From Caring to Caregiver Advocate

9th 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

Pfizer

Easter Seals

Right at Home

MassMutual

Mallinckrodt Pharmaceuticals
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
50,000 Foot – 50 State Challenge

Find Your Champion

Please Select ▼
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

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Moderator:

Rick Greene, MSW
Executive Advisor
National Alliance for Caregiving

#CareAdvocate  @NA4Caregiving
Jed Johnson, MSW, MBA
Vice President,
Strategic Initiatives

Easter Seals, Inc.
Many Faces of Caregiving Study

made possible by MassMutual Financial Group
“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
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.
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.
METHODOLOGY
• 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.
KEY FINDINGS
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.
• Meet Andrea Simone

• Hallmark “Home and Family” segment
To see the full report visit:
www.rand.org/military-caregivers
• 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.
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.
• 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.
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.
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
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.
Challenges Yield Rewards

13% of respondents weren’t able to identify a negative consequence of caregiving
Positive and beneficial outcomes

• Developing closer relationships
• Having a good sense of self
• Enjoying time spent with those for whom they provide care
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
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
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.
Paul Blom
Board Vice-Chair
Training to Serve
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.trainingtoservec.org
Sexual Orientation

Biological Sex

Gender Identity

Gender Expression

Self
Biological Sex

• Objectively measureable organs, hormones and chromosomes.

Female  Intersex  Male
Sexual Orientation

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

Heterosexual  Bisexual  Homosexual

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=WlxDiQ5uOY&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

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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

- Supervised Residential Setting: 634,509 (13%)
- Alone or with Roommate: 786,156 (16%)
- With Family Caregiver: 3,557,246 (71%)

TOTAL: 4,977,911 PERSONS

Roughly ¼ Live at Home with Aging Caregivers

United States 2013

- Caregivers Aged <41: 35%
- Caregivers Aged 41-59: 40%
- Caregivers Aged 60+: 25%

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

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

Family Support Spending

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
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

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: A Future Planning Curriculum for Families and Adults with Developmental Disabilities

Elisabeth Department, M.Ed.
Joe Caldwell, M.S.
Alan Foster, Ph.D.
Tamar Holler, Ph.D.

Rehabilitation Research and Training Center on Aging with Developmental Disabilities
Department of Disability and Human Development
University of Illinois at Chicago

Chicago ABC
Illinois Council on Developmental Disabilities
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
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
Pls: 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 9-30th
fsneedtoknow.ideascale.com
afdiganos.ideascale.com

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- 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.idealascale.com
   - AFDíganos.idealascale.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
Serving Central Texas since 2011

With Free Evidence Based Education

Through a collaboration of

Central Texas non-profit agencies and community organizations
Family Caregiver Education and Fall Prevention Education
Program Director, Faith Unger

Professional Educator

Personal Caregiver

Passionate about Wellness Education
CaregiverU is a program of AGE of Central Texas

“Tackling the challenges of aging with expert solutions”

(512) 451-4611

www.AGEofCentralTX.org
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”
Caregiver Education and Resources

- Assistance by phone, e-mail, or walk-in
- Educational Seminars and conferences
- Caregiver Support Group
- 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 funding provided through a generous grant from St. David’s Foundation and AGE of Central Texas.
For more information:

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)
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

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.

Share The Care

Cappy Cavanaugh and Sheila Warnock
Projects Currently Are:

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

- Increased outreach to rural and underserved areas

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

- Caregiver Resource fairs and presentations at major employers

- Development of a distribution list and method of disbursing Caregiver Toolkits

- Ongoing branding and marketing
**Funding**

Federal
- Older Americans Act National Family Caregiver Support (NFCSP)

State
- Greater Wisconsin Agency on Aging Resources (GWAAR)

County
- Outagamie County Aging and Disability Resource Center (ADRC)
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

Aging & Disability
Resource Center
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

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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)
- 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
- Share the Caregiving Champions Videos – go to www.youtube.com/user/NA4Caregiving
- Identify Champions for all 50 states by the end of 2015
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

9th 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.

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.

The National Family Caregivers Association and the National Alliance for Caregiving by Lake Snell Perry & Associates
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.
"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
“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
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, RN and 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
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

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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

Catalyzing Technology to Support Family Caregiving

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

Ravi Nemana, MBA
Healthcare & Innovation Expert

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

- Poor Houses / Almshouses “pauper”
- Insane Asylum “inmate”
- Hospital “patient”
- Assisted Living “resident”
- Nursing Home “senior citizen”
- Home “grandma”
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
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 IS HAPPENING
TRENDS: CONVERGENCE & AGING

Examples:
- Exergaming
- Telemedicine
- Entertainment
- Out-tasking
- Communication
- “Wellness”
- ADLs
- Living Independently

HealthBuddy (Bosch)
**HIGHLIGHTS: TELEMEDICINE / REMOTE MONITORING**

**Home Activity Tracking**

**Personal Emergency Response Systems**

**Geo-tracking**

- **Live!y**
  - Here's how Live!y works
  - **1. Learn**
    - The Live!y system places small sensors within the home to detect and track the location of family members and more.
  - **2. Gather**
    - Once plugged in, the Live!y hub captures activity data, including movements, location, and more.
  - **3. Share**
    - Family and friends can be notified if a sensor detects motion or if the system detects unusual activity.
  - **4. Connect**
    - Connecting the activity tracking with a remote monitoring system can help ensure that medical professionals are notified in real-time.

- **Philips Lifeline**
  - **How would you get help at a moment like this?**
  - Only one medical alert pendant can call for help even when you can't.

- **Life360**
  - **Stay connected to the people who matter**
  - **Answer an age-old question**
    - Where are you?
    - Philips Lifeline medical alert service provides peace of mind by letting you know you're safe and sound.
  - **Why Lifeline?**
    - When you experience a fall, medical issue, or other emergency, every second counts.
    - Philips Lifeline Medical Alert System can help you get the help you need.
  - **The Lifeline Difference**
    - Our industry-leading, standard medical alert service provides peace of mind by letting you know you're safe and sound.
  - **NEW**
    - Our new Lifeline with AutoAlert® feature stores your last known location and date of birth.
    - AutoAlert provides an added layer of protection by automatically calling a caregiver even if you're unable to initiate the call.

- **Healthsense**
  - eNeighborhood® Remote Monitoring System
    - eNeighborhood® remote monitoring system allows caregivers to monitor activity levels, location, and more.
    - Features:
      - Automatic fall detection
      - Customizable alerts
      - Real-time location
      - Customizable activity levels
    - Benefits:
      - Increased safety
      - Improved communication
      - Enhanced quality of life

*Images and content are for illustrative purposes only.*
HealthSense

HIGHLIGHTS: CONNECTED HOME ENVIRONMENT
HIGHLIGHTS: MONITORING + SERVICES

DROPCAM

LIVELY

CANARY

HD Camera
Microphone
Night Vision
Motion Detection
Temperature
Air Quality
Humidity

AGING

168
HIGHLIGHTS: TECHNOLOGY FOR CAREGIVING

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

LiftWare spoon (Liftware)
SERVICES + TECHNOLOGY FOR AGING

- taproot
- Elance
- Lyft
- Fluential
- TaskRabbit
- lumosity
- RINSE
- Skype™
- FaceTime
- KINECT

© Microsoft
© Apple, Inc.
FAMILY COORDINATION & COMMUNICATION

Family Care Coordination & Communication

- **Designed for Caregivers**
  - CareZone
  - LotsaHelpingHands

- **General Purpose**
  - Google Calendar
  - Google Docs
  - Evernote
  - JoinMe

- **Old but Useful**
  - Notebooks & Binders
  - FaceTime © Apple, Inc.
FOR FURTHER INFORMATION:

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Great Call Inc.
FORWARD THINKING: HOW TECHNOLOGY IS CHANGING FAMILY CAREGIVING
HOW TO SUCCEED

• BENEFITS senior & caregiver

• EASY, convenient, affordable

• They WANT TO USE it

• 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 senior’s 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