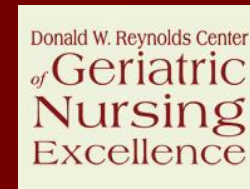


# Distance Family Caregiving and Support for Older Persons: US Perspectives and Irish Context

**20 Years of Family Carer Research in Ireland  
Research Conference, 20 November 2015  
Care Alliance Ireland**

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# Key Points



- Distance family/friend caregivers in the US do provide actual caregiving, including trail and error care coordination
- Caregiving challenges are not sufficiently impacted by current and available interventions
- Technology can assist; caregiver support is required
- Innovation with family caregivers is required to connect across distance using technology and care coordination coaching
- Distance care is “time limited;” care at home not for everyone



# When I am 80.....



## Ageing policy in Ireland – north and south

### Northern Ireland

- Investing for health (2002)
- Ageing in an inclusive society (2005)
- Lifetime Opportunities: Government's Anti-Poverty and Social Inclusion Strategy (2007)
- Commissioner for older people in NI (2012)
- New ageing strategy

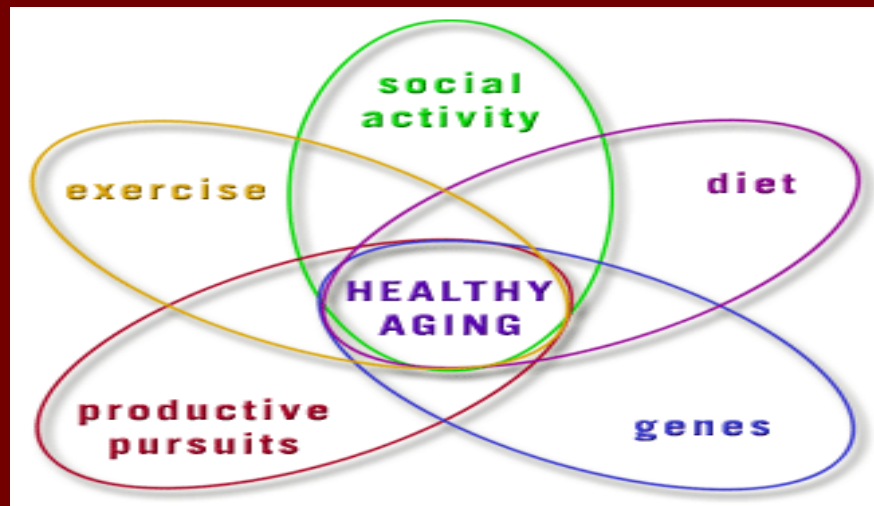
### Republic of Ireland

- The Years Ahead (1998)
- Quality and Fairness: A Health System for You (2001)
- Towards 2016: Ten Year Framework Social Partnership Agreement 2006 – 2015
- Positive Ageing Strategy 2013 -forthcoming



# Definition of Healthy Aging

- World Health Organization (WHO)
- Your definition – is personal –likely with commonalities
- We all aim for a trajectory of wellness

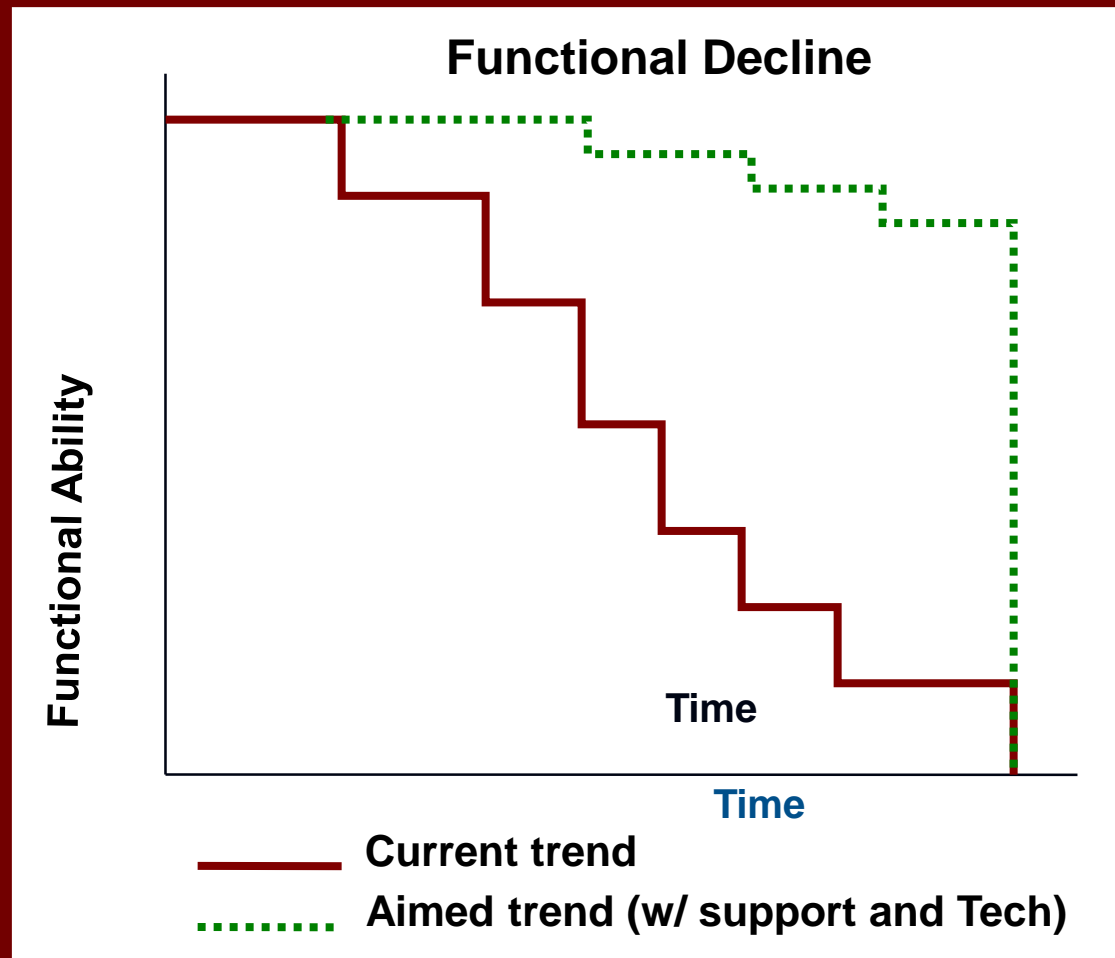


# Healthspan

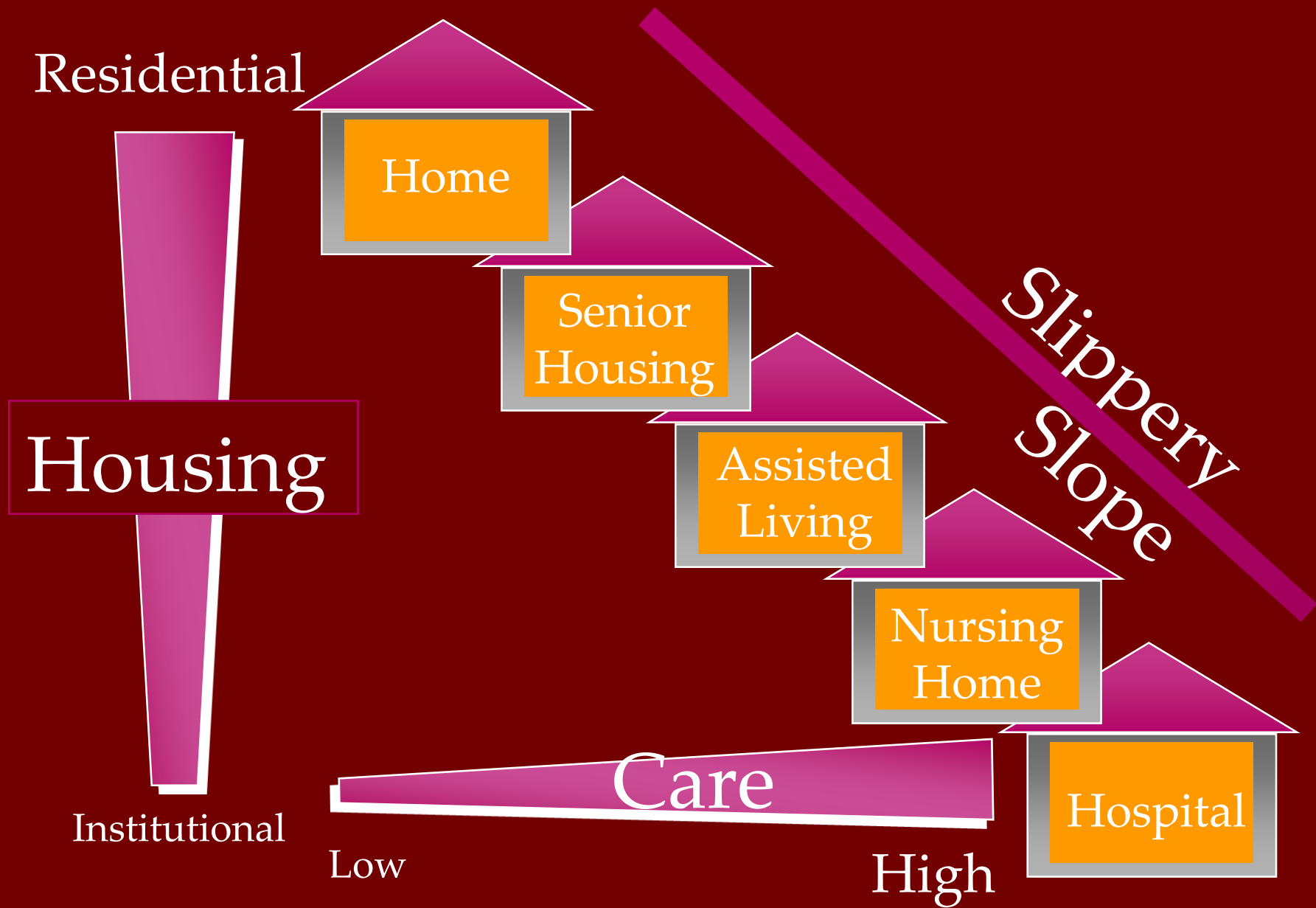
- Lifespan..... ...the average or maximum length of time an organism, material, or object can be expected to survive or last
- **Healthspan**...the length of time an individual is able to maintain good health

The National Academies Keck Futures Initiative: The Future of Human Healthspan: Demography, Evolution, Medicine, and Bioengineering, Task Group Summaries. Conference - Arnold and Mabel Beckman Center - Irvine, California - November 14-16, 2007 THE NATIONAL ACADEMIES PRESS Washington, D.C. [www.nap.edu](http://www.nap.edu)

# Trajectory of Functional Decline







# Healthy Aging by older persons includes living at home

## *Aging in Place*

the ability to live in one's own home and  
community safely, independently, and  
comfortably, regardless of age, income, or  
ability level

Centers for Disease Control (CDC). Healthy places terminology. 2013;  
<http://www.cdc.gov/healthyplaces/terminology.htm>. Accessed 1.11.2015

Benefield, L.E. and Holtzclaw, B.H (2014) Facilitating Aging Place: Safe, Sound,  
and Secure. Nursing Clinics of North America, (49), 2, 123-268.

# Aging in Place (AIP) in the US

- 80% of older persons live at home or in community settings
- 95% receive some level of caregiving from family/friends
- Most prefer this care at home



# US family caregivers

- 43.5 million provide care for someone 50+
- Many family members live > 1 hr travel distance
- Distance caregiving is a growing alternative to elder and family caregiver(s) in the same household or nearby

Benefield, L. E. and Beck, C. Reducing the distance in distance-caregiving by technology innovation. Clin Interv Aging. 2007;2(2):267-72. <http://www.ncbi.nlm.nih.gov/pubmed/18044143>

Selected Long-Term Care Statistics. Family Caregiver Alliance. National Center on Caregiving. From Alzheimer's Association (2011) [www.caregiver.org](http://www.caregiver.org). Alzheimer's Disease Facts and Figures, Alzheimer's and Dementia. Vol. 7, Issue 2. (updated Feb 2015)

# Distance Caregiving

- 7 million Americans are long-distance caregivers for older persons
- Up to 14 million within 15 years
- 23% are the sole primary caregiver
- On average, the caregiver travels 450 miles (725 km); 7.3 hrs to reach older person

*Miles Away: the MetLife Study of Long Distance Caregiving, MetLife Mature Market Institute & National Alliance for Caregiving, July 2004.*

*Long Distance Caregiving Guide – MetLife* <https://www.metlife.com/assets/.../mmi-long-distance-caregiving.pdf>

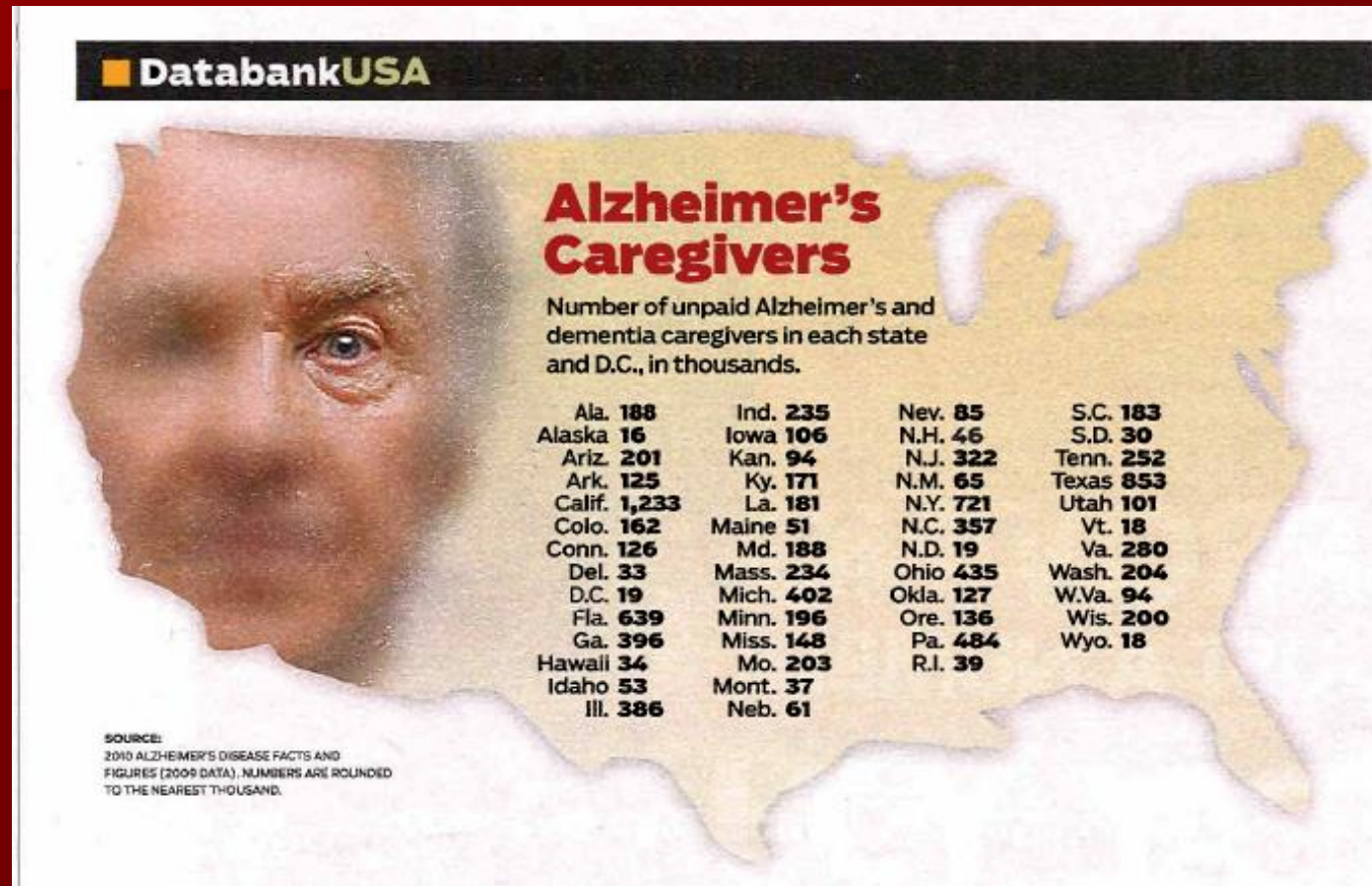
# Distance Caregiving

- Averaging 35 hours/month giving care
  - 25% spend >41 hours/month
  - Miss at least one day of work per month to care
  - 15 million days of work lost each year as a result of distance care
  - Caregiving impacts their personal, social, family needs



- My work addresses improving the care process across distance - with aim of older person's dignity and independence for as long as possible in one's preferred environment
- Older persons with memory loss living at home with a caregiver/carer at distance
- What is happening in caring? Challenges and facilitators? Care coordination?
- How can healthcare providers support?

# PWD 5.3m now, 13m by 2050



# Alzheimer's takes a devastating toll...

15.7 million **family and friends** provided 17.9 billion hours of unpaid care valued at **\$217.7 billion**

**Direct health care costs = \$226 billion**

60% of Alzheimer's and dementia US caregivers rate the emotional stress of caregiving as high or very high; about 40 percent suffer from depression.



# We know....

- Family caregiving is a multidimensional construct and includes cognitive, psychomotor, and affective dimensions that include “complex reasoning and behavioral processes.”
- Caregiving is complex because it involves physiological, social, contextual, and physical location dimensions in the process.

Schumacher, Stewart, Archbold, Dodd, and Dibble, 2000  
Family Caregiver Alliance 2001

# Issues and Challenges in the Science

- Caregiving from a distance involves
  - less physical contact
  - greater coordination of care\*
- Yet we know little about
  - specific needs of these caregivers
  - how their needs and caregiving processes may differ from direct caregivers

What would assist in skill development?



# One Example from the Field

## Distance Family Care Coordination of Home Dwelling Persons with Dementia

The Alzheimer's Association Grant #: IIRG-07-58318

L. Benefield (PI)

2007 –2010

### Acknowledgement:

The work of this study could not be completed without the thoughtful contributions of distance family caregivers. The authors' acknowledge and thank the many family caregivers who participated.

# The Research Team

Lazelle E. Benefield, PhD, RN, FAAN - PI

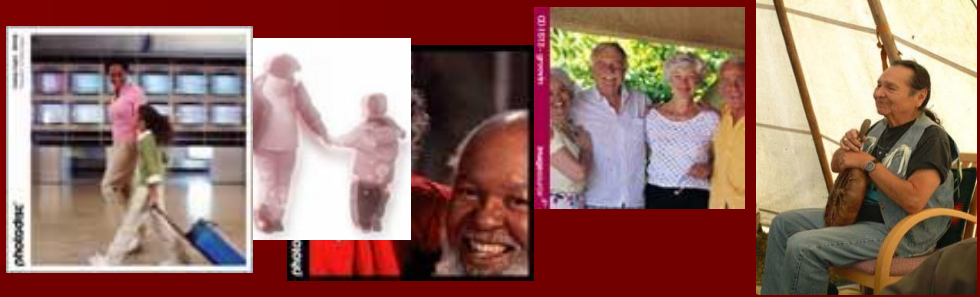
D. Elaine Wood, MS, RN, CNE - Project Director

Jane Thomas, MBE - Research Project Coordinator

Vicki Glenn - Senior Administrative Assistant

Norma Goff, Pati Prior-Huffman, Alison Moreland - Interviewers





- Identify care coordination needs of distance caregivers who support older persons with dementia (PWD) living at home and
- Explore these needs and challenges across ethnically diverse caregiver groups

Goal: inform interventions that support distance caregiving

# Care Coordination

Care Coordination is a distinct and comprehensive service. It entails investigating a person's needs and resources, linking the person to a full range of appropriate services, using all available funding sources and monitoring the care provided over an extended period of time.

Virginia Department for the Aging Service Standard. Revised 4/14/2009

# Methodology

- Taped individual semi-structured telephone interviews  
9 to 59 minutes (M=22.5, Mdn=20)  
80 caregivers    20 African American, 23 Caucasian  
17 Hispanic, 20 Native/American Indian
- Interviewers sought caregivers' description of  
“doing” the care across distance and the concerns  
and needs that impact the process....eliciting  
challenges to caregiving coordination
- Narrative coded using ATLAS.ti qualitative data analysis  
software



“We need to hear your voice. You may qualify for this study if you have a relative or friend with some memory loss who lives at home and some distance from you.”

- Are you in touch by phone?
- Do you help your relative or friend remain at home?
- Do you offer help with safety matters?
- Do you assist with paying bills or banking?
- Do you help manage medical care, meals or rides?
- Do you visit to provide care?

# Age and Relationship

- 20–29 = 5% (n=4)
- 30–39 = 15% (n=12)
- 40–49 = 33% (n=26)
- 50–59 = 34% (n=27)
- 60–69 = 14% (n=11)

88% female urban/suburban

- daughters (n=46)
- granddaughters (n=11)
- nieces (n=2)
- daughters-in-law (n=3)
- step-daughters (n=3)
- sisters (n=2)
- friends (n=3)
- sons (n=8)
- son-in-law (n=1)
- grandson (n=1)

# Additional care responsibilities

- One or more adult dependents 34% (n=26)
- Minor children at home 32% (n=25)
- Both other adults and children 8% (n=6)

+

80% work outside the home



- Caregiving from 3 months to 17 years  
(M=4.7yrs, Mdn=3 yrs)
- Travel 20 minutes to 30 hours  
(M=4.2 hours, Mdn=45 minutes)
- Caregiver-reported older person memory loss  
Mild 43.7% (35), Moderate 43.7% (35), Severe 12.5% (10)

# Indicators of Caregiving (doing the care)

Schumacher et al

Monitoring	Interpreting	Making Decisions
Taking action	Making Adjustments	Accessing Resources
Providing Hands-on Care	Working Together w/ the Person	Negotiating the Health Care System

# Caregivers shed light on the dynamics of care coordination\* as including

- ✓ direct care
- ✓ safety assistance
- ✓ cognitive assistance
- ✓ negotiation with healthcare providers
- ✓ engagement (to some degree) with community agencies and entities, and
- ✓ work with family/friends/neighbors

\*across distance

Conclusions:

## Caregivers *are* attempting care coordination

1. There are challenges/barriers and supports identified for actually “doing” the distance caregiving.

*Caregiving from afar includes acting on perceived PWD care needs.*

2. Care coordination happens, but not elegantly.  
for example.....



Conclusions:

Caregivers *are* attempting care coordination

2. Care coordination happens, but not elegantly.

*Available resources are not used routinely.*

*Actions are often haphazard and punctuated by trial and error. Caregiving needs are rarely addressed within a caregiving coordination model.*

*There is a surprising variability in understanding the older persons' trajectory of decline and anticipating caregiving changes and adjustments that must be made over time.*

## Conclusions

# Caregivers *are* attempting care coordination

3. Family is one prime example of a potential resource where use is uneven.

Interviewed caregivers approach the process within a mission statement, contextually identified as (1) *I will take care of my family* and (2) *My role in caring for my loved one is important for the family.*

On the actual process of caregiving, goals are worked toward or reached with a real-time tension between *I will take care of my loved one despite my family* and *I will care for my loved one with my family.*

## Conclusions

# Caregivers *are* attempting care coordination

### *Family....*

In some cases there is a strong fit to one side, in other cases the family works extremely well together and in other cases there is a mixture of each. Key family actions, some intense and others seemingly trivial, define caregiving within the challenges of day-to-day tasks and decision making to balance and manage the expected and the unexpected. This unevenness is important as it represents an imbalance in general application of resources to care coordination.

## Conclusions

# Family as resource

- With few exceptions distance caregivers were not engaging in a systematic examination of who among family/friend (or professional provider ranks) can address what responsibility for a PWD
- Caring happens on an as needed basis and is so consuming that it doesn't afford the time and energy to do the necessary research and work to access and integrate resources like family into the efforts at coordinating and executing care.

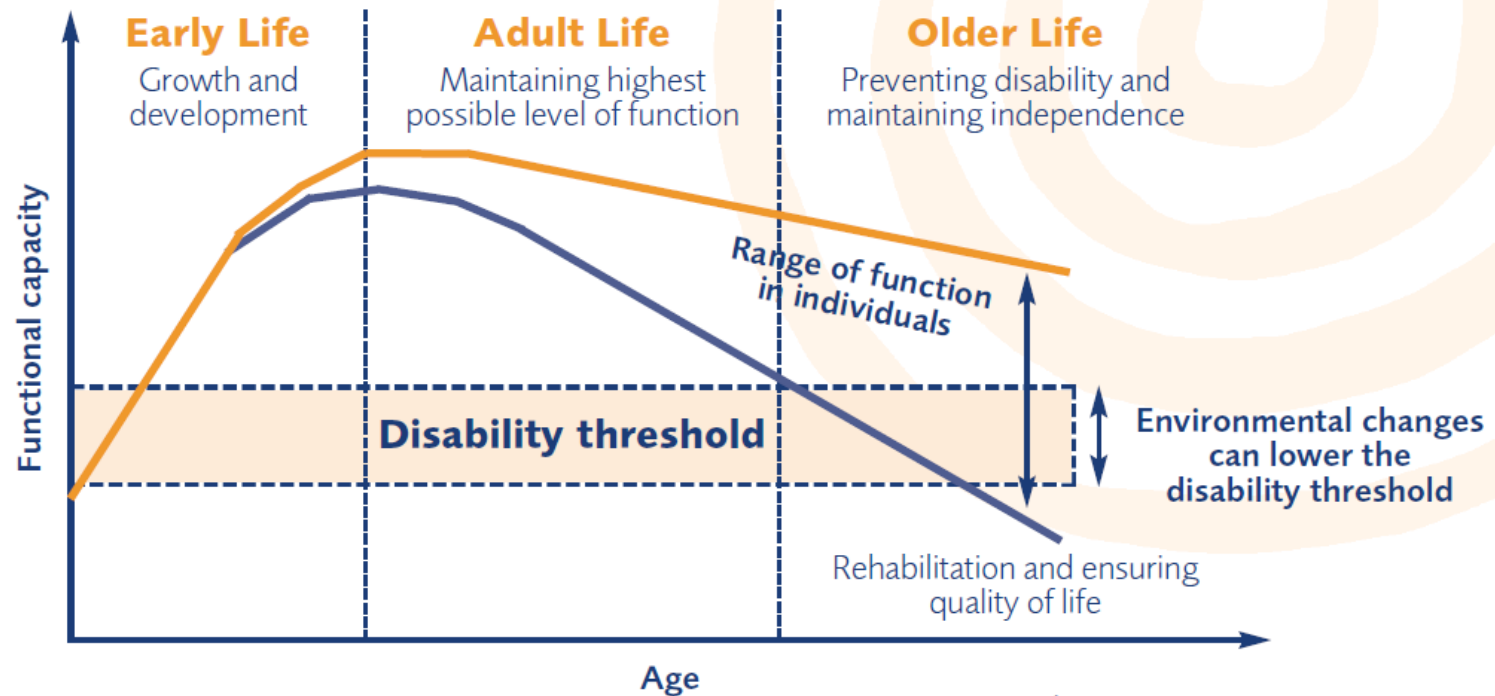
## Conclusions

# Family as resource

- Assuming family as a resource ignores the contextual realities of the complex nature of family relations that pre-exist care. Family relations, philosophies and a family's capacity to care all vary greatly and must be understood in order to truly know how strong a resource family might be to addressing the caregiving situation.
- The speed at which the health situation progresses leaves little time for learning and disagreement further complicates matters.

# Recommendations

## A life course perspective for maintenance of the highest possible level of functional capacity



Source: WHO/HPS, Geneva 2000

World Health Organization (WHO). The implications for training of embracing: A life course approach to health. World Health Organization; 2000:

[http://www.who.int/ageing/publications/lifecourse/alc\\_lifecourse\\_training\\_en.pdf](http://www.who.int/ageing/publications/lifecourse/alc_lifecourse_training_en.pdf) 13.11.2015



# Irish Context

- 161,000 caregivers in Ireland

*Being in close proximity to at least one child is a good indicator of potentially available practical and emotional support...two-thirds (74%) of older adults in Ireland are in this position. (p 39)*

*Among those aged 75 and over, i.e. the age group most likely to need care and support, 71% either live with their children or have at least one child living in the same county. However, members the oldest age-group are also more likely to have all of their children living abroad than younger age groups, reflecting historical patterns of emigration. (p.40)*

*Kamiya and Timonen. Older People as Members of Their Families and Communities*

<http://tilda.tcd.ie/assets/pdf/glossy/Chapter3.pdf> accessed 11 Nov 2015 T [ILDA The Irish Longitudinal Study on Ageing]

# Our Future in the US.....

Caregivers at distance ARE attempting to do care coordination:

Care Coordination is a distinct and comprehensive service. It entails investigating a person's needs and resources, linking the person to a full range of appropriate services, using all available funding sources and monitoring the care provided over an extended period of time.

Virginia Department for the Aging Service Standard. Revised 4/14/2009

*Care networks are changeable. Ability to provide care based on geographical proximity, availability of alternative care-givers, and gender are primary factors in the stability of care networks. (p. 7)*

[http://www.ageuk.org.uk/Documents/EN-GB/For-professionals/Research/CPA-Changing\\_family\\_structures.pdf?dtrk=true](http://www.ageuk.org.uk/Documents/EN-GB/For-professionals/Research/CPA-Changing_family_structures.pdf?dtrk=true)

# In Conclusion: Next Step Priorities

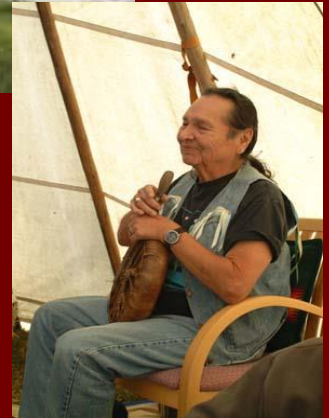
- Continue to define **distance caregiving** in terms broader than reflected in traditional models.
- Studies are needed to evaluate conceptualization of distance caregiving.
- Studies lag behind traditional “caregiver of elder” research; there is insufficient descriptive and intervention feasibility work to inform next-step studies.

# In Conclusion: Next Step Priorities

- Intervention studies to assist distance caregiving and older adult. Push technology innovation.
  1. Focus on clinical significance: person/family centered
  2. Address cost-effectiveness
  3. Develop multidisciplinary teams of researchers; multi-site
  4. Reflect HP2020 goals in distance caregiving research priorities

Coordinate care - Help older adult manage own care – Establish quality measures -  
Identify minimum levels of training for health providers - Research and analyze  
appropriate training to meet needs of older adults

“We do not stop playing because we grow old; we grow old because we stop playing”



Donald W. Reynolds Center  
of Geriatric  
Nursing  
Excellence



# Additional References

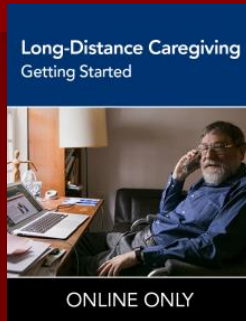


# Family Caring Ireland

- 148,000 provided unpaid care in 2002
- 160,000 in 2006
- 182,000 in 2011 (13.7% increase over 5 years)
- 48,000 PWD (persons with dementia)
- 50,000 dementia family carers

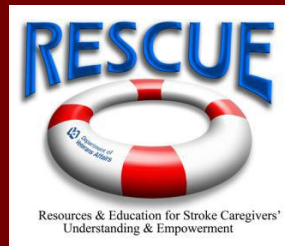
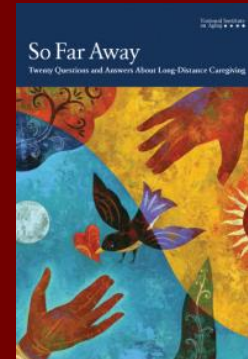
Guiding support for family carers. Family Caring in Ireland Care Alliance Ireland. March 2015

[Long Distance Caregiving Guide - MetLife](https://www.metlife.com/assets/.../mmi-long-distance-caregiving.pdf)  
<https://www.metlife.com/assets/.../mmi-long-distance-caregiving.pdf>



<https://www.nia.nih.gov/health/publication/long-distance-caregiving-getting-started>

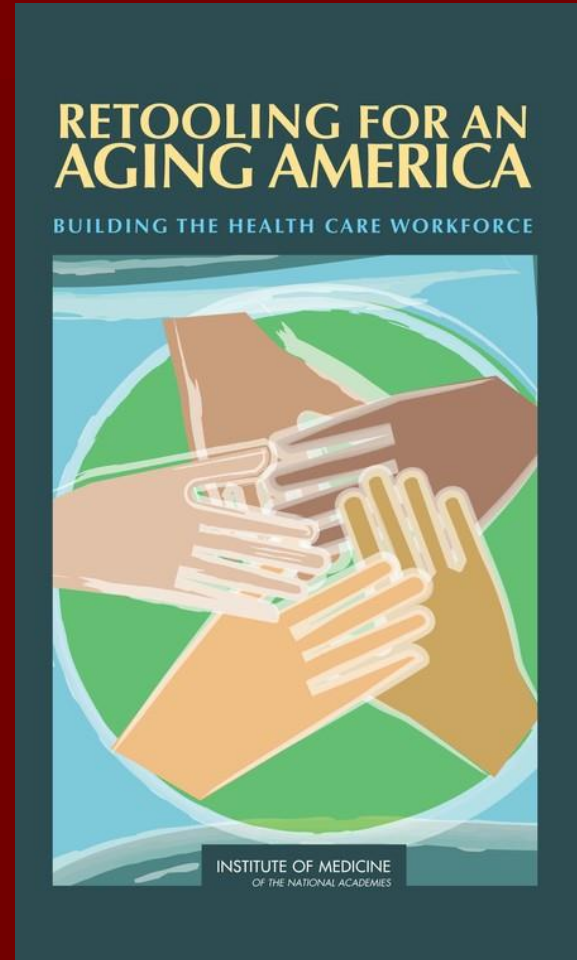
<https://www.nia.nih.gov/health/publication/so-far-away-twenty-questions-and-answers-about-long-distance-caregiving/getting>



<http://www.rorc.research.va.gov/rescue/docs/caregiver-needs/long-distance-caregiving.pdf>

# Challenges in the U.S.

- Between 2005 and 2030, adults  $\geq 65$  will almost double
  - Vast majority have chronic illnesses that take them to multiple providers
  - This will overwhelm the number of health professionals
  - Specific skill sets are required to treat older persons



Retooling for an Aging America.: Building the Health Care Workforce. The National Academies Press, 2008

# Challenges in the U.S.

- What is the best use of the paid health care workforce?
- What is the best use of family/friend caregivers?\*
- What new roles or new types of providers might be necessary to facilitate efficient, high-quality care?
- How should the health care workforce be educated and trained to deliver high-value care to older adults?
- How should this training be financed?

Retooling for an Aging America: Building the Health Care Workforce. The National Academies Press, 2008

# HP 2020 Health of Older Adults

Improving the health of older adults must include efforts to:

Coordinate care

Help older adults manage their own care.

Establish quality measures

Identify minimum levels of training for health providers who care for older adults

Research and analyze appropriate training to equip providers with the tools they need to meet the needs of older adults

