

# *From Caring to Caregiver Advocate*

9<sup>th</sup> Annual National  
Conference of Caregiving  
Coalitions

March 24, 2015



#CareAdvocate @NA4Caregiving

# *About the Alliance*

- Nonprofit coalition of over 40 national organizations focused on family caregiving issues
- Established in 1996 to support family caregivers and the professionals who work with them
- NAC Activities:
  - Conduct research and policy analysis;
  - Develop national programs;
  - Strengthen state and local coalitions;
  - Increase public awareness;
  - International work and awareness.

# Our Conference Sponsors



UnitedHealthcare®



# *A Word From Our Sponsors*



Joanne Gruskos, Director, SpecialCare Program  
Mass Mutual Financial Group



#CareAdvocate @MassMutual

# *Caregiving Advocates Perspectives*

**C. Grace Whiting, JD**  
**Director, Strategic Partnerships**



#CareAdvocate @NA4Caregiving



# *Caregiving Champions*





# *Your Mission, Should You Choose to Accept It*

- Complete the Evaluation Form
- Fill out the Family Support Survey (UIC)
- Share info on the Older Americans Act
- Nominate a Caregiving Champion
- Join the National Network of Caregiving Coalitions



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***Discussion Panel:  
Underserved Caregivers –  
Supporting Special Populations***



#CareAdvocate @NA4Caregiving



***Moderator:***

***Rick Greene, MSW  
Executive Advisor***

***National Alliance for  
Caregiving***



#CareAdvocate @NA4Caregiving



*Jed Johnson, MSW, MBA  
Vice President,  
Strategic Initiatives*

*Easter Seals, Inc.*



#CareAdvocate @Easter\_Seals





# Many Faces of Caregiving Study

made possible by MassMutual Financial Group



CHANGING THE CONVERSATION ABOUT CAREGIVING - [EASTERSEALS.COM](http://EASTERSEALS.COM)



**“There are only four kinds of people in the world:  
Those who have been a caregiver; those who  
currently are caregivers; those who will be  
caregivers and those who will need a caregiver.”**

**- First Lady Rosalynn Carter**





# Many Faces of Caregiving Study



## Easter Seals and Caregiving

- Easter Seals is changing the national conversation about caregiving by raising awareness and interest around what has become “the new normal” for 66 million Americans of all ages.
- Committed to empowering caregivers across the lifespan to focus on their own health & their loved ones
  - Many people don’t self-identify
  - Opportunity to provide supports & counsel
    - Know they’re not alone
    - Tremendous contributions to their loved ones, our communities and the economy.





# Many Faces of Caregiving Study



## Easter Seals and Caregiving

- Thanks to MassMutual Financial Group, Easter Seals conducted the *Many Faces of Caregiving Study* to learn more about this important group of people doing an even more important job – caring for loved ones.



MADE POSSIBLE BY MASSMUTUAL FINANCIAL GROUP



# Many Faces of Caregiving Study



## METHODOLOGY

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# Many Faces of Caregiving Study



- Impulse Research conducted an online survey with a random sample of 1043 Millennials, men and women ages 25-49.
- The respondents are representative of American men and women 25-49.
- The overall sampling error rate for this survey is +/-3% at the 95% level of confidence.
- Conducted in January 2015.





# Many Faces of Caregiving Study



## KEY FINDINGS

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# Many Faces of Caregiving Study



## Caregivers – Younger than We Think

One-third of Millennial and Gen X respondents identify themselves as caregivers – many individuals between the ages of 25 and 45 are already serving in this role.





# Many Faces of Caregiving Study



- Meet Andrea Simone
- Hallmark [“Home and Family”](#) segment



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# Many Faces of Caregiving Study



## Elizabeth Dole Foundation Hidden Heroes: The National Coalition for Military Caregivers

To see the full report visit:

[www.rand.org/military-caregivers](http://www.rand.org/military-caregivers)



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# Many Faces of Caregiving Study



- **36%** of consumers ages **18-29** are currently serving as caregivers.
- 67% of **Millennials** and 55% of **GenX** caregiver respondents report **providing care on a daily basis**.
- One million new caregivers are now providing care for post-9/11 veterans.
- Millennial caregivers are 18 percent more likely to ask for help than their Gen X counterparts.





# Many Faces of Caregiving Study



## We're Not Ready to Care

When preparing for caregiving roles, most of us think of helping others through physical challenges they may be facing.

Overall, the general public is not prepared to either be a caregiver or to need care.





# Many Faces of Caregiving Study



- **70%** of respondents have not yet had the critical conversation with their families and loved ones about the future as it relates to their **medical and financial planning**.
- Overall, 37% of respondents admitted to being “**not quite ready**” or “**not ready**” for handling a projected caregiving role (men – 33% and women – 42%)
- Only 47% of caregivers surveyed are very **satisfied with the care they are currently providing** to their loved ones.





# Many Faces of Caregiving Study



## Perceptions vs. Realities of Caregivers

Just as many **men** as **women** are stepping up to the plate to provide care.

77% of caregivers **provide care for emotional and mental health conditions, memory problems or dementia.**



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# Many Faces of Caregiving Study



## Top Challenges of Caregiving

### Greatest Concerns:

- Less time for self
- Increased anxiety/stress and poor sleep
- Financial impact
- Less time with friends, less time to exercise, and less time with children/family





# Many Faces of Caregiving Study



## Challenges Differ: Man v Woman

- **For men**, respondents reported to be **smoking** more than female respondents and are a bit **more concerned with the financial burdens** of caregiving than women
- **For women**, **anxiety/stress** and **less time for self** are much higher than male respondents





# Many Faces of Caregiving Study



## Challenges Yield Rewards

13% of respondents weren't able to  
identify a negative consequence of caregiving



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# Many Faces of Caregiving Study



## Positive and beneficial outcomes

- Developing closer relationships
- Having a good sense of self
- Enjoying time spent with those for whom they provide care



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# Many Faces of Caregiving Study



## Investing in Care

- 85% of caregivers provide care at least several times a week
  - *59% of which provide care at least daily*
- 42% of caregivers have been providing care for less than two years
- 59% of respondents have been serving as caregiver for less than three years





# Many Faces of Caregiving Study



## Where to go for Help

- *The Many Faces of Caregiving Study* respondents shared an overwhelming preference to **accessing information about caregiving via the web**
- **Easterseals.com** has caregiving information designed to support caregivers throughout the lifespan
  - Regardless of the stage at which you are providing care
  - with tips on how to better plan for the future





# Many Faces of Caregiving Study



## Where to go for Help

- 60% of all respondents cited **financial planning as a helpful tool as they planned for the future**
- Our partner, MassMutual Financial Group, offers resources and approaches to financial planning for all stages of caregiving
- Visit **massmutual.com** to learn more.



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***Paul Blom***  
*Board Vice-Chair*

*Training to Serve*



#CareAdvocate @PaulRBlom





# Understanding the Unique Needs & Barriers of the Older LGBT Community

## National Alliance for Caregiving



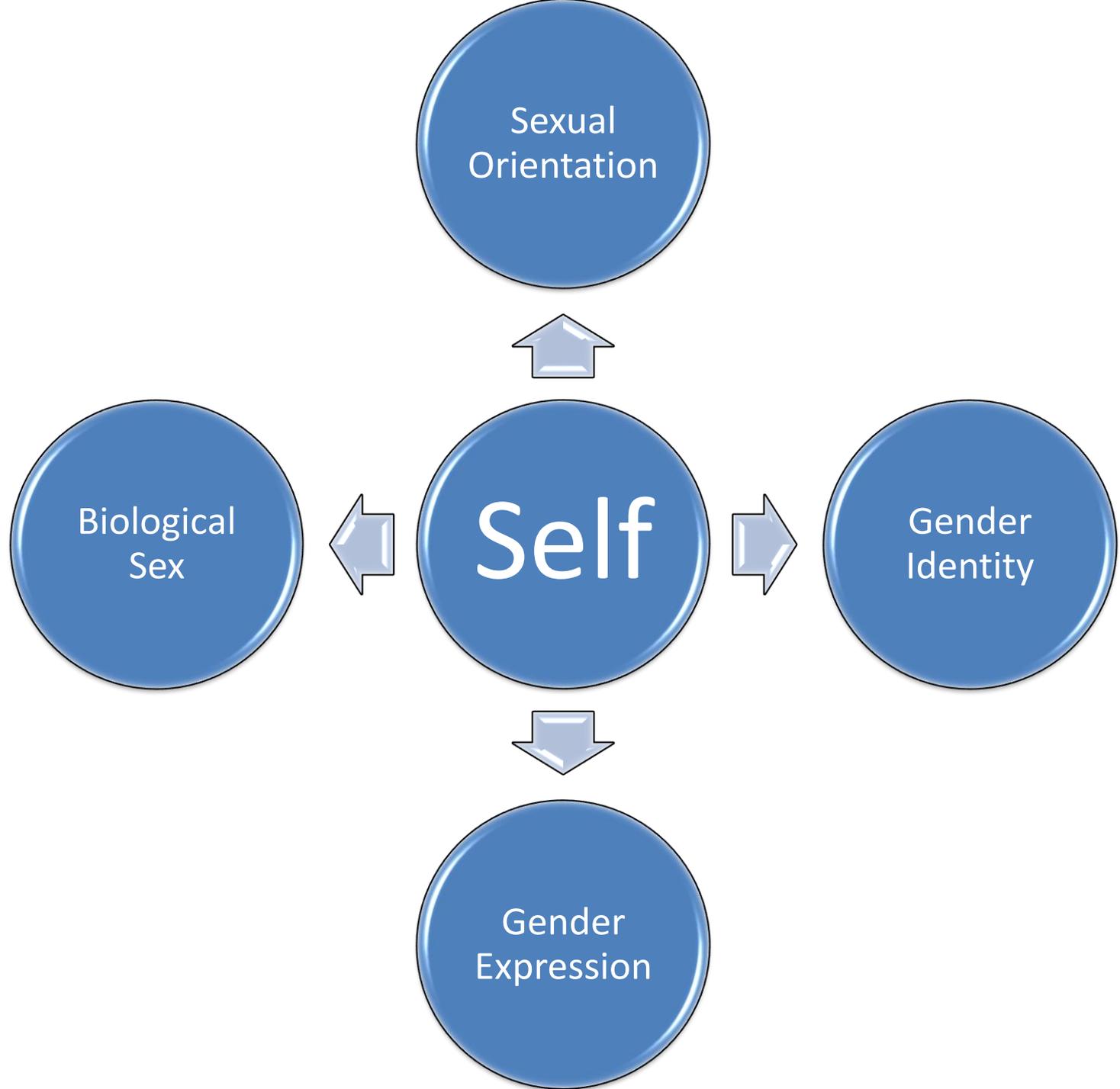
Paul R. Blom, B.A.

Training to Serve Vice-Chair  
Owner, Right at Home Twin Cities

March 24, 2015

[www.trainingtoserve.org](http://www.trainingtoserve.org)





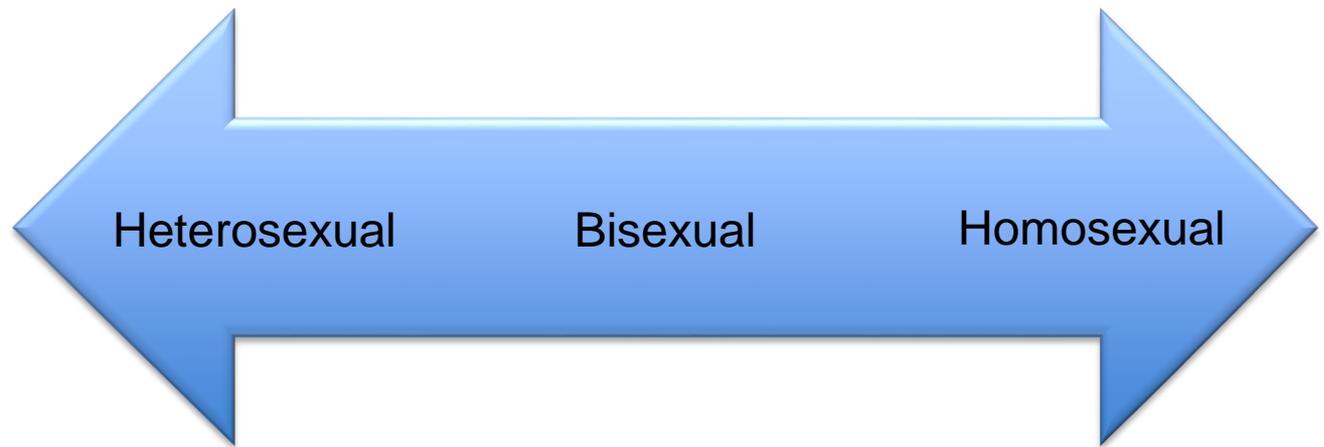
# Biological Sex

- Objectively measureable organs, hormones and chromosomes.



# Sexual Orientation

- Who you are physically, spiritually and emotionally attracted to based on their sex/gender in relation to your own

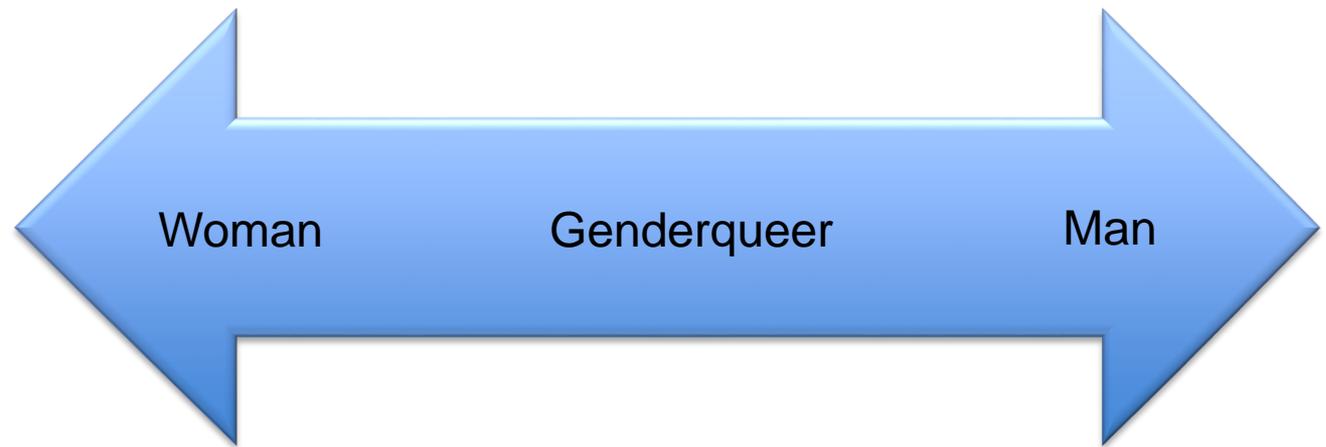


Straight

Gay Man  
Lesbian

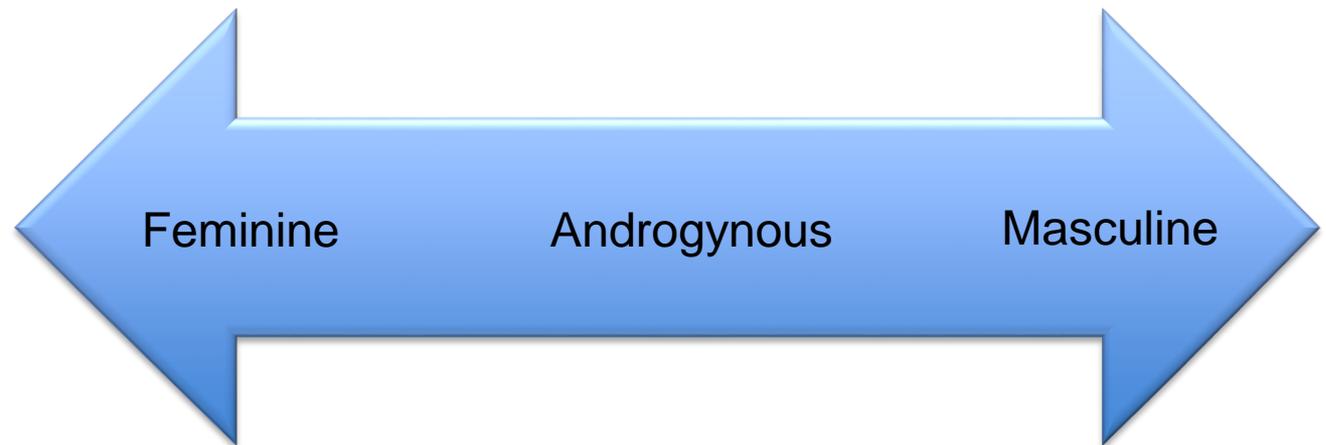
# Gender Identity

- How you, in your head, think about yourself. It's the chemistry that composes you and how you interpret what that means.



# Gender Expression

- How you demonstrate your gender (based on traditional gender roles) through the ways you act, dress, behave, and interact.



# Transgender

- People whose gender identity differs from the gender assigned at birth.
  - Transwoman (MTF – male to female)
  - Transman (FTM – female to male)
- Cisgender

# Overview

- Pre-Stonewall (1969) life experiences
- Baby Boomers (1946-1964)
- Estimated 2.8 million nationwide



# Reluctance to Access Services

- LGBT elders are 5 times less likely to access social services than larger population
- Tend to wait for crises
- Feel need to return to closet
- Heterosexuality assumed
- Cisgender assumed

# Isolation

- Live Alone (1.5X)
- No Children (4X)
- No Caregiver (2X)

Gay Seniors: No Kids, No Partner

<http://www.youtube.com/watch?v=WlxZDiQ5uOY&feature=colike>

# Assumptions

- Inform programs/services
- Limit language for intake
- Limit discussion of relationships
- Limit life reminiscing
- Marginalize/alienate LGB&T elders

# Differences in Aging

- Face old age alone
- Lack traditional family supports in times of crisis
- Invisible to providers/policy makers
- Discriminated against because they are gay or transgender
- Shunned because they are old

# Data on Victimization

- 82% victimized at least once
- 64% victimized 3 or more times
- 40% contemplated suicide
  
- Nursing Homes:
  - 89% predicted staff would discriminate against an LGBT elder
  - 43% reported instance of mistreatment

# Rates of Victimization

- 19% physical assault
- 20% property damage
- 21% denied job promotion
- 23% threat of being outed
- 27% hassled by police
- 43% threat of physical violence
- 68% verbal assault

# Suggestions

- Inclusive infrastructure
- Welcoming environment
- Effective communication
- Open-ended questions
- Gender-neutral language
- Staff & Resident Sensitivity Training

*Tamar Heller, PhD*

*Professor & Head of  
Disability and Human  
Development, UIC*

*Co-Founder, Sibling  
Leadership Network*



#CareAdvocate @NA4Caregiving



# Supporting Families of Adults Aging with Developmental Disabilities

Caregiving Coalitions Conference

Underserved Caregivers: Supporting Special Populations

Chicago

March 24, 2015

Tamar Heller

Funding was provided by Grants # H133B130007 and H133B140046 from the U.S. Administration on Community Living's National Institute on Disability, Independent Living and Rehabilitation Research.

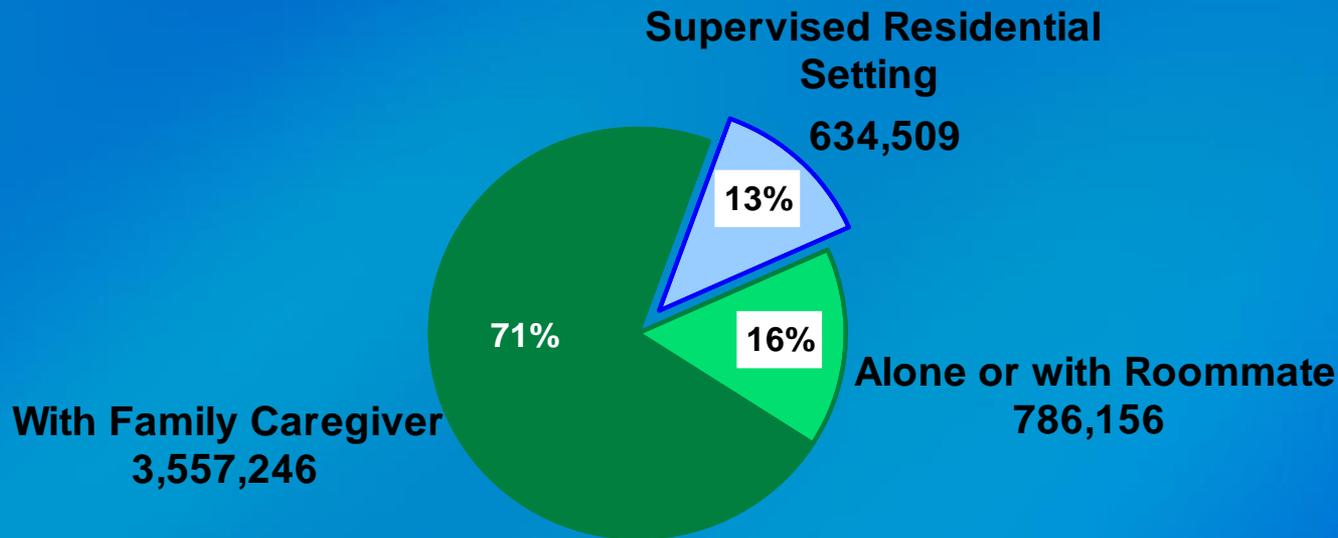
**Rehabilitation Research and Training Center on  
Developmental Disabilities and Health and Family Support RTC  
Department of Disability and Human Development  
University of Illinois at Chicago  
<http://www.rrtcadd.org/>**

# Families are the Primary Providers of Care

- Longer period caregiving
- Traditional parental roles persist into adulthood
- Fewer family members to provide care
- Families provide most of social-recreational support
- Many are not known to the disability service system
- Adult child with disabilities provides support to parents or others in the family

# Most People with I/DD Live with Family Caregivers

## United States 2013



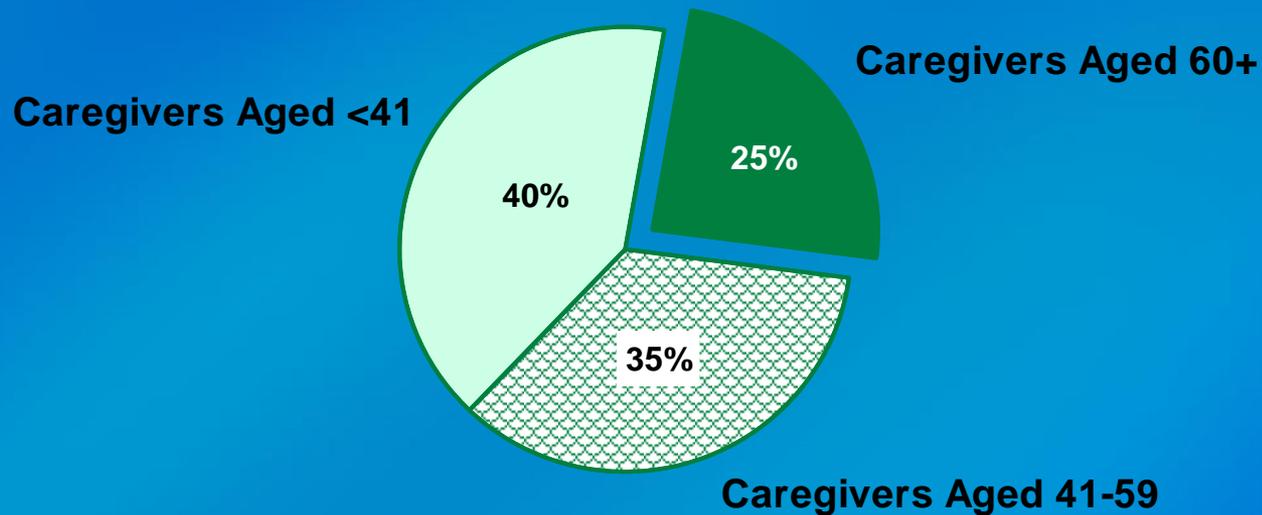
**TOTAL: 4,977,911 PERSONS**

Source: Braddock, D., et al., State of the States in Developmental Disabilities, 2015, based on Fujiura (2012)



# Roughly ¼ Live at Home with Aging Caregivers

## United States 2013



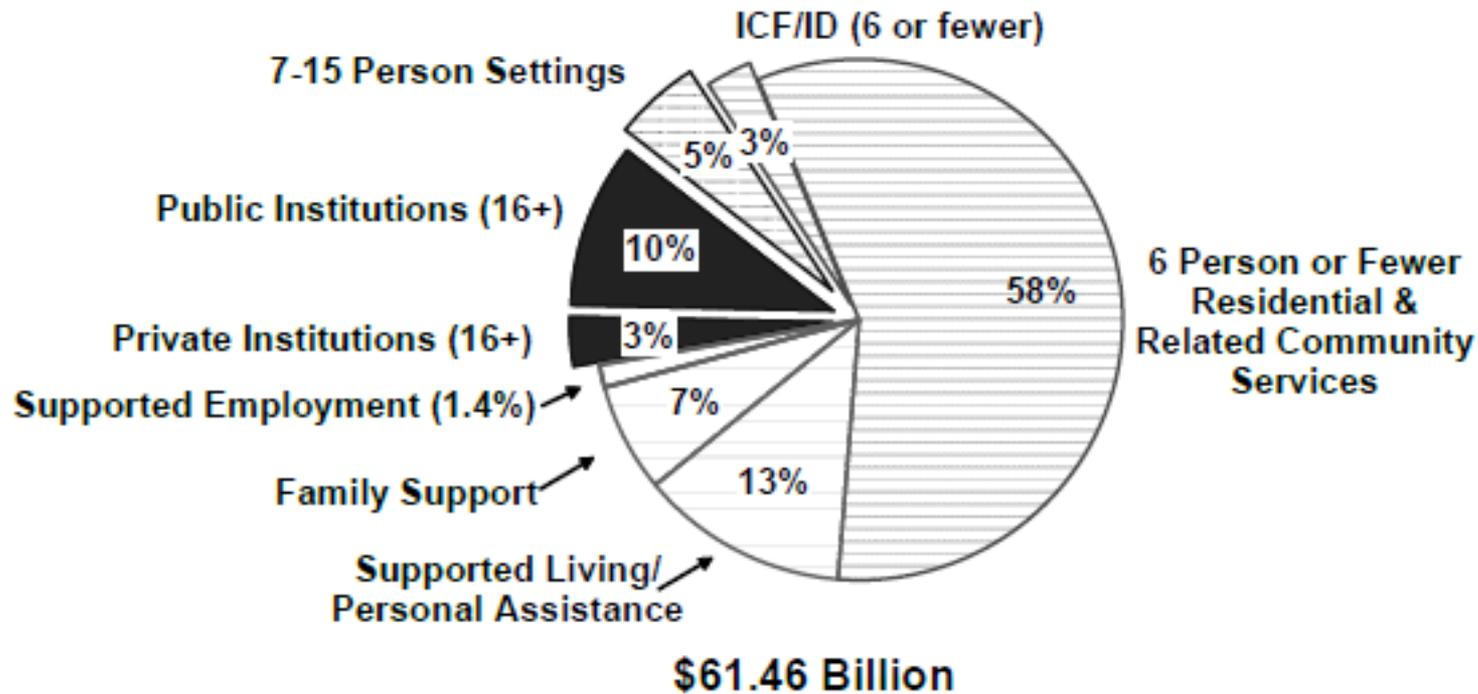
**TOTAL: 3,557,246 Persons**

**Source:** Braddock et al., Coleman Institute and Department of Psychiatry, University of Colorado, 2015 based on Fujiura (2012).



# In FY 2013, only 7% of public funding went to family support

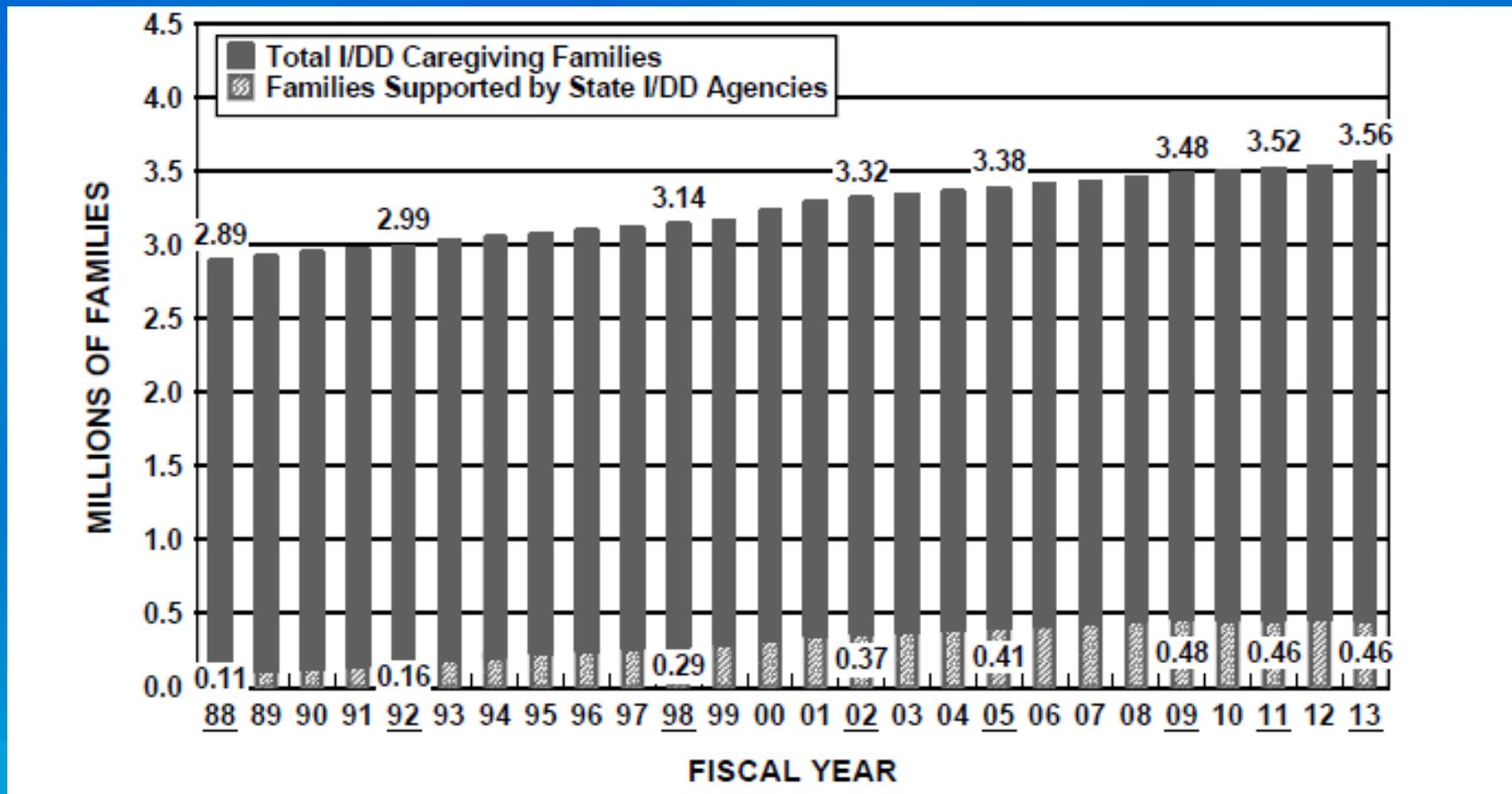
## United States



Source: Braddock, D., et al., State of the States in Developmental Disabilities, 2015.



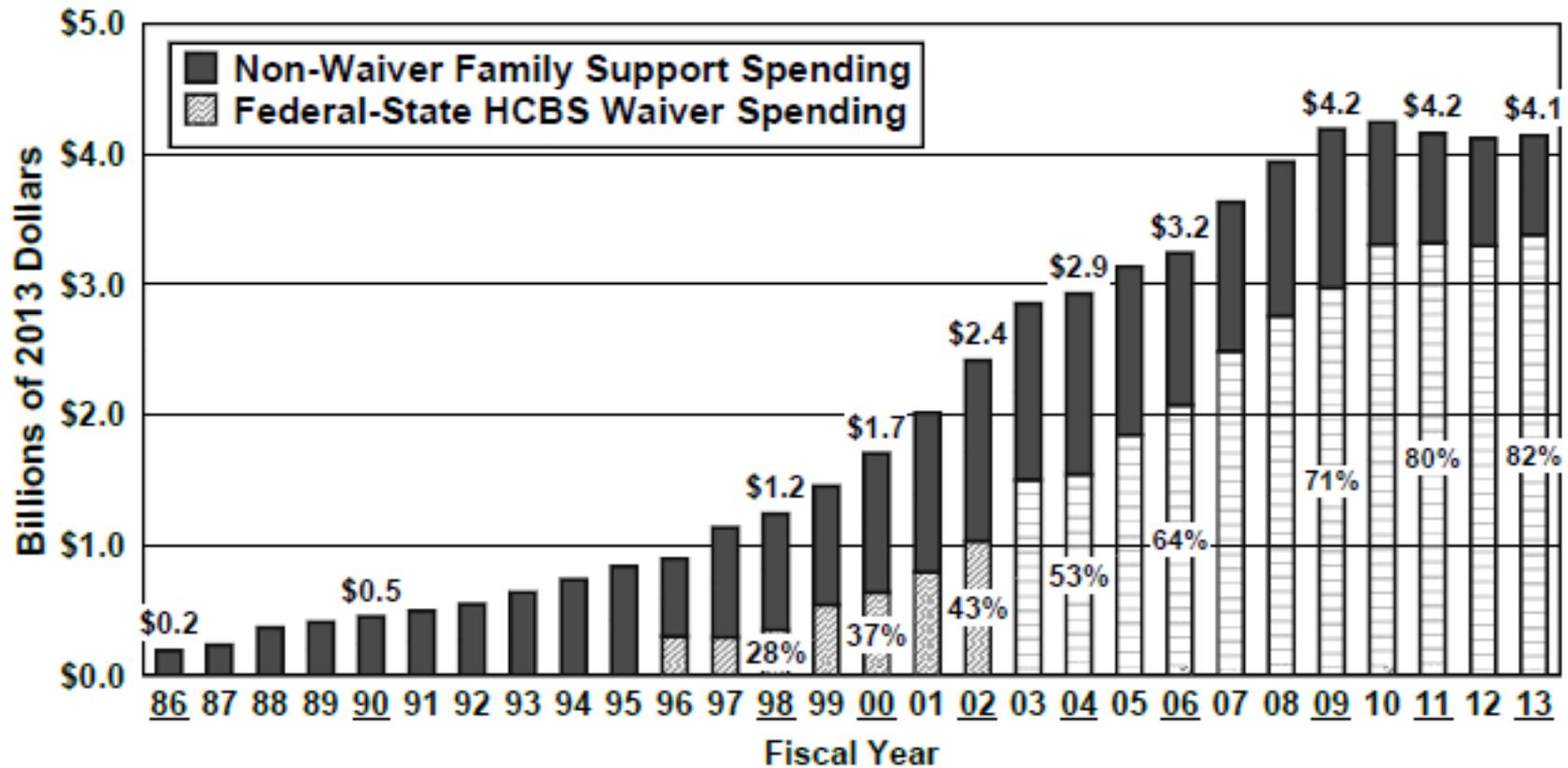
# An estimated 13% of families receive formal supports in the home



Source: Braddock, D., et al., State of the States in Developmental Disabilities, 2015.



# Family Support Spending



Source: Braddock, D., et al., State of the States in Developmental Disabilities, 2015.



# Family Needs

- The Arc of the US (2010) FINDS national survey
  - 4,962 caregivers and 558 people with I/DD
  - Majority were not fully included in schools, despite schools being major sources of support
  - Many families not prepared in terms of future planning
  - 88% of families experienced physical strain and 81% experienced financial strain

# Consequences for Families

- Fewer opportunities for employment
- Restricted social network
- Greater impact on minorities
- Needs and rights of families distinct from needs and rights of person with I/DD
- Caring also has its positive aspects

# What is Family Support?

- No consensus on definition
- Supports offered to the individual living at home (including for individual and/or family caregivers) vs calling services directed at the individual with IDD as “in-home” support .
- Confusion regarding what is best practice and policies
- Know a lot about needs not how best to meet them

# Trends in Policies: US

- Shrinking of federal/state DD budgets
  - Great Recession (starting 2007) resulted in largest spending drops in 35 years
  - Weak recovery (Braddock et al., 2012)
- Increasing residential waiting lists
  - Estimate of 115,059 (Larson et al., 2012)
- Greater use of supported and family living

# Trends in Family Support (2)

- In last decade shift from residential facilities to supporting people to live with family
- Medicaid funding for family support grew fourfold
- By 2011 five states reported that 65% or more of people receiving support resided with family (Larson et al., 2012)
- Newer models of family support grants and self-directed options allow hiring of family members

# Family Support Services Some States are Providing

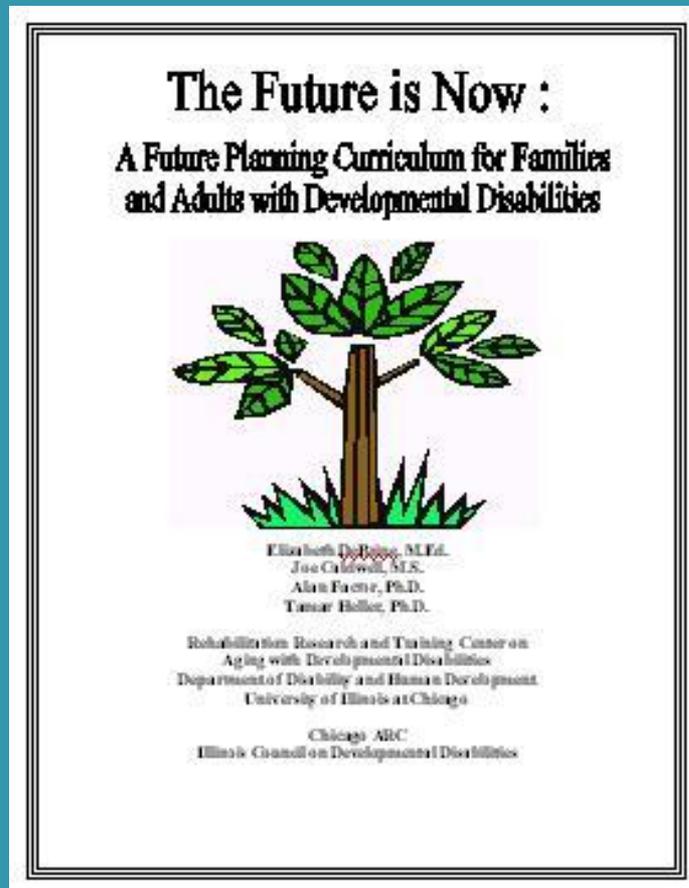
- respite care
- family counseling
- future planning
- architectural adaptation of the home
- in-home training
- sibling support programs
- behavior management services
- purchase of specialized equipment

Braddock et al. (2008). The State of the States in Developmental Disabilities.

# Need to Plan for Future Needs

- Many families do not make plans and are unaware of legal and financial options
- Planning is related to resources, ways of coping, and options in the community
- Lack of collaboration between aging and disability service system
- Many families have avoided contact with formal disability services

# The Future is Now Curriculum



# Workshops for Individuals with DD



# Workshop: Family Caregivers

Use of family and self-advocate peer trainers

Joint goal planning

Developing letter of intent



# Sibling Relationships and Support



# Relationships of Siblings

- 14% of siblings co-reside with their sibling with I/DD, 23% are primary caregivers. (Easter Seals, 2013)
- Relationships are generally positive with frequent contact (Heller & Arnold, 2010; Orsmond & Seltzer, 2000).
- Less positive and less contact with sibling with autism vs Down syndrome (Orsmond & Seltzer, 2007).

# Concerns of Siblings

- Availability of services
- Social isolation of sib
- Making sure sib's voices are heard
- Financial security for sib
- Helping from a distance
- Personal costs: Financial, time, relations with spouse/partner
- Dividing responsibility among family
- Death of parents and future responsibilities
- One's own death

# Support Needs of Siblings of People with Disabilities

- Inclusion in programs, including distant siblings
- Better access to services (legal, residential)
- Transition program when sibs take over
- Support and psycho-educational groups
- Workshops and information on future planning
- Use of internet networking groups (e.g., sibnet)



# Sibling Leadership Network

- Provides siblings of individuals with disabilities the information, support, and tools to advocate with their brothers and sisters and to promote the issues important to them and their entire families
- 19 state chapters, 4000 siblings and supporters
- Research, Support, Advocacy



SIBLING   
LEADERSHIP  
NETWORK

# FS Need to Know

A project of the Family Support Research and Training Center at the University of Illinois at Chicago in Partnership with Easter Seals  
Goal is to identify relevant family support research topics and questions from multiple groups in order to identify research agenda



# RRTC on Family Support

PIs: Magaña, Heller, & Caldwell

## National Advisory Council

### Research Projects

1. Developing a strategic plan for family support research (Magaña & Grossman) →
2. Identifying promising practices in family support services (Caldwell & Arnold) →
3. Family member roles and well-being in self-directed waiver programs (Warfield & Parish)
4. Understanding experiences, trends and needs in self-directed support programs (Mahoney & Mahoney)
5. Family Support in Managed-Care (Heller, Owen, & Caldwell)
6. Parents Taking Action: A parent training program for Latino families (Magaña & Morales)

Stakeholder participation

Promising practices workgroups

### TA/Dissemination Committee:

NIDRR required and additional family and disability organizations

Collaborating Partners: The Arc, Easter Seals, Sibling Leadership Network, National Alliance for Caregiving, Institute on Community Integration at UMN, and the Association of University Centers on Disabilities

#### Dissemination

- \*Creating dissemination plan
- \*Hosting state-of-the-Science conference
- \*Creating briefs from *Caregiving in the US* and *NCI*

#### Training

- \*Training for ADRC staff and families
- \*Implementing train-the-trainer caregiver interventions
- \*Training students on family support

#### Technical Assistance

- \*Sponsoring state family support coalitions
- \*Supporting siblings
- \*Establishing family support hotline and clearinghouse

## National Resource Center on Family Support

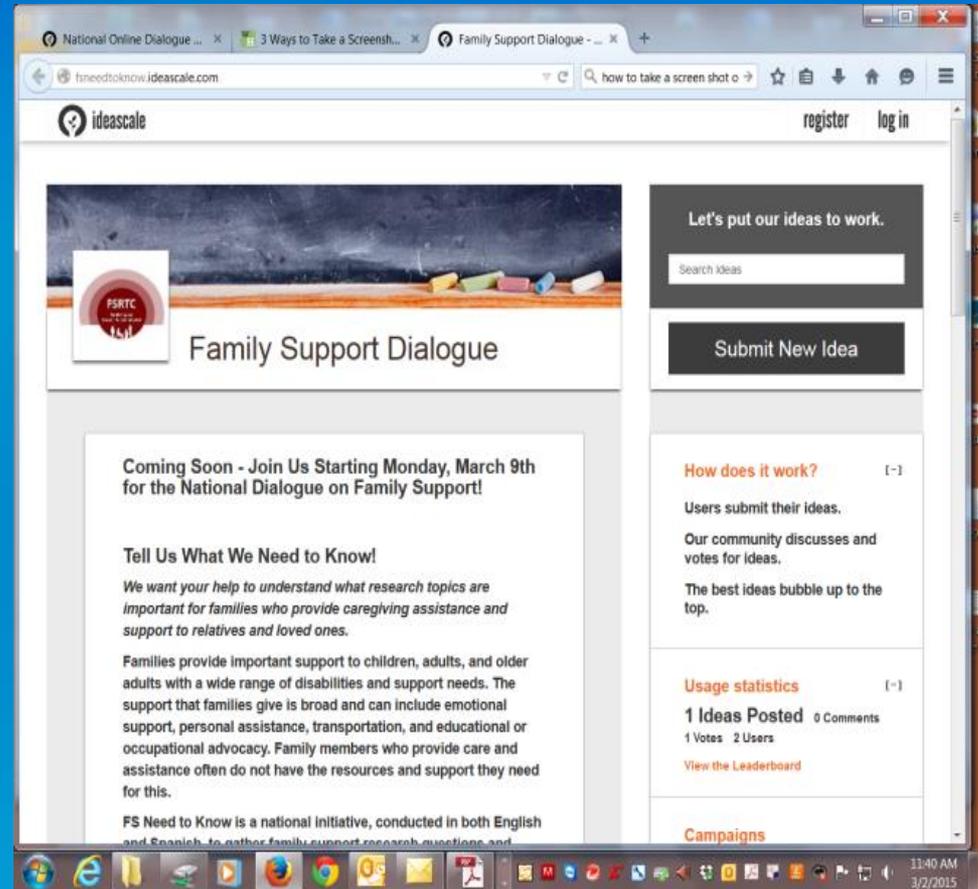
Co-Directors: Magaña & Arnold

# Upcoming Dialogue March 9-30<sup>th</sup>

fsneedtoknow.ideascale.com  
afdiganos.ideascale.com

Please feel free to contact us

- Brian R. Grossman
  - brg@uic.edu
- Sandy Magana
  - maganas@uic.edu
- Karen Lukaszewski
  - klukas3@uic.edu
- Miguel Morales
  - mmoral29@uic.edu
- Lisa Peters-Beumer
  - lpeters@easterseals.com
- Rachel Beyerle
  - dialogue@easterseals.com



# How can you help promote FS Need to Know?

**1) Log in to the dialogue, read comments, register, and participate.**

- [FSNeedtoKnow.ideascale.com](https://FSNeedtoKnow.ideascale.com)
- [AFDíganos.ideascale.com](https://AFDíganos.ideascale.com)

**2) Let your network know about the dialogue on social media.**

- Twitter event hashtags for the national event are #FSNeedtoknow and #AFDíganos.
- Friend Easter Seals on [Facebook](#) to follow news and updates on the dialogue

**3) Post article on your agency website, Facebook page, or share in your e-newsletter.**

***Discussion Panel:  
Creative Solutions to Grow and  
Sustain Your Coalitions***



#CareAdvocate @NA4Caregiving



***Moderator:***

***Karen Marshall, JD  
Executive Director***

***Kadamba Tree  
Foundation***



#CareAdvocate @kadambatree



*Faith Unger  
Caregiver U  
Program Director*

*AGE of Central Texas*



#CareAdvocate @austinelderly





# CAREGIVERU

A PROJECT OF ST. DAVID'S FOUNDATION  
AND AGE OF CENTRAL TEXAS

**Faith Unger**  
**Director, CaregiverU**



# CAREGIVERU

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A PROJECT OF ST. DAVID'S FOUNDATION  
AND AGE OF CENTRAL TEXAS

**Serving Central Texas since 2011**

**With Free Evidence Based Education**

**Through a collaboration of**

**Central Texas non-profit agencies and  
community organizations**



# CAREGIVERU

A PROJECT OF ST. DAVID'S FOUNDATION  
AND AGE OF CENTRAL TEXAS

## Family Caregiver Education and Fall Prevention Education





# CAREGIVERU

A PROJECT OF ST. DAVID'S FOUNDATION  
AND AGE OF CENTRAL TEXAS

Program Director, Faith Unger

Professional Educator

Personal Caregiver

Passionate about Wellness  
Education





# CAREGIVERU

A PROJECT OF ST. DAVID'S FOUNDATION  
AND AGE OF CENTRAL TEXAS

## CaregiverU Is A Program of AGE of Central Texas

*"Tackling the challenges of  
aging with expert solutions"*

(512) 451-4611

[www.AGEofCentralTX.org](http://www.AGEofCentralTX.org)





# CAREGIVERU

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AND AGE OF CENTRAL TEXAS

## AGE of Central Texas Programs:

Adult Day Health Care

Caregiver Education and Resources

Early Memory Loss Support

Health Equipment Lending

Peer-Based Computer Classes



*"To Make Aging a Shared Journey of Triumph"*



# CAREGIVERU

A PROJECT OF ST. DAVID'S FOUNDATION  
AND AGE OF CENTRAL TEXAS

## Caregiver Education and Resources

Assistance by  
phone, e mail, or  
walk-in

Educational Seminars  
and conferences

Caregiver Support  
Group

CaregiverU





# CAREGIVERU

A PROJECT OF ST. DAVID'S FOUNDATION  
AND AGE OF CENTRAL TEXAS

## AGE of Central Texas Is:



Local Non-Profit  
Organization



Funded by Grants  
& Donations



Led by a Board of  
Directors





# CAREGIVERU

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A PROJECT OF ST. DAVID'S FOUNDATION  
AND AGE OF CENTRAL TEXAS

CaregiverU funding provided  
through a generous grant from

**St David's**  
**FOUNDATION**





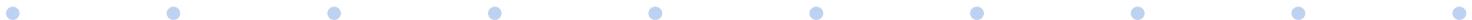
# CAREGIVERU

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For more information:

[www.CaregiverUcentx.org](http://www.CaregiverUcentx.org)



*Toula Wootan  
Founder*

*Caregiver Coalition  
of Northeast Florida*



#CareAdvocate @toulastips





# About the Caregiver Coalition of Northeast Florida

*The Caregiver Coalition of Northeast Florida is a program of Community Hospice of Northeast Florida, in partnership with other locally based nonprofit organizations.*

# Why a caregiver coalition?

- University of North Florida study
- Lack of knowledge
- No focus on caregivers in our area, in Florida
- Need for collaboration

## Beginnings: 2007

- Informal partnership of six organizations working together to offer free caregiver conferences
- Created mission and vision: 2008
- Dedicated to caregivers of a senior
- Mission: ***to promote awareness and knowledge of, sensitivity to and support for family caregiving in Northeast Florida.***

## Caregiver Coalition Members:

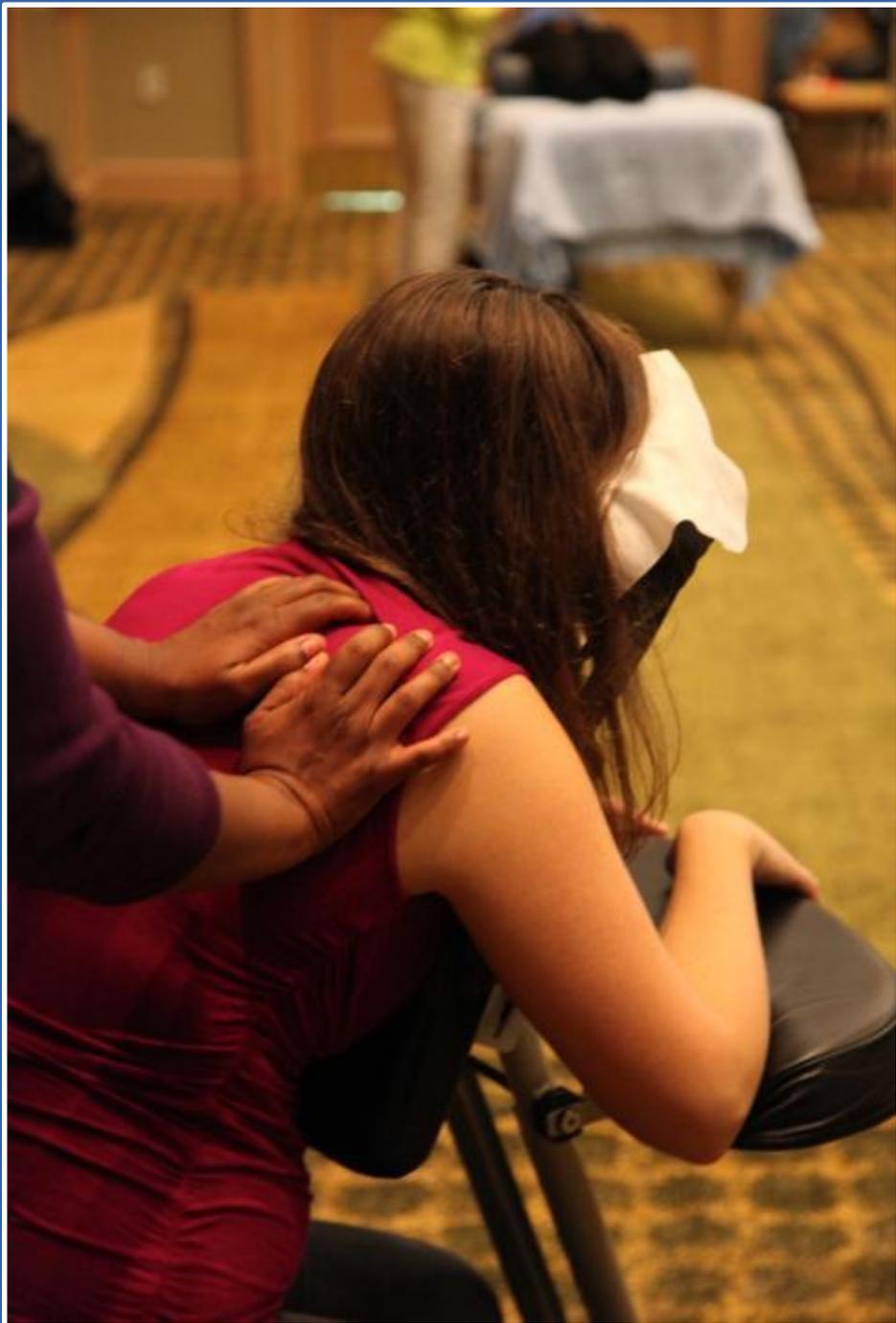
- Community Hospice, ElderSource, Aging True, Alzheimer's Association, City of Jax Senior Services Division, Mayo Clinic Memory Disorders Clinic
- Later added: AgeWell Institute/Baptist Health, YMCA of Florida's First Coast, Taylor Residences, Brooks Rehabilitation, area Councils on Aging

# Caregiver Coalition Programs:

- Free conferences: 58 to date
- Annual Caregiver Expo
- Caregiver Newsletter: “Caregiver Connections”
- Caregiver Support Line
- MyCaregiverConnection.org
- More to come!

- How we are organized
- Charter
- Funding
- Sustaining and Growing
- Best Practices and lessons learned
- Looking to the future









*Sue Coyle,  
COTA, BA, CMC*

*Geriatric Care Manager*

*Outagamie County  
Caregiver Coalition  
(Wisconsin)*



#CareAdvocate @SueCoyleCMC



# Outagamie Caregiver Coalition

**A Network  
Dedicated to  
YOU!**



- ❖ Providing you with education
- ❖ Helping you access resources
- ❖ Reducing your stress
- ❖ Developing your support systems

## **Vision Statement**

*Empowering families and friends to care for their loved one*

## **Mission Statement**

*The Outagamie Caregiver Coalition is dedicated to the caregiver by providing needed support through comprehensive education and resources.*

# Began as a group of independent providers to...

- ...provide more means for Caregivers to receive education and resources and identify as Caregivers
- ...carry out the mission and vision
- ...have active participation in at least one of the sub-committees and/or activities of the group

# Projects have been....

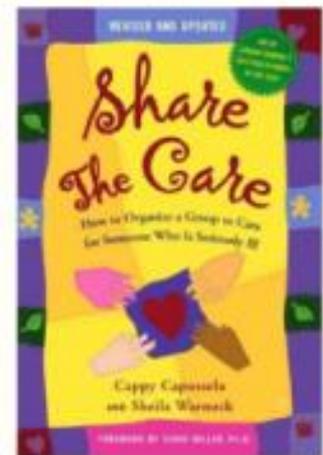
**Technical  
College OTA  
student  
projects –  
Caregiver  
Resource Fairs  
and Toolkits**

**OUTREACH TO  
EMPLOYERS**

**AARP**  
FOUNDATION

**Prepare  
to Care**

Our Mission is to improve the quality of life for anyone who needs support and to reduce the stress, depression, isolation and economic hardship of their caregivers.



# Projects Currently Are:

Caregiver Cafes  
(Thursday, (9:00,  
Skyway 265)

Development of an  
updated “Caregiver  
Toolkit” to distribute  
to employers, clinics,  
etc.

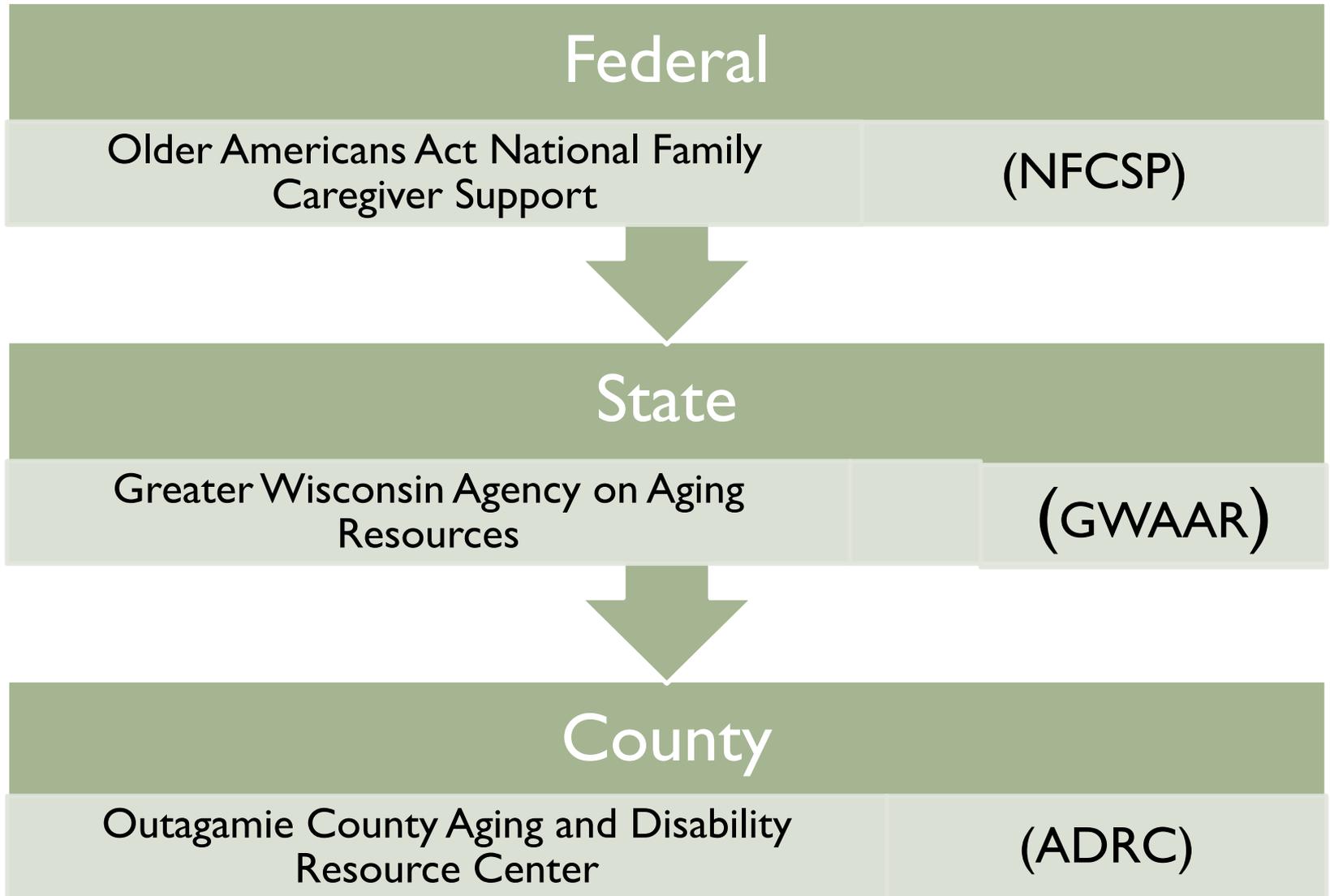
Increased outreach to  
rural and underserved  
areas

Development of a  
distribution list and  
method of disbursing  
Caregiver Toolkits

Caregiver Resource fairs and  
presentations at major  
employers

Ongoing branding and  
marketing

# Funding



# Other Support: In-Kind Donations

- Facilities –Linwood Commons, Encircle Health, Fox Valley Technical College, Thompson Community Center, Churches
- Printing – Theda-Care Health system, K-C
- Mailing and distribution – ADRC, members
- Partnerships – Kimberly Clark, FVTC, LSS, ADRC

# Challenges

- Family Caregivers as members of the group
- Connecting with Caregivers and employers of caregivers
- Members volunteering time for projects
- Reaching and obtaining community and leader support

# Goals and Plans

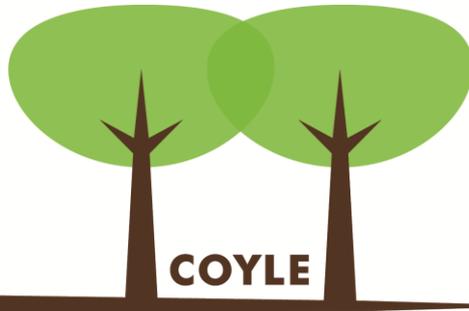
(Determined From Recent Strategic Planning)

- Reach CG's in rural, underserved areas; create connections with homebound, reach diversity of CG's
- Create a Caregiver Toolbox and share more broadly
- Create a marketing plan and brand for the Outagamie Caregiver Coalition
- Conduct a focus group to identify Caregiver needs
- Legislative breakfast with community leaders and policy-makers, instrumental groups
- Utilize current County and Prevention programs to distribute materials
  - *Strong Bones* and *Stepping On* classes, Meal Sites, Caregiver Cafes, Support groups, etc.
  - Coalition members distribute through own job duties if able

# Contact Information

Sue Coyle

920-740-8441



**CARE MANAGEMENT**  
and **CONSULTING, LLC**



Serving Calumet, Outagamie and Waupaca Counties

1-866-739-2372 (Toll Free)

920-832-5158

# *Update from the National Alliance for Caregiving*

Gail Gibson Hunt, President & CEO

C. Grace Whiting, JD,  
Director of Strategic Partnerships



#CareAdvocate @NA4Caregiving



# 2014 Highlights: Technology

- Palo Alto Roundtable
- *Catalyzing Technology to Support Family Caregiving* White Paper
- White House Data Jam
- Senate Special Committee on Aging Telehealth Hearing

# *Highlights: Advocacy*

- State C.A.R.E. Act
  - Passed in OK, NJ, VA, but not HI
- New State Task Forces on Caregiving
  - New Mexico, Mississippi
- Likely reauthorization of the Older Americans Act

# *Renewed Congressional Interest*

- In HOME Care Act (Sen. Booker)
- Caregiver Corps Act (Sen. Casey)
- National Care Corps Act (Rep. Grisham)
- Social Security Caregiver Act (Rep. Lowey)
- Healthy Families Act (sick leave, including caregiving) (Rep. DeLauro, Sen. Harkin)
- FAMILY Act (paid family and medical leave) (Rep. DeLauro, Sen. Gillibrand)
- Assisting Caregivers Today (“ACT”) Caucus

# *2015: The Year Ahead*

- New Research
  - Caregiving in the U.S.
  - Caregivers of Persons with Mental Illness
- White House Conference on Aging
  - Family Caregiving Tele-Town Hall
  - Letter to Executive Director Nora Super
- International Work in Caregiving
- IOM Caregiving Report

# Key Coalition Work

- *From Plan to Practice: Implementing the National Alzheimer's Plan in Your State*
- *Second Coalition Guidebook, Growing Your Coalition: What to Do After You've Planted the Seed*
- Social Media Chats: #CultureOfCare, #CoPayCards, #CareAdvocate
- Webinars & Conference Calls

# Caregiving Champions!

- Initial 10 Champions Named
- Mini-grants in 8 states and Toolkits
- Nomination Form is live – go to [www.caregiving.org/nominate](http://www.caregiving.org/nominate)
- Share the Caregiving Champions Videos – go to [www.youtube.com/user/NA4Caregiving](http://www.youtube.com/user/NA4Caregiving)
- Identify Champions for all 50 states by the end of 2015

# www.caregiving.org

info@caregiving.org

Membership Partner Join Our Email List



**NATIONAL ALLIANCE *for* CAREGIVING**

*Advancing Family Caregiving Through Research, Innovation, and Advocacy*



Home About ▾ Research ▾ Advocacy ▾ State & Local Coalitions ▾ Caregiving Champions ▾ Resources ▾ News ▾



## FROM CARING TO CAREGIVER ADVOCATE

The Annual Caregiving Coalitions Conference | March 24, 2015

Get Involved

### RESEARCH

Family caregivers provide important societal and financial contributions for their loved ones. Through national surveys, our research identifies important new trends and sheds light on the varying needs of this huge and diverse group.

### CAREGIVING CHAMPIONS

The Caregiving Champions program recognizes policymakers and persons of influence who have raised awareness of the issues facing family caregivers in our society.

Find Your Champion

### INTERNATIONAL CARING

Caregiving is truly an international phenomenon. No nation is without family caregivers, and the ways in which nations support the needs of caregivers are many. The Alliance is proud to serve as Secretariat for the International Alliance of Carer Organizations, a global coalition dedicated to recognizing the issues

# *Table Topics Networking Lunch!*

Consult your agenda for Table Topics & Presenter Information.



#CareAdvocate @NA4Caregiving

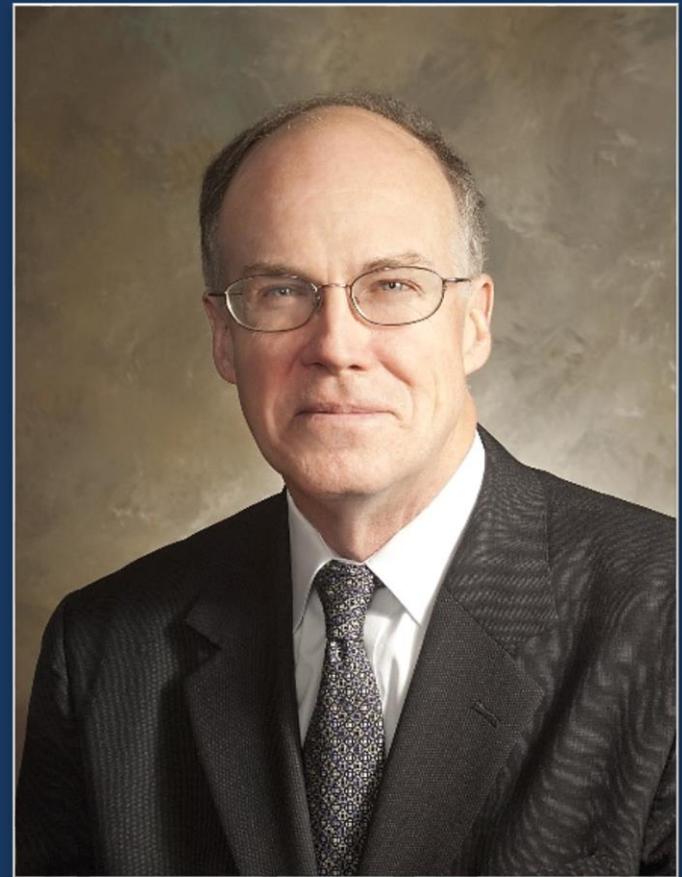


# *Keynote Presentation*

***Brian Duke,  
MHA, MBE (Bioethics)***

Caregiving & Aging Advocate

Former Secretary of Aging,  
Commonwealth of  
Pennsylvania



#CareAdvocate @NA4Caregiving



# Empowerment and Engagement: Caring to Advocating

9<sup>th</sup> National Caregiver Coalitions Conference  
National Alliance for Caregiving  
March 19, 2015

# Monica

Year 1- Began showing signs of forgetfulness

Year 2 -Husband died

Year 3 - Journey toward diagnosis of AD began

Years 4- 7 - Progression of disease, co-morbid conditions, complications

Years 1-7 - Caregiving journey

Year 7 - Death

# My Story with Monica

- ▶ The difference between capacity and capability among siblings
- ▶ Need for respite arose
- ▶ Creative options out of conversations
- ▶ Admission to SNF did not end caregiver role—it changed it
- ▶ Bereavement and caregiver

# The Family Role

- ▶ Primary family caregiver
- ▶ Adult child/ parent
- ▶ Spouse
- ▶ Life/family history

# Unspoken Expectations

- ▶ Family
  - ▶ Capacity under duress
  - ▶ Deferred conversations
  - ▶ Caregiving career
  - ▶ Cumulative loss
  - ▶ Geographically distant
  - ▶ Perception of responsibility
  - ▶ Disagreement and agreement
  - ▶ Knowledge of system
  - ▶ Culture of family

# Expectations

- ▶ Of care recipient
- ▶ Of health care system
- ▶ Of health professionals
- ▶ Of long term services and supports

# Caregiving

Definition

Progression

# What are caregivers doing?

- ▶ Transportation
- ▶ Housework
- ▶ Grocery shopping
- ▶ Preparing meals
- ▶ Managing finances
- ▶ Helping with medications
- ▶ Arranging or supervising paid services

*Care for the Family Caregiver, A Place to Start*, Emblem Health/National Alliance for Caregiving, March 2010

# What are caregivers doing?

- ▶ Getting in and out of bed
- ▶ Getting dressed
- ▶ Helping bathe or shower
- ▶ Getting to and from the toilet
- ▶ Feeding the care recipient
- ▶ Dealing with incontinence and diapers

*Care for the Family Caregiver, A Place to Start*, Emblem Health/National Alliance for Caregiving, March 2010

# Who are caregivers

- ▶ Capacity
  - ▶ Resilience
  - ▶ Growth/Stress
  
- ▶ Capability

# Areas of Concern

- ▶ Legal
- ▶ Financial
- ▶ Medical Care
- ▶ Home-Safety and Maintenance
- ▶ Transportation
- ▶ Social
- ▶ End of Life
- ▶ Care of the Caregiver

# Loss of Self

- ▶ Health and Wellness
- ▶ Patience and Endurance

# What have we done?

- ▶ Caregiver recognition
- ▶ Educational outreach
- ▶ Caregiver support

# Advice to male caregivers

- ▶ Men and women different
- ▶ Simply aware that more men are filling caregiver roles
- ▶ Suggest support groups
- ▶ Educate yourself
- ▶ Meditate or Me time
- ▶ Have all necessary documents - insurance, deeds, wills,
- ▶ Stay involved in hobbies
- ▶ Lead with strengths - arranging doctor appointments, managing finances, running errands
- ▶ Ask for help - fragmented health care and aging system

# So what does it mean to be aware?

## ▶ Recipient

- ▶ Is more aware of him/herself and current lived experience
- ▶ Knows more about a resource, service, diagnosis, prognosis
- ▶ Knows how to find help
- ▶ Is inspired to act
- ▶ Connects with others

# Empowered

- ▶ Relationship
- ▶ Role
- ▶ Responsibilities

# Advocacy cycle

- ▶ Identify issue or problem
- ▶ Research cause and effect
- ▶ Plan goals, objectives, indicators, methods, activities, and timeline
- ▶ Act
- ▶ Monitor and evaluate actions and results

# Effective Advocacy

- ▶ Know the facts.
- ▶ Use the facts
- ▶ Have clear and concise message
- ▶ Nurture relationships and work collaboratively
- ▶ Engage the public
- ▶ Make your voice heard!
- ▶ Say thank you
- ▶ Citizen's Committee for Children of New York

# Barriers to Empowerment

- ▶ Caregivers focus on their loved one, not on themselves.
- ▶ Many caregivers are hesitant to share duties with other family members.
- ▶ Most caregivers are unfamiliar and uncomfortable with outside services.
- ▶ Caregivers are reluctant to discuss their caregiving responsibilities at work.
- ▶ Many caregivers are reluctant to talk about - or even speculate on - whether or how caregiving affects their own health.

Family Caregivers Self-Awareness and Empowerment Project A  
Report on Formative Focus Groups FINAL Report September  
2001 The National Family Caregivers Association and the  
National Alliance for Caregiving by Lake Snell Perry &  
Associates

# Barriers to Empowerment

- ▶ There is little or no awareness of caregiving organizations
- ▶ While there are significant barriers to self-awareness, there are some who have crossed the barrier emphatically to become empowered.

Family Caregivers Self-Awareness and Empowerment Project A  
Report on Formative Focus Groups FINAL Report September 2001  
The National Family Caregivers Association and the National  
Alliance for Caregiving by Lake Snell Perry & Associates

# Caregivers and Advocacy

- ▶ The idea of caregivers as a political constituency is foreign to most caregivers, and some are very wary of it. Nevertheless, the potential advantages of political mobilization are clear and powerful to some caregivers.

Family Caregivers Self-Awareness and Empowerment Project A  
Report on Formative Focus Groups FINAL Report September 2001  
The National Family Caregivers Association and the National  
Alliance for Caregiving by Lake Snell Perry & Associates

# Required engagement

- ▶ “As new state demonstrations to improve and integrate care for Medicare-Medicaid enrollees (also known as “dual eligibles”) move forward, health plans and provider groups (here, referred to collectively by the term “delivery systems”) must employ meaningful consumer engagement strategies. Federal guidance from the Centers for Medicare and Medicaid Services calls upon states to ensure the voices of older adults, persons with disabilities, and their caregivers are heard in the design, implementation, and oversight of the demonstrations. ”

<http://www.communitycatalyst.org/resources/tools/meaningful-consumer-engagement>

# Engagement in care delivery

- ▶ “To sum it up, active, meaningful consumer engagement gives delivery systems and their consumers the tool they need the most to improve and maintain health and quality of life - information that leads to action. Delivery systems need information from consumers and their caregivers about the stronger and weaker aspects of care delivery - aspects that impact the system’s bottom line as well as consumers’ health outcomes and quality of life. Similarly, consumers and their caregivers need easy-to-understand information about how to best navigate their newly integrated delivery system and how the system is using consumer feedback for continued quality improvement. This “feedback loop” between consumers, their caregivers, and the entire health care delivery system will be critical to the success of the demonstrations.+

<http://www.communitycatalyst.org/resources/tools/meaningful-consumer-engagement>

# Moving to Empowerment

The background features abstract, overlapping geometric shapes in various shades of blue, ranging from light sky blue to deep navy blue. These shapes are primarily located on the right side of the frame, creating a dynamic, modern aesthetic. The text is centered on the left side of the image.

# Drivers- Desire for change

- ▶ Has to be better
- ▶ Need info to help me now
- ▶ Change for others benevolence
- ▶ Fight to change
- ▶ Gather support

# Attributes effective caregiver

- ▶ Meaning-Focused Coping
- ▶ “The processes of appraisal and reappraisal allow for interpretation of the meaning and significance of the demands and challenges the caregiver is facing. When appraised as deeply meaningful and important to an individual’s values and purposes, energy for coping expands empowering individuals to persist, survive, and grow.”

Development of a Caregiver Empowerment Model to Promote Positive Outcomes Patricia S. Jones, PhD, RN, FAAN1 , Betty W. Winslow, PhD, RN1 , Jerry W. Lee, PhD, RN2 , Margaret Burns, DNSc, RNand Xinwei Esther Zhang, EdS, MS1 Journal of Family Nursing 2011 17(1) 11-28

# Messengers

- ▶ To Caregivers or With Caregivers
- ▶ Importance of seeing themselves

# Message: Advocacy can work

- ▶ You can make a difference
- ▶ People working together can make a difference
- ▶ People can change laws
- ▶ Lobbying helps find real solutions
- ▶ Policymakers need your expertise

Center for Lobbying in the Public Interest: Strategies for Nonprofit  
Engagement in Legislative Advocacy

[https://www.councilofnonprofits.org/sites/default/files/documents/Make\\_a\\_Difference\\_RG%5B1%5D.pdf](https://www.councilofnonprofits.org/sites/default/files/documents/Make_a_Difference_RG%5B1%5D.pdf)

# Conclusion

- ▶ Lived experience empowers the caregiver as they care
- ▶ There are drivers which comprise the desire for change
- ▶ Effective caregivers are more aware , know more, know how, are inspired and connect with others
- ▶ Effective advocacy needs to know the facts; be engaging and achieve success through nurtured relationships.

# Conclusion

- ▶ Meaning focused coping
- ▶ Meaning driven empowerment and engagement
- ▶ Integrate into advocacy

# Contact Information

Brian M. Duke

201 Bruce Road

Washington Crossing, PA 18977

Cell: 215-327-5343

Email: [brianmduke@aol.com](mailto:brianmduke@aol.com)

***Discussion Panel:***  
***Forward Thinking – How***  
***Technology is Changing Family***  
***Caregiving***



#CareAdvocate @NA4Caregiving



***Moderator:***

***Gail Gibson Hunt  
President & CEO***

***National Alliance for  
Caregiving***



#CareAdvocate @NA4Caregiving



# Technology & Caregiving

- What We Know
  - 77% of family caregivers found that Personal Health Record tracking would be helpful
  - 70% wanted a shared Caregiving Coordination System
  - 70% wanted a Medication Support System device

National Alliance for Caregiving, *The e-Connected Family Caregiver* (2011), available at [www.caregiving.org/research/technology](http://www.caregiving.org/research/technology)

# Technology & Caregiving



Rajiv Mehta and Richard Adler, *Catalyzing Technology to Support Family Caregiving* (2014), available at [www.caregiving.org/research/technology](http://www.caregiving.org/research/technology)



# Technology & Caregiving

- What the Round Table Recommended
  - Better “concept maps”
  - New data on caregiving and technology
  - A broad, national conversation
  - Business case for employers
  - Caregiving coaching
  - Social conversations between families and communities

Rajiv Mehta and Richard Adler, *Catalyzing Technology to Support Family Caregiving* (2014), available at [www.caregiving.org/research/technology](http://www.caregiving.org/research/technology)



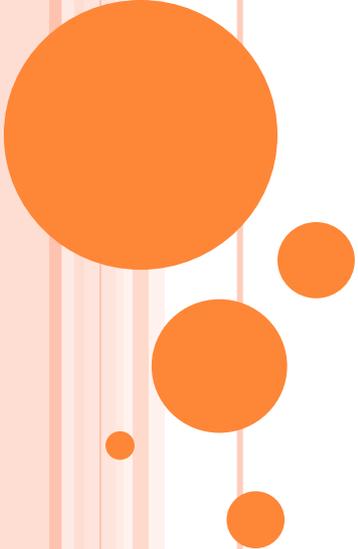
***Ravi Nemana, MBA  
Healthcare &  
Innovation Expert***

*Speaking on behalf of CITRIS  
(Center for Information  
Technology Research in the  
Interest of Society)*



#CareAdvocate @citriscnews





# **EMERGING TECHNOLOGY & AGING**

**Why service matters so much.**

**Ravi Nemana**

# AGENDA

- A few key trends
  - Highlight Technology Developments
  - Highlight Technology Implications
- 
- Financial Conflicts of Interest: None
- 
- Special Thanks: David Lindeman, CITRIS Executive Director

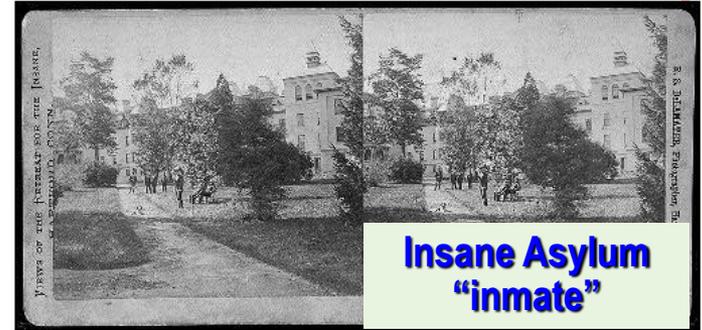
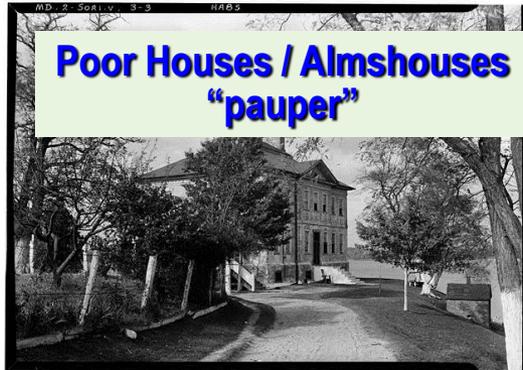


*We tend to overestimate the effect of a technology in the short run and underestimate the effect in the long run*

*--Roy Amara  
"Amara's Law"*



# TRENDS: SENIOR CARE IS RETURNING "HOME" AGAIN



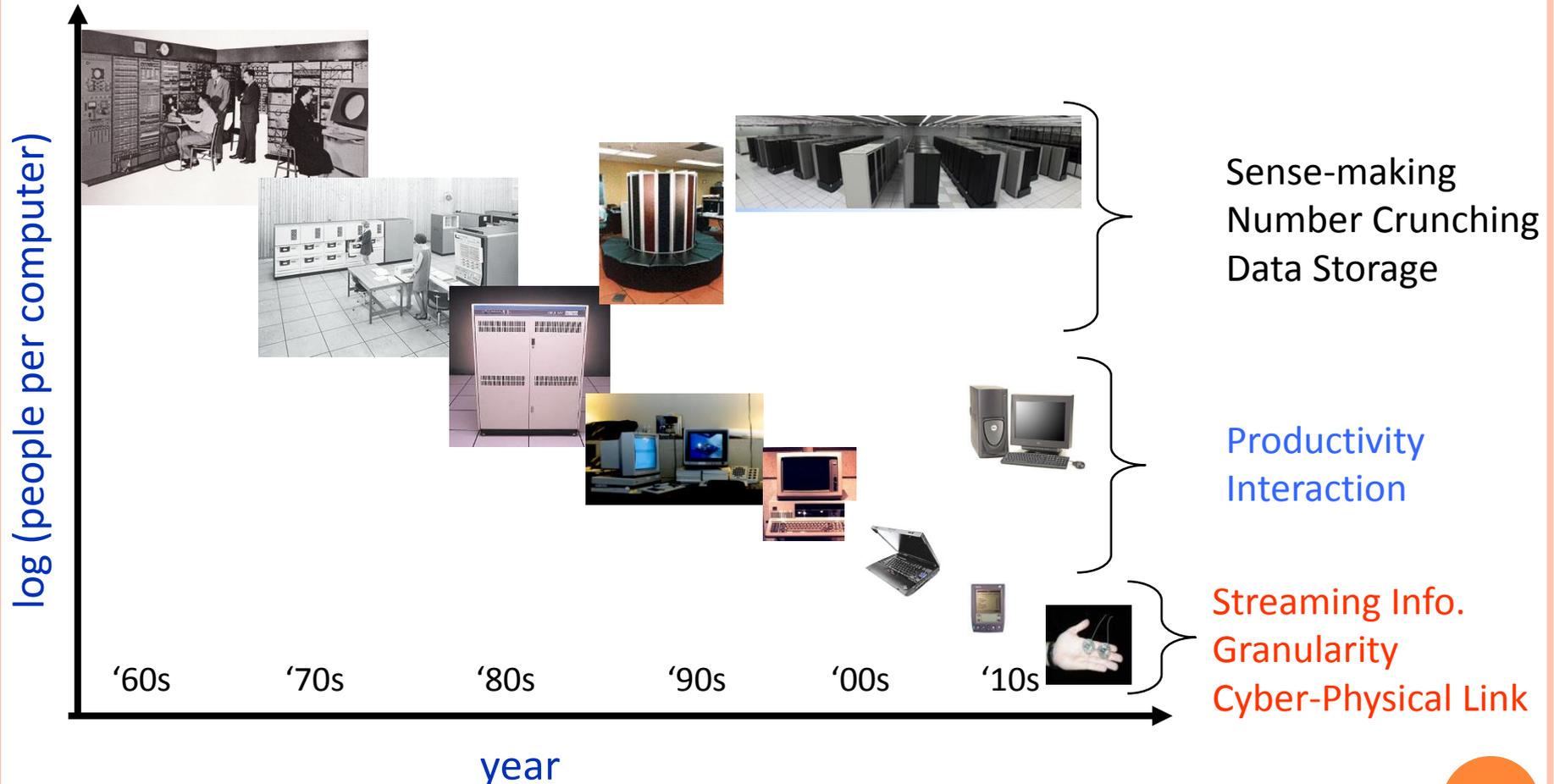
Move toward **home care** & **self care**.

Home care is one of the fastest growing segments of health industry.

Productivity of Home Care services is **poor**.



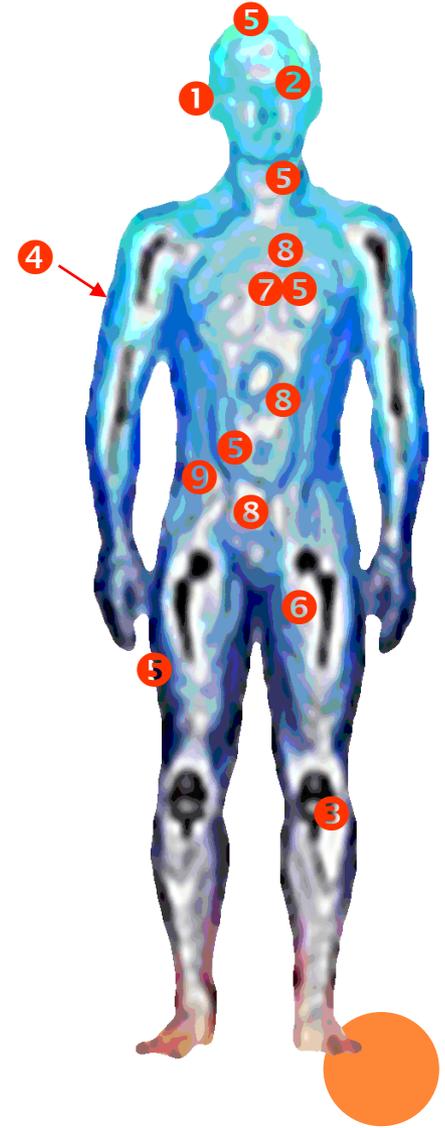
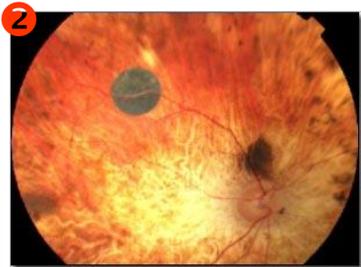
# TRENDS: NEW COMPUTER CLASS EVERY 10 YEARS



Nearly all new technologies transmit or capture something & IT will process, sort, send, track and store these streams.



# TRENDS: WE HAVE ACCEPTED THE "BIONIC MAN" MODEL



# TRENDS: CONVERGENCE IS HAPPENING

- Everyday health through everyday devices
- Everything is a touchpoint / interface to other devices
- Every device has a chip, every chip as a radio



# TRENDS: CONVERGENCE & AGING



DETECT



HealthBuddy  
(Bosch)



ANALYZE  
& TRACK

DO

**Examples:**  
Exergaming  
Telemedicine  
Entertainment  
Out-tasking  
Communication  
"Wellness"  
ADLs  
Living Independently



# HIGHLIGHTS: TELEMEDICINE / REMOTE MONITORING

## Home Activity Tracking

The screenshot shows the Lively website with a navigation bar and a main content area titled "Here's how Lively works". It features four numbered steps: 1. Learn (explaining sensors on objects), 2. Gather (capturing activity signals), 3. Share (sharing activity patterns), and 4. Connect (creating a LivelyGmail mailbox). The page includes images of a person, a smartphone, and a mail icon.

Live!

## Personal Emergency Response Systems

The screenshot shows the Philips Lifeline Medical Alert Service website. It features a headline "How would you get help at a moment like this?" with an image of an elderly person on the floor. Below, it explains "Why Lifeline?" and "The Lifeline Difference", highlighting that it is the #1 medical alert service, trusted by over 65,000 healthcare professionals, and has helped more than 6 million people. A "NEW" badge is present next to the "AutoAlert" feature.

Philips Lifeline

## Geo-tracking

The screenshot shows the Life360 website with a headline "Stay connected to the people who matter". It features a central image of a smartphone displaying a map with location pins. Text on the page includes "Answer an age-old question: Where are you?" and "It's the 21st century: automate".

Life360

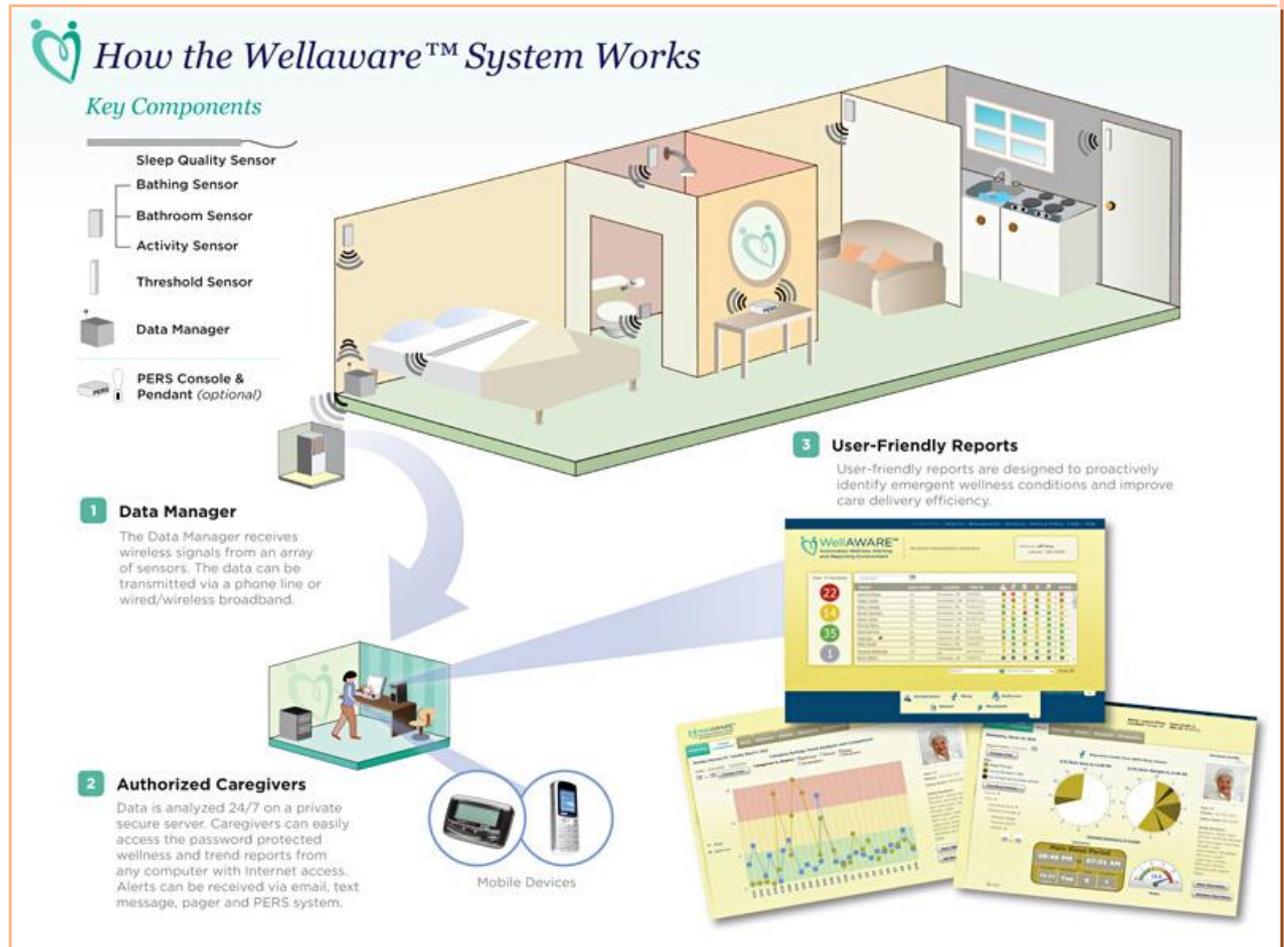
The screenshot shows the Healthsense website for the eNeighbor Remote Monitoring System. It includes a navigation bar, a "CONTACT US" button, and a list of features such as "Automatic fall detection", "Emergency call pendant", and "Custom monitors designed for monitoring falls or missed medication". There is also a 3D floor plan diagram and a photo of two elderly women.

Healthsense



# HIGHLIGHTS: CONNECTED HOME ENVIRONMENT

## HealthSense



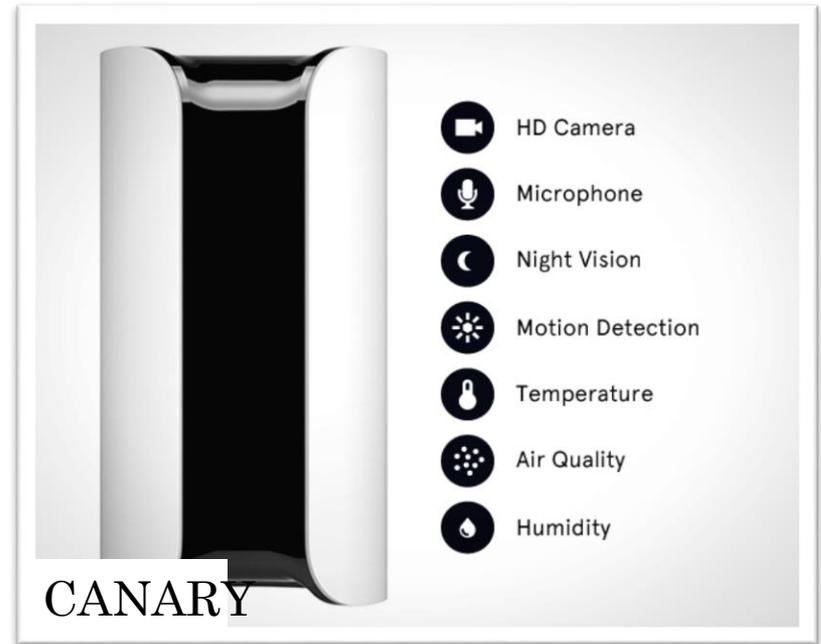
# HIGHLIGHTS: MONITORING + SERVICES



DROPCAM



LIVELY



CANARY

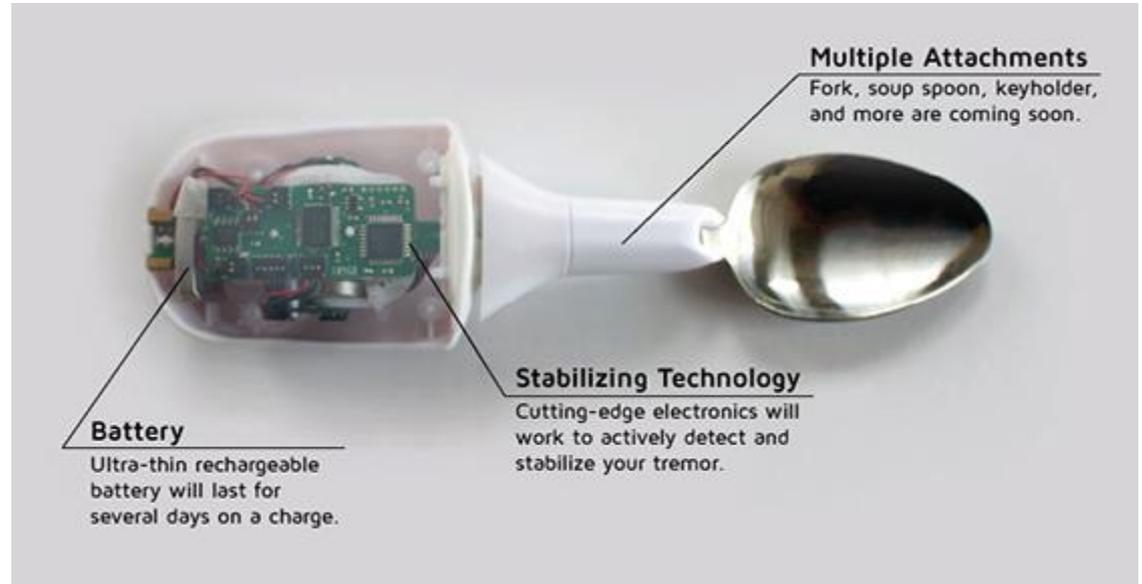
AGING<sup>2.0</sup>



# HIGHLIGHTS: TECHNOLOGY FOR CAREGIVING



**Research Kit**  
(Apple, Inc)  
DM, CAD, BRCA, PD,  
asthma...



**LiftWare spoon**  
(Liftware)



# SERVICES + TECHNOLOGY FOR AGING



© Microsoft



FaceTime

© Apple, Inc.



KINECT

© Microsoft



# FAMILY COORDINATION & COMMUNICATION

Designed for Caregivers

General Purpose

Old but Useful



Google Calendar

Google docs



Google Docs

Notebooks & Binders

LotsaHelpingHands



CareZone



Evernote



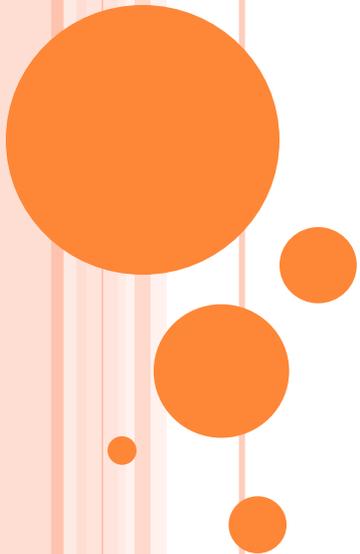
FaceTime © Apple, Inc.



# FOR FURTHER INFORMATION:

Ravi Nemana

[rnemana@gmail.com](mailto:rnemana@gmail.com)



*David Inns, MBA  
Chief Executive Officer*

*Great Call Inc.*



#CareAdvocate @GreatCallInc



# TECHNOLOGY AND CAREGIVING

FORWARD THINKING:  
HOW TECHNOLOGY IS CHANGING  
FAMILY CAREGIVING



# HOW TO SUCCEED

---

- **BENEFITS** senior & caregiver



- They **WANT TO USE** it



- **EASY**, convenient, affordable



- Respect **PRIVACY**



# WHERE WE'RE HEADED

- **SMARTPHONES ARE THE FUTURE OF CAREGIVING:** smartphones with bluetooth peripherals
- **BUT THAT'S THE FUTURE.** Today, smartphones aren't a part of every seniors life.



# AND NOW

WHAT CAN WE DO  
**TODAY?**  
NEXT GENERATION  
PERS

AFFORDABLE  
SIMPLE  
EASY TO USE



*Thank You for a Great Day!*

*[www.caregiving.org](http://www.caregiving.org)*



#CareAdvocate @NA4Caregiving

