Discussion Panel: Underserved Caregivers – Supporting Special Populations

#CareAdvocate @NA4Caregiving
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#CareAdvocate @Easter_Seals
“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 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
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

MADE POSSIBLE BY MASSMUTUAL FINANCIAL GROUP
• **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
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
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

#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
Self

Sexual Orientation

Biological Sex

Gender Identity

Gender Expression
Biological Sex

- Objectively measurable 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

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=WIxZDiQ5uOY&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 outing
• 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

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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

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

TOTAL: 4,977,911 PERSONS

Roughly ¼ Live at Home with Aging Caregivers

United States 2013

- Caregivers Aged <41: 40%
- Caregivers Aged 41-59: 35%
- 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.

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.
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
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; Ormond & Seltzer, 2000).

Less positive and less contact with sibling with autism vs Down syndrome (Ormond & 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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How can you help promote FS Need to Know?

1) Log in to the dialogue, read comments, register, and participate.
   - FSNeedtoKnow.ideascale.com
   - 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.