What is the Future of Eldercare in the United States?

Joanne Lynn, MD, MA, MS
Eldercare Consultant and Advocate

Anne Mercer, CIA, CFE, CFSA
Board Member, the Commission for Case Manager Certification
Welcome and Introductions:
  • Commission for Case Manager Certification

Presentation:
  • Joanne Lynn, MD, MA, MS
    Eldercare Consultant and Advocate
After the webinar, participants will be able to:

➢ Describe the challenges facing frail elders in the United States;

➢ List community and institutional resources available to elders near the end-of-life;

➢ Demonstrate advocacy for clients who have eldercare and end-of-life challenges; and

➢ Evaluate the pros and cons of the U.S. long-term care system
Exam Prep Resources

Quiz App  Practice Exam  Glossary App

Certification 360 Virtual Workshops  Printable Glossary  Exam Prep References  8-Week Prep Circuit
If you’re watching this webinar and do NOT need CE credit, please take a moment to complete our survey found here:

http://bit.ly/3J04e68

Your feedback helps us provide speakers and topics most relevant to you and the important work you do!
What is the Future of Eldercare in the United States?

Anne Mercer, CIA, CFE, CFSA
Board Member, the Commission for Case Manager Certification
Key Considerations for Eldercare in the U.S.

- Life expectancy increase → Greater need for resources
- Resource access varies regionally

Areas of concern:

- Transportation
- Housing
- Disability accessibility
- Nursing homes
- Community resources
- Transitions of care
- Nursing staff
- Long-term care funding
How Case Managers Can Help

- Negotiating eldercare issues
- Advocating for elderly clients
- Supporting families through tough decisions
- Connecting clients and families with relevant resources and services
What is the Future of Eldercare in the United States?

Joanne Lynn, MD, MA, MS
Eldercare Consultant and Advocate
Present & Future
ELDERCARE: Our Predictable DISASTER

JOANNE LYNN, MD, MA, MS
MARCH 10, 2023
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Case Managers Know the Problems

Most of your older patients/clients/families have complicated situations
Made more complicated by
- the lack of reliable supportive services
- the variation in the quality of medical/nursing services, and
- the mismatch of client aspirations and preferences with personal resources and community realities

RIGHT?
Take a Moment –

Write down the names of yourself and 4 people roughly your age who you know and care about, and who are employed or homeowners.

Think about how you all will be living at about 80 or 85 years old.
On Average -

At most only one of you will be dead
4 out of 5 will be needing LTC (or will soon)
2 or 3 of you will be impoverished
Prediction of Poverty in Old Age in 6 Years

We project that by **2029** there will be 14.4 million middle-income seniors. At any one time -

- 60% will have mobility limitations and
- 20% will have high health care & functional needs.
- While many of these will need at least the level of care provided in seniors housing, we project that **54% of middle-income seniors will not have sufficient financial resources to pay for food, housing, and medical care.**

Pearson CF et al.
Some Key Facts -

- Most Americans will need long-term social services in old age, averaging 2 yrs
- Average cost >$250,000 – not covered by Medicare
- Average assets at retirement - $50,000 + Soc. Security
- “Volunteer” care costs the caregiver >$300,000 (average)
- Half of women >85y.o. have no potential volunteer
- Nursing homes are already failing in large numbers
- LTC insurance is costly, limited, and uncommon
- Numbers of elders needing care will double in the next dozen years
- Most Americans do not know, and do not want to know, these facts
Single Classic “Terminal” Disease: “Dying”

Onset incurable disease

Function

Time

Mostly cancer

Hospice starts

Often a few years, but decline usually over a few weeks or months

Death

Onset incurable disease
Onset could be deficits in ADL, speech, ambulation. Function decreases over time, with death occurring quite variably, often 6-8 years later. Prolonged dwindling often includes frailty and dementia. Now, most Americans have this course. The numbers will double in 20 years.
Disaster for the Frail Elderly: A Root Cause

**Social Services**
- Funded as safety net
- Under-measured
- Many programs, many gaps

**Medical Services**
- Open-ended funding
- Inappropriate “standard” goals
- Dysfx quality measures

Inappropriate
Unreliable
Unmanaged
Wasteful “care”
Our Agenda Today

1. *Where are we headed – without change?*

2. What changes are being pursued?

3. What would be better?

4. Why aren’t we pursuing those better policies?
Current status of long-term care

• In many areas, a huge variety of services with changing criteria for access and uneven and changing quality – home-delivered meals, personal care, assisted transportation, senior centers, PACE, hospice, ethnic, etc.

• Huge waiting lists for most services

• Medicaid as a “safety net” with required nursing home coverage (at about 70-80% of costs of care) and optional home and community-based services (with long waiting lists in most states)

• Medical care of uneven quality and availability – few geriatricians, few attentive primary care physicians/NPs/PAs – much reliance on ER/hospital

• Still – with luck (geographic and happenstance) and a good navigator (often a case manager) – many elders make it through with no serious shortcomings – and the family says, “Weren’t we lucky that _____”
So – left to drift... our “system” will deliver

Homelessness
Hunger
Isolation
Medical aid in dying or other suicides
Bankrupting families, burdening caregivers (women)
Coercing Medicaid into severe restrictions
Current examples

More than a Meal
https://www.mealsonwheelsamerica.org/learn-more/research/more-than-a-meal

Local county in MD

Adult Protective Services

You most likely have experiences of the serious dysfunctions!
Health Care Spending ≠ Health Status

2013 Per Capita Health Services Spending ($US)
-- Top 12 OECD Countries --

United States 8,713
Switzerland 6,325
Norway 5,862
Netherlands 5,131
Sweden 4,904
Germany 4,819
Denmark 4,553
Austria 4,553
Canada 4,351
Belgium 4,256
France 4,124
Australia 3,939

Average = 29th (of 34!)

38% > Swiss spending
81% > avg of other 10

US Rank:
5 OECD Health Stats, 34 Nations

#27 Life Expectancy at Birth
#31 Infant Mortality
#27 Men/Years of Potential Lost Life
#31 Women/Years of Potential Lost Life

Want your money back?
But, We Can’t Afford Social Supports, Right?

2013 Per Capita Spending ($US)
-- Top 12 OECD Countries --

Recall US’s #29 avg. ranking?
Sweden’s avg. = 5th
Switzerland is 10th

It’s the ratio!
US ratio = 0.75
Avg. of 11 = 1.86
The Older Americans Act at 50 – Community-Based Care in a Value-Driven Era (NEJM 2015)
Ravi B. Parikh, M.D., M.P.P., Anne Montgomery, M.S., and Joanne Lynn, M.D.

The Older Americans Act clearly affirms our Nation’s sense of responsibility toward the well-being of all of our older citizens….Every State and every community can now move toward a coordinated program of services and opportunities for our older citizens. We revere them; we extend them our affection; we respect them.

Lyndon B. Johnson, 1965

“The Ratio” in Our Work—Eldercare

Cumulative % Change (since 2004)

The ratio is getting much worse!
My Mother’s Broken Back
The Cost of a Collapsed Vertebra in Medicare - 2015

![Cost Comparison Graph]

- **Actual**: 10,000
- **Usual**: 35,000
- **Optimal**: 5,000

Dollars
Our Agenda

— Facts & Discussion

1. Where are we headed – without change?

2. What changes are being pursued?

3. What would be better?

4. Why aren’t we pursuing those better policies?
What changes are being discussed now?

Direct care workforce – wages, benefits, career ladders
Nursing home ownership transparency
Improved infection control
Enhanced Adult Protective Services
Specialty palliative care
Care coordination or case management

ESPECIALLY HOME AND COMMUNITY SERVICES (rather than nursing home)

Not likely to happen, Mostly not fundamental changes, and
Likely to reverse within a few years without more stable financing
Our Agenda

— Facts & Discussion

1. Where are we headed – without change?

2. What changes are being pursued?

3. **What would be better?**

4. Why aren’t we pursuing those better policies?
What Good Care Arrangements Should PROMISE To People Living with Serious Chronic Illnesses

- Correct $R_x$
- Symptoms
- Gaps
- Help to live fully
- Surprises
- Customize
- Family Role
We know we could do so much better – efficient, reliable, desired

PACE and some D-SNPs — and Green Houses/Eden Alternative
Case managers, care managers, navigators, community workers
Singapore’s housing
Comprehensive care planning – with an interdisciplinary team
Community management
Supportive care option in Medicare
Catastrophic long-term care insurance
Comprehensive Care Planning

- Appropriate for all living with serious illness, disability, or old age
- Starts with “what matters to you?”
- Conditioned by “tell me about your family and living situation.” and “tell me your understanding of your medical condition.”
- Makes short-term plans and longer-term goals
- Attends to all that makes for comfort and meaningfulness - housing, personal care, transportation, isolation, food – not limited to medical treatment and placement
- Plans for follow up and modification
Comprehensive Care Planning

• Shaped by the client’s medical and social situation
• Also shaped by client & family values & preferences
• Constrained by what’s available (including “volunteer”)
• Rarely done
• Even more rarely documented
• And almost never transferred across providers

BUT – IMPORTANT TO DO, and TO DO WELL!
The Constraints of Service Availability

• In urban areas, usually quite an array of services, which change often, have restrictive and changing requirements, often have waiting lists, usually leave gaps – some coordinating services are arising (e.g., FindHelp)

• In more rural areas – more reliance on ad hoc volunteers, churches, police and fire – fewer agencies, many “organized” services simply unavailable

• Area Agency on Aging (federal funding and contracts) tallies services, some provide assessments/referrals

• Awareness and advocacy are important everywhere
My husband after aortic valve replacement, with many complications

- Coughed in recovery room
- Dislodged epicardial pacer
- Found to have total heart block with no escape rhythm
- “Permanent” pacer implanted
- No escape rhythm to this day
- Would you be sure to tell him about the possibility of stopping the pacing in order to die?
Why a geographic population perspective for eldercare?

- Because elders needing care are profoundly dependent upon their geographic community –
  - Housing
  - Food
  - Direct care workforce
  - Family/friend caregiving
  - Transportation
  - Medical care

- None can be fixed for just one provider’s patients, or one insurer
  - at least not efficiently
The MediCaring Community

- Recognize Frailty
- Elder-Directed Care Plans
- Geriatricize Medical Care
- Enhance Supportive Services
- Determine Community Priorities
- Use Medical Care Savings for Community Priorities

Lynn J., MediCaring Communities: Getting What We Want and Need in Frail Old Age at an Affordable Cost, 2016. at MediCaring.org
Major Need #1 - Affordable excellence for all elders in a geographic population

- An entity to monitor, manage – set priorities – evaluate – respond to the residents – with authority and funding
- Data to enable monitoring and managing
- Leadership
- The will to make changes
- Flexibility in regulations and financing
  - Better Care, Lower Cost – it’s within reach!
Why do I prioritize --
LTC Financing?

Without that, all other gains will backslide when we double the numbers of elders needing care.

Most of the current shortcomings have their roots in the currently inadequate funding.

Americans are becoming aware of the threat of LTC costs to their families – a ripening political moment.
Strategies to get added $ to LTC?

- Expand Medicare
- Expand Medicaid
- Expand PACE and SNP (e.g., to Medicare-only!)
- Expand private LTC insurance
- Manage at the community level
- Federal catastrophic long-term care insurance
HR 4289 - theWISH Act: Well-Being Insurance for Seniors to be at Home (WISH) Act

Proposal for Federal Catastrophic Long-Term Care Insurance

Congressman Thomas R. Suozzi (NY-03)
Rationale for the WISH Act -

- Why federal?
- Why only catastrophic?
- What level of disability?
- Why social insurance?
- The ramp-up challenges
**Well-Being Insurance for Seniors to be at Home (WISH) Act**  
Congressman Thomas R. Suozzi (NY-03)

### Illustrative Examples of the WISH Act’s Benefits for Elders

#### Person Who Made $80 Thousand Per Year and Later Needs 10 Years of Long-Term Care

- This person needs more years of long-term care than 90% of Americans...
- ...However, because of private front-end coverage combined with federal catastrophic coverage, this person is able to live at home and not impoverish his/her family

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Description</th>
<th>Coverage</th>
</tr>
</thead>
<tbody>
<tr>
<td>21-64 Years Old</td>
<td>Makes annual insurance contribution (~0.3% of earnings)</td>
<td></td>
</tr>
<tr>
<td>65-80 Years Old</td>
<td>Retired; No long-term care needed</td>
<td></td>
</tr>
<tr>
<td>81-83 Years Old</td>
<td>Long-term care need; Covered by private insurance</td>
<td></td>
</tr>
<tr>
<td>84-90 Years Old</td>
<td>Long-term care needed; Covered by WISH Act</td>
<td></td>
</tr>
</tbody>
</table>

#### Person Who Made $30 Thousand Per Year and Later Needs 4 Years of Long-Term Care

- This low-income person needs more years of long-term care than most Americans...
- ...And because of Medicaid combined with federal catastrophic coverage, this person still receives all the care he/she needs without impoverishing family

<table>
<thead>
<tr>
<th>Age Group</th>
<th>Description</th>
<th>Coverage</th>
</tr>
</thead>
<tbody>
<tr>
<td>24-68 Years Old</td>
<td>Makes annual insurance contribution (~0.3% of earnings)</td>
<td></td>
</tr>
<tr>
<td>68-85 Years Old</td>
<td>Retired; No long-term care needed</td>
<td></td>
</tr>
<tr>
<td>86 Years Old</td>
<td>Long-term care need; Covered by Medicaid</td>
<td></td>
</tr>
<tr>
<td>87-89 Years Old</td>
<td>Long-term care needed; Covered by WISH Act and some Medicaid</td>
<td></td>
</tr>
</tbody>
</table>
Well-Being Insurance for Seniors to be at Home (WISH) Act
HR 4289

The Benefits of the WISH Act

- Americans will be able to age in their homes more often
- Working people will be able to protect themselves and their families financially
- The government will not often need to be investigating personal family matters
- Elders will much less often face homelessness or other deprivation
- Workers will not often be forced to leave their jobs to provide family caregiving
- Americans will know about the likely need for long-term care later in life
- Medicaid costs (both state and federal) will be reduced by a quarter or more
- Nursing homes and other long-term care providers will be better funded
- The pressure to increase hospital and nursing home capacity will be reduced
- The personal service workforce will be better funded and provide better care
Our Agenda
— Facts & Discussion

1. Where are we headed – without change?

2. What changes are being pursued?

3. What would be better?

4. Why aren’t we pursuing those better policies?
   What could must we do?
Case Study in Denial: How Most Americans (and Congress) are Dealing with the Age Wave
SO – in the next 20 years

We could look forward to serving elderly people living with joy and confidence, despite disabilities –

Or we could watch the perpetuation of the seriously dysfunctional “care” system now in place, and the collapse of hard-won gains

Let’s work now to prevent homelessness, hunger, poverty, and warehousing of disabled elderly people — by making it possible to live with comfort, dignity, and economic security in old age
Make Eldercare a Prominent Policy Issue!

@MULawPoll

Follow

“Very concerned” percentages for other issues (beyond inflation): Crime, 61%; accurate vote count, 56%; public schools, 56%; gun violence, 55%; abortion policy, 53%; taxes, 51%; climate change, 44%; illegal immigration, 38%; coronavirus, 22%. #mulawpoll

1:47 PM · Sep 14, 2022
How you can help to get better LTC financing

Raise awareness (generate outrage)

- Talk with politicians, tell stories, write to newspapers, engage with Twitter – get info into public education like MyMedicare

Specifically focus attention on whatever matters most to your clients, but include retirement security (Social Security!), long-term care costs (WISH), and family burden

Get organizations to weigh in –

- Caregiver organizations, AMDA/PALTC, ACP, ANA, AlzAssn, etc. – mobilize eldercare organizations and philanthropies
“Unless someone like you cares a whole awful lot, Nothing is going to get better. It's not.”

— Dr. Seuss, *The Lorax*
ELDERCARE: Our
Opportunity for
Affordable
Excellence

JOANNE LYNN, MD, MA, MS
MARCH 10, 2023
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A resource for community management of eldercare

"For decades, Joanne Lynn’s has been the clearest, strongest, most soulful voice in America for modernizing the ways in which we care for frail elders. This essential book is her masterpiece. It offers a magisterial, evidence-based vision of that new care, and an entirely plausible pathway for reaching it. Facing a tsunami of aging, our nation simply cannot afford to ignore this counsel."
— Donald M. Berwick, MD, President Emeritus and Senior Fellow, Institute for Healthcare Improvement, and former Administrator, Centers for Medicare & Medicaid Services.

"MediCaring Communities integrates good geriatrics and long-term services and supports, and building upon an expanded PACE program can be a tangible start. We should try this!"
— Jennie Chin Hansen, Lead in Developing PACE; Past President, AARP; and Past CEO of On Lok Senior Health Services and the American Geriatrics Society.

About the Author

Joanne Lynn, MD, MA, MS, is Director of the Center for Elder Care and Advanced Illness at Alaris Institute, which aims to shape health care in the U.S. so that every person can count on living comfortably and meaningfully through the period of serious illness and disability in the last years of life, at a sustainable cost to the community. More about the work at MediCaring.org.
Resources

• LTSS Financing, an issue brief at https://medicaring.org/faq/ltss-financing/


• SUOZZI INTRODUCES LEGISLATION TO TRANSFORM AMERICAN ELDER CARE, CREATE FEDERAL LONG-TERM CARE INSURANCE at https://suozzi.house.gov/media/press-releases/suozzi-introduces-legislation-transform-american-elder-care-create-federal-long see especially the links at the bottom


• Milken Institute Financial Innovations Lab, New Approaches to Long-Term Care Access for Middle Income Households. At https://milkeninstitute.org/sites/default/files/2021-04/LTC%20Access-Final_1.pdf

• Lynn J, https://drjoannelynn.org/2022/03/08/wish-act-ltc-financing/ and other blogs at https://drjoannelynn.org
Closing Remarks

Joanne Lynn, MD, MA, MS
Eldercare Consultant and Advocate

Anne Mercer, CIA, CFE, CFSA
Board Member, the Commission for Case Manager Certification
Thank you!

- Please fill out the survey after today’s session
- Those who signed up for continuing education will receive an evaluation from the Commission.

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