinary Literature</u> is available for librarians, policy makers, health & human services professionals that contributes–
 --(1)-- To an understanding of practical issues faced by Family Caregiving and Care Recipients, Their Basic Needs, Activities of Daily Living (ADLs), Long-term Care Planning, Aging Network System Navigation, and Health Literacy
 --(2)-- To the development of Public Policy,, Legislation, and Support Programs in the workplace, in local communities, and at the state and federal levels of government

--(3)-- To interpret and address Global Demographic Trends and Issues

--(4)--To reduce gaps in the U.S. Human Health and Human Services Network for Family Caregiver and Care Recipient Well-being through Year 2050

## **A Citation Analysis Conducted of the "Family Caregiving Literature"** (January – April 2018)

Dr. Mary conducted a Citation Analysis and Scoping Review of 135+ Sources

from January – April 2018, Spring Semester 2018, at Florida Atlantic University.

Top "Hits" Found in Online and Print Literature, Publications, and Websites--

- Ad Hoc Institute of Medicine Committee (IOM) (November 3, 2014) Chaired by Richard Schulz with Jill Eden, Study Director.
- > AARP Public Policy Institute and National Alliance for Caregiving. Caregiving in the **U.S. Report** (June 2015).
- Dr. Jacene Zauszniewki's "Resourcefulness" Editorial in Western Journal of Nursing Research (2016).
- Families Caring for an Aging America (September 2016) issued by National Academies of Sciences, Engineering & Medicine, Health and Medicine Division.
- United Nations (May 15, 2017) 2017 International Day of Families Theme: "Family, Education, and Well-Being."

Family Caregiving Act of 2017 (January 22, 2018). Passed with bi-partisan support in Congress and signed into law by President Donald J. Trump. This Act authorizes the U.S. Department of Health & Human Services (DHSS) and DHSS Secretary to form a family caregiving taskforce that will develop a national strategy for improving and coordinating ting services to informal, unpaid family caregivers and care recipients. The goal is to assist family caregivers with long-term care and the delivery of effective patient- and family centered healthcare and social services for improved family health and well-being outcomes.

Participatory Action Research Approach... "Mixed Methods" Research Strategy Incorporating— Needs Assessment, Field Notes, "Your Family Caregiving Story" Interviews & Content Analysis + A Scoping Review of 135+ Policy & Scholarly Resources

**Contributed Paper Outline** 

✓ Support Group "Best Practices"

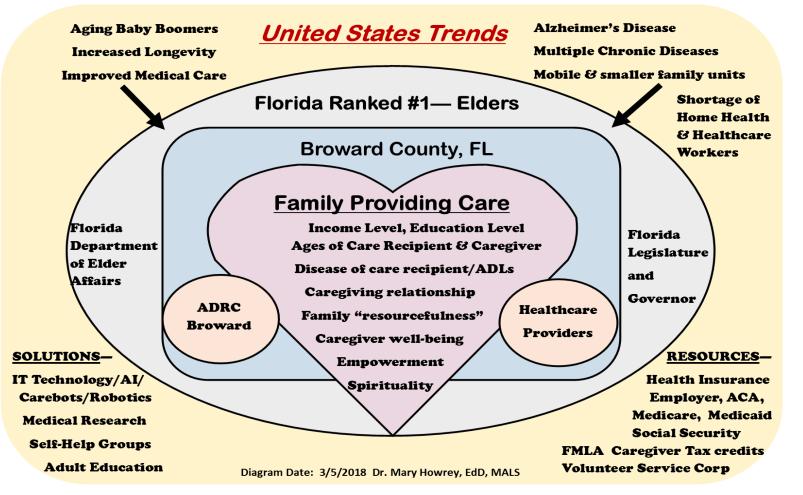
✓ Dynamic Library Partnerships for Identifying & Navigating Resources

✓ Empowering & Strengthening Family Caregivers

✓ Building the "Caregiver's Circle of Care" Plan and TLM CARE NETWORK

## The Context of "*Caregiver Resourcefulness*" Skills in the U.S. & State of Florida

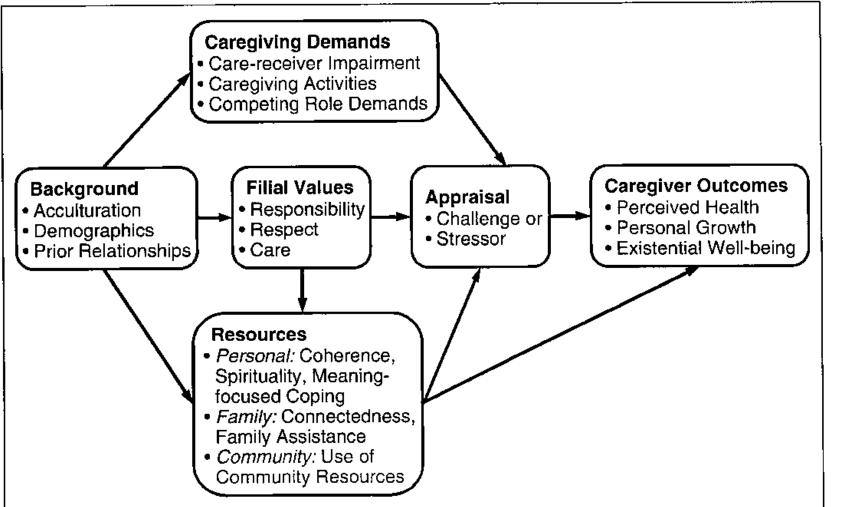
#### Context of "Resourcefulness" Skills Tied to Florida & U.S. Family Caregiver-Care Recipient Case Management



#### <u>Source</u>:

Howrey, Mary M. (2017). Family Resilience and Long-Term Administration Best Practices: A Review of the Literature for Caregiver Empowerment. Unpublished Paper for Florida Atlantic University, Boca Raton, FL. Spring Semester 2017, Long-term Care Services Administration.

## A Family Caregiver "Empowerment Model" (The <u>Resource</u> Context)



#### Source:

Jones, Patricia S., **Betty W. Winslow**, Jerry W. Lee, Margaret Burns, and Xinwei Esther Zhang. (2011). "Development of a Caregiver Empowerment **Model to Promote Positive Outcomes.**" Journal of Family *Nursing* 1 (1): 11-28. https://doi.org/10.1177/ 1074840710394854

# The Elder CARE Continuum for....Navigators

## THE ELDER CARE CONTINUUM



**Community Services** 

Social Security

Family Caregivers Medicare/Medicaid

**Private Funding** 

**VA Benefits** 



#### Source:

http://www.tn-elderlaw.com/blog/the\_continuum\_-\_\_spring\_2015/what\_is\_the\_elder\_care\_continuum\_\_

## Informal, Unpaid Family Caregivers are... <u>Practical Problem-Solvers</u> & <u>Consumers of Health Information</u>

**Resourcefulness** (<u>Definition</u>) has two key components related to family caregiver "capacity and strengths-building and quality-of-life (QOL) for both the caregiver and care recipient." (<u>Source</u>: Zauszniewski, 2016)

### 1. Self-help

2. The ability to seek help & support from professionals, other family members, and the community-at-large

## The Current "Self-Help Innovators/Influentials" Associations, Government Agencies, Foundations

**<u>Retrieve</u>** the free PDF and READ this seminal report--

*Families Caring for an Aging America* (September 2016)

\*\*A "State-of-the Aging Field and Care for Older Adults" Consensus Study Report from Leaders in the Field of Geriatrics/Gerontology/ Medicine\*\* from the National Academies of Sciences, Engineering, and Medicine's Health and Medicine Division; Board on Health Care Services;

**Committee on Family Caregiving for Older Adults** 

Editors:Dr. Richard Schulz, PhD (Professor of Psychiatry, University of Pittsburg) and Jill Eden, Health Policy Research, Washington, DC

**Access** these U.S. government websites for caregiving trends-

National Institutes for Health/National Institute on Aging website &

**Family Caregiver Act of 2017** that was passed & signed into law on 1/22/2018

## **Programming Calendar to Celebrate & Honor... Family Caregivers & Their Care Recipients**

- Mav **Older Americans Month in May**
- October

**Health Literacy Month in October** National Disability Awareness Month

- November **Family Caregivers Month in November**
- **First Week of December Intergenerational Week** Sponsored by the--**Florida Department of Elder Affairs**
- See the Disabled World Tomorrow's Future for an Annual Calendar of Events to Celebrate



adults, and elders. This week lets us celebrate people of diverse backgrounds, ages, and experiences, as well as the gifts they share with each other. Intergenerational programs and initiatives provide opportunities for individuals, families, and communities to enjoy and benefit from the richness of an ageintegrated society.

#### Intergenerational Initiatives

Our elders give us a mature, historical perspective of who were are, where we are, where we came from, and how we got there. Our youth give us a childlike vision of the future and all that we can still be. Intergenerational programs give us the opportunity to bridge these vantage points, creating a strong sense of community and an appreciation for the contributions of each group.

#### Intergenerational Programs:

· Improve the lives of children, youth, and elders through intergenerational collaboration, public policies, and programs for the enduring benefit of all; and

· Enhance family and civic responsibilities

ter 430.07 the Office of Volunteer & Community Services within DOEA is required to develop comprehensive programs with intergenerational components. The Department's role is to develop and serve as a resource center, information warehouse, and technical assistant within the State

of Florida

The Department works to ensure the cornerstones are in the state and local levels to reach this goal. Local aging network providers (i.e. youth groups, elder groups, private businesses, and other organizations) have programs that mutually benefit all age groups. At the state level, the Department provides an education and outreach component, coordinating and developing intergenerational activities that connect generations.

For additional information, contact:

Florida Department of Elder Affairs Tallahassee, Florida 32399

4040 Esplanade Way

elderaffairs.state.fl.us/doea/intergenerationalconnection.php

partnerships, and · Encourage elders and young people to make the connections necessary to bridge the generation

partment seeks to:

The Benefits of Intergenerational Initiatives

 Improved relationships between all age groups in a community,

Increase intergenerational

- A willingness to cross cultural boundaries to solve problems, and
- · Cultivated relationships across age groups that result in caring, respectful, and active communities



## <u>AARP Policy Institute</u> & "*Prepare to Care*" and Family Caregiving Advocacy

- *"Prepare to Care" for Diverse Caregivers* (African-American, Asian, Latinos, LGTQ and White Caregivers)
- Family Caregiving Website
- Long-term Insurance Products
- Medicare Supplemental Insurance
- Safe Driving Program for Auto Insurance Discounts
- Careversations Workshops
- "Digital Literacy" Tech Workshops and Job Search Workshops for older adults, ages 50+ with AARP membership AARP Family Caregiving Website is found at— <u>https://www.aarp.org/caregiving/?intcmp=GLBNAV-PL-CAR</u>

## **NLM 4 Caregivers &** National Institute on Aging Health



Website <u>https://sis.nlm.nih.gov/outreach/caregivers.html</u> National Institute on Aging/Health Information <u>https://www.nia.nih.gov/health</u>

*MedlinePlus* Tutorials for Caregivers Videos <u>MedlinePlus Homepage http://www.medlineplus.gov</u>

- 1. MedlinePlus Health Topics
- 2. MedlinePlus Drugs and Supplements
- 3. <u>MedlinePlus Cool Tools</u>

## **Alzheimer's Association--***Support Groups 2018*



Featured Event

#### Face-to-face

Call the 24/7 Helpline 800-272-3900 for 24/7 Information and Support

#### ALZConnect ed®

A free online community where people living with Alzheimer's, caregivers, family and friends can ask questions, get advice and find support. Year-round



#### **Online Community**

We host ALZConnected<sup>®</sup>, a free online community where people living with Alzheimer's, caregivers, family and friends can ask questions, get advice and find support. Year-round

## Family Caregiver Alliance Find Care Journey™

PERSONAL CAREGIVER SUPPORT

- National Center on Caregiving Library (Policy & Advocacy) With legislative analyses, research reports, and newsletters document emerging trends, public policy, and caregiver needs and services. Consultation on program development and best practices in caregiving services offered.
- Toll-free Number 4 Caregivers-- 800-445-8106 <u>Visit--</u> <u>Caregiver Connect</u> <u>Explore</u>-- FCA CareJourney<sup>™</sup> for Personal Caregiver Support
- FCA Learning Center is an online website for family caregiver education. With resources from FCA's vast library of caregiving knowledge, visit the Learning Center to READ, WATCH, LISTEN, and LEARN online anywhere at anytime.
- Over four decades of information, education, and support provided to US family caregivers and professionals by social service professionals located in San Francisco, CA.

## **Caregiver Action Network**



#### Purpose:

Caregiver Action Network (CAN) (Washington, DC) is the nation's leading family caregiver organization working to improve the quality of life for the more than 90 million Americans who care for loved ones with chronic conditions, disabilities, disease, or the frailties of old age.

#### Services Offered:

- 1. <u>National Family Caregivers Month (November)</u>
- <u>Care Community</u> with Post to Forums Offered for Disease Specific Groups— Alzheimer's Disease, Huntington's Disease, Parkinson's Disease, and COPD
- 3. Family Caregiver Toolbox

## Gary Barg, *Today's Caregiver* & Caregiver.com (Location: Southeast Florida)

- Subscribe to weekly updates of Today's Caregiver magazine articles, advice, and "Fearless Caregiver Conference" announcements
- Website URL— <u>https://caregiver.com/</u>
- Care Tips
- Book Club
- Local Resources
- E-Newsletter

The Caregiver Media Group is a leading for-profit provider of information, support and guidance for family and professional caregivers. Founded in 1995, we produce *Today's Caregiver* magazine, the first national magazine dedicated to caregivers, Caregiving books, Custom publications, the *Fearless Caregiver Conferences*, and our website, caregiver.com.

## Rosalyn Carter Institute for Caregiving (RCI)Key Resources

#### Caring for You...Caring for Me Family Caregiver Training Program

Available for purchase at the RCI Website-- http://rosalynncarter.org/

**RCI Training Center for Excellence** 

#### **Academic Programs**

#### **Education and Training Products for Family and Professional Caregivers**

For many, caring for a chronically ill family member is "the right thing to do", but it is also often a source of emotional hardship, physical stress, and social isolation. In response, skill-building, coping, and psychoeducational programs have emerged to help caregivers meet the changes and challenges in their – as well as the patients' – lives.

The RCI Caregiving Book Series aims to educate and inform students in caregiving-related fields as well as professional caregivers.

**Caring for You, Caring for Me: Education and Support for Family and Professional Caregivers, 3rd Edition** is the RCI's signature, evidence-informed program that addresses the needs of family and professional caregivers by bringing them together in a relaxed setting to discuss common issues, share ideas, and gain a better understanding of each other's perspective on what it means to be a caregiver.

Dealing with Dementia guide is a comprehensive reference tool for family and professional caregivers.

**10 Tips for Caregivers** is a 24-page booklet that is a compilation of our best advice for caregivers.

## John A. Hartford Foundation

- Dedicated to improving the care of older adults through research focused on age friendly health systems, end-of-life care & family caregiving.
- The John A. Hartford Foundation invests in aging experts and practice innovations that <u>transform</u> how the care of older adults is delivered.
- <u>Current Funding Priorities</u>: 1. Age-Friendly Health Systems,
   2. Family Caregiving, and 3. Serious Illness and End of Life
- Since 1982, The John A. Hartford Foundation has awarded more than <u>\$565 million in grants</u> to enhance the health and well-being of older adults and family caregivers.
- <u>Website URL</u>: <u>https://www.johnahartford.org/</u> Accessed 10/23/18

## **TLM Network Special Library in Context & in Action** Family Caregiver Education and Support February 2016 to Date

 A Non-profit 501 c3 Florida Corporation formed in February 2016 / A Membership Special Library, Self-Help, and Advocacy organization of committed volunteers

## • "Resourceful-U Family Caregivers Support Group"

(December 2017 to date)

- Website with Blog and Community Resources (WordPress) (April 2016 to date)
- Joined <u>NNLM SEA Region</u> (April 2016)
- •

Meets at Regional Branch Library in Coral Springs, FL 4<sup>th</sup> Thursday, 2pm

 "Powerful Tools for Caregivers" in partnership with our Broward County (FL) Area Agency on Aging--<u>ADRC Broward</u>, Sunrise, FL (6-week evidence-based class with 2 hr. workshop sessions) (September)

## TLM Network Special Library Outreach via...Social Media Channels

- Facebook Page (Social Media) (April 2016 to date)
   YouTube Channel (2013 to date-)
- <u>MeetUp</u> (Social Media plus Free Community Local News & Public Library System Marketing) (December 2017 to date)
- <u>Google+Community</u> (Social Media) (<u>NEW</u> as of September 2018 to date)

## **Who?** Unpaid, Informal Caregivers

Loving & Loyal Caregivers & Their Care Recipients we've met through our...

"*Resourceful-U Family Caregivers Support Group*" (Support Group <u>Start-up Date</u>: January 25, 2018)

and

Education/Outreach Programs such as...

"Thriving Families=Healthier Communities"

(Public Library Learning Expo <u>Date</u>: November 12, 2016)

Jane (Son)

Jessie (Mother)

William (Wife)

Shelly (Mother)

**Goldie (Daughter)** 

Patty (Husband)

Alexa (Husband)

**Carmen & Jeanie (Mother)** 

Tim & Ursula (Mother & Stepfather)

## <u>What?</u> Education & Local Resources for the *Resourceful-U* Family Caregivers Support Group

- Resourceful-U Family Caregivers Support Group serves informal, unpaid caregivers of older adults with chronic conditions and/or disabled adults (Down's Syndrome, autism)
- Organized in December 2017 with two co-leaders
- Support Group first met on January 25, 2018 and meets monthly
- Initial family caregivers were friends, co-workers, and AARP members from a "Careversations" workshop training session held October 2017
- "Best practices" for support groups from the professional literature— Education, community resources, computer skills training, emotional support, practical problem-solving

## <u>Where?</u> At the Local Broward County (FL) Regional Library

Broward County Library System, 7<sup>th</sup> Largest US Library System <u>http://www.broward.org/library</u>

Northwest Regional Library, Coral Springs, FL

**Conference Room provided at no charge to non-profit organizations** 

Computer Training Lab with 15 PC workstations and LCD projector available for booking

Support Group meets the fourth Thursday of each month for 2 hours. The group is offered from 2pm – 4pm and attracts retired caregivers or caregivers who quit full-time work to assume informal, unpaid caregiving. \*\*A second group for employed caregivers will meets Saturday afternoons in 2019. An <u>LIVE</u> online support group is next.

## Why? Caregivers Have Difficulty Navigating the Health & Human Services System

- Knowledge of community resources and fear are issues faced by caregivers providing round-the-clock care in one's home
- Case management is available from your county's Area Agency on Aging available to disabled adults, ages 18-59, and older adults age 60 and above
- ADRC Broward Helpline Phone: 954-745-9779
   <u>http://www.adrcbroward.org/infoandreferral.php</u>
   Online Searchable Directory of Resources
   <u>http://www.referweb.net/psa10/Search.aspx</u>
- 2-1-1 Broward "Get Connected. Get Answers" 954-537-0211 http://www.211-broward.org

## How?

## **Organizing, Funding, Outreach, & Outcomes to Date**

- Marketing, marketing, and outreach to the county's Area Agency on Aging, Broward County Coalition on Aging, voluntary associations, county and city social services departments, public library announcements, flyers, posters in Library's main lobby, senior centers, universities with social work programs, AARP, League of Women Voters, churches
- Free community news columns
- *MeetUp* social media website (basic site-\$120 per year)
- Educational component draws in members and builds self-confidence in identifying needed resources (such as in-home respite companions or eldercare attorneys or a high quality assisted living facility or skilled nursing facility)
- The *Resourceful-U Family Caregivers Support Group* has grown from 8 initial members in January 2018 to 18 active members in October 2018. "*Powerful Tools for Caregivers*," a six-session course emphasizing care for oneself, active communication skills, and stress management, had 12 participants from September 19 October 24 at the public library. Training was provided by the Health and Wellness Program of ADRC Broward. Two certified instructors conducted the evidence-based course.

## Take Action!! Share Your Local Community's Resources. This is <u>Your</u> "Call to Service", Advocacy Role, & Way of "Empowering the Voices & QOL" of Family Caregivers and Their Loved One(s)

- Visit the *TLM Network Special Library's Resources* Page <u>https://tlmnetwork.org/resources/</u>
- Locate your county's or regional through your local public library system or AIRS-certified I&R Agencies— Orange County (FL) Library System's "The Right Service at the Right Time" Detroit Public Library's TIP Service
- Identify your county's Area Agency on Aging, 211 Information & Referral Services Agency, AARP, Mental Health Association, Public Health Department, and other Disease-specific Voluntary Health Associations (American Cancer Association, American American Diabetes Association, Heart Association, American Lung Association, Parkinson's Association, Domestic Violence organizations, Homelessness support agencies, Addictions & Substance Prevention organizations such as AA or the Salvation Army), and Specialty Hospitals & Medical Centers (VA, trauma centers, Medical institutes (cancer, heart, brain, neurological, developmental disabilities, substance abuse, etc.), and State and Local grant-funded "Alzheimer's Initiative" family caregiver providers and programs)
- Visit U.S. federal government websites such as the National Institute on Aging's <u>Eldercare Locator</u> services website or <u>SAMHSA's Behavioral Health Treatment Federal Locator</u>
- Contact your local public library's Reference Desk for additional assistance. Don't forget to refer your library
  patrons to
  local Library of Congress services, offered through your public library system to blind, disabled, and bandicanne

local Library of Congress services offered through your public library system to blind, disabled, and handicapped persons—

Talking Books and Large Books by Mail programs.

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 TLM Network Library

 & Information Service

 Website: https://www.tlmnetwork.org

 Google+
 Community:

 https://plus.google.com/u/0/+DrMaryHowreyTLMNetwork?tab=mX



## <u>A Family Love Story of My Mom-in Law</u> Barbara Jane Bolles Howrey (1919 – 2001)

- Barbara Howrey meet her future husband, James E. Howrey, at Danville (IL) High School in 1936. They were part of the "Silent Generation" that loved the "Big Band" music and Danville's Bobby Short, a cabaret singer and pianist.
- Barb worked as a secretary in Chicago after high school graduation, and Jim was drafted into the Airforce. During World War II, Jim flew a B-17 bomber plane for 28 strategic missions over Germany. In 1943, Barb and Jim married and had their first son David Kirby Howrey in 1944. In 1949, a second son, James Murray, joined the family. Danville was a small town with a peak population of 39,000.
- The Danville, IL community benefited economically with major industries in the 1940s-1970s—General Electric, General Motors, Western Brick, C&El Railroad, Rose Packing Company, Lauhoff Grain Company, Lakeview Hospital, Tee Pap, Aerosol, Bohn Aluminum, and Hyster Company.

## Barbara's Medical History– Adult Depression & Late Onset Multi-infarct Dementia

- Over the course of her marriage, Barbara suffered from depression and was hospitalized three times due to suicide attempts. While hospitalized three times in Peoria, IL, Barbara received electroconvulsive shock therapy (ECT) to treat her depression which resulted in long-term memory loss. To maintain her daily functioning as a wife and mother, Barbara was diagnosed lithium, the drug of choice in the 1940's – 1970's. In 1983, Barbara experienced her third and final bout of depression when her youngest grandchild of three, Kenneth J. Howrey, was born in Aurora, Illinois.
- Husband Jim Howrey was a patient and loving caregiver to his wife for over 50 years.
- In 1992, Barbara was diagnosed with <u>multi-infarct dementia</u> and remained at home until 1996 when Jim could no longer care for Barbara at home.
- Jim visited his wife Barbara daily at the Danville, IL nursing home despite the fact that Barbara could no longer identify Jim as her husband. Barbara called her husband a "nice man" due to his daily visits to entertain and to talk with her and the nursing home staff.
- For respite and enjoyment in his retirement, Jim fished often in a small motor boat on a private pond that was stocked with crappie and blue gill. Jim loved to dip the fish in a beer batter, fry the fish, and serve it with his homemade tartar sauce.
- Jim predeceased Barbara in December 1999 from a stroke and heart attack at age 81. Barbara passed away in February 2001 as a result of multi-infarct, pneumonia and influenza.

## Family Photos of Barbara J. & James E. Howrey



Below:Top Right: Jim & Barb'sBarb at Home50th Wedding Anniversary,19925/22/93







Above: Jim & Barb Howrey (1987)

Bottom Right: Son Jim & Grandson Ken with Barb (1997)