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The Long and Winding Road to Long-Term Services and Supports Reform:

The Good, the Bad, and the Aspirational

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DISCLOSURE(S)

I have no commercial relationships to disclose.



Background

- Increased longevity and medical advances resulting in more individuals in need of long-term services and supports (LTSS) than ever.
- Projections show this group doubling between now and 2040.
- COVID 19 impact on LTSS-- the many system cracks into large and growing faults.
 Quality, financing and staffing challenges abound
- The question today is what must America do to create a high-quality long-term services system?



Where we have made advancements

Choice in where,

how, when and

by whom

individuals

receive LTSS

- Choice of setting, expansion of HCBS, both private and public, including AL.
- Assessment of preferences in home and residential settings to ensure person centeredness.
- Legislation such as Americans with Disabilities Act.

- · More HCBS needed in some communities.
- Support services funded primarily by Medicaid.
- Expand range of person-centered outcomes that matter to LTSS recipients and caregivers.
- Access to NH and AL need to be improved.





Financing

Where we have made advancements

policies, despite limited adoption.

Financing Have created a better Medicaid balance between HCBS and institutional care. Some states and even local communities have developed new funding for HCBS. Improvements in private long-term care insurance Public LTSS almost to Unclear if LTSS is fed Fewer private long-term Very low take up rate No political consensus

- Public LTSS almost totally reliant on Medicaid.
- Unclear if LTSS is federal or local responsibility
- Fewer private long-term care insurance carriers and very low take up rate.
- No political consensus on financing responsibility or solutions as the federal level.





Ccoordination/Transitions

Where we have made advancements

Coordination and Integration and Transitions in Care

- Evidence-based models that improve transitions in care for individuals.
- Managed LTSS models, PACE, medical homes –
 efforts to integrate care have been expanded.

- LTSS siloed limited coordination across services.
- Funding is reimbursement- focused by setting.
- Integrated care demonstrations have not been rigorously evaluated; results are mixed.





Caregivers, Informal

Where we have made advancements

Where there is room for improvement

Friend	land

Family Caregiver

Support

- Family Medical Leave Act expanding across nation.
- National family caregiver support program supported by OAA.
- Recognition about the importance of services designed to support family and friend caregivers.

- Major responsibility still falls to family and friends with limited support.
- Programs don't assess caregiver strengths/needs.
- Hospitals discharging individuals quicker and sicker placing additional pressure on families.





Direct Care Workforce

Where we have made advancements

High quality direct care workforce

- Recognition of importance of direct care workers,
 some pockets of hazard pay for direct care workers
 during pandemic.
- Efforts to track provider and worker outcomes,
 such as turnover have been expanded.
- Innovative management practices being explored in organizations across the nation.

- Low pay/benefits the norm.
- Turnover high and retention low across LTSS settings.
- Limited PPE/testing during COVID.
- Immigration policies have not been supportive.
- Research needed on staffing levels, career growth, and retention.





Prevention, Promotion of Well-Being and Equity

Where there is room for improvement

Where we have made advancements

Promotion of Expansion of evidence-based chronic disease selfPromotion of management practices. Well-Being CARES Act increases for Older Americans Act Expansion of Age-Friendly Communities and don't think about it (Ageism) State's Developing Master Plans for Aging OAA has not kept up with inflation or growth in older population Vast majority of communities in US are not age friendly and don't think about it (Ageism) Not focused on positive outcome measures (e.g., joy, hope, meaning in life)





Inclusivity & Justice

Where we have made advancements

Where there is room for improvement

Inclusivity &

Justice

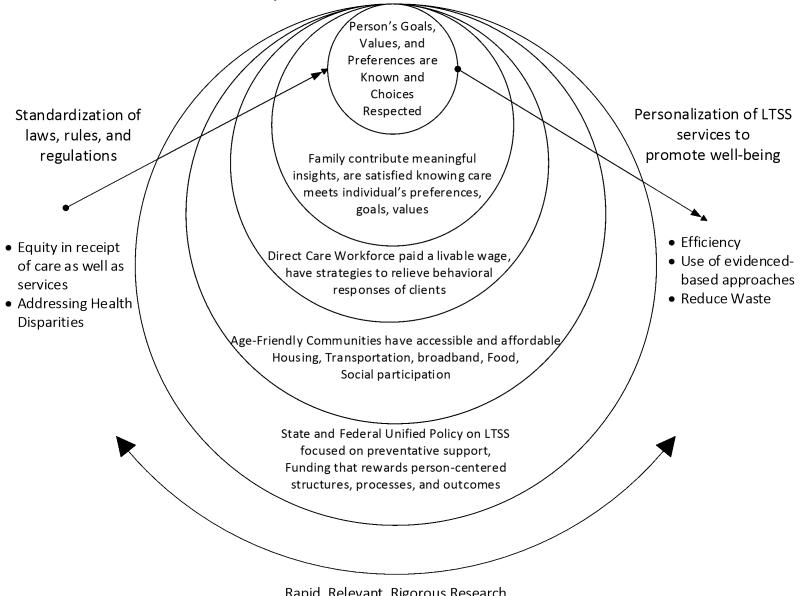
- More Medicaid HCBS has increased access to people of color and people in rural communities.
- Legalization of same sex marriage allowing better sharing of retirement and health benefits.
- Recognition of access limitations in system.

- Rates of disability are higher for people of color
- Access and quality concerns for people of color and individuals with fewer economic resources remain.
- Limited resources allocated to housing options for persons of color and low-income individuals.



Figure 1. Aspirational Person and Caregiver Centered National LTSS System in the U.S.*

(*informed by Alkema, 2016 and NASEM, 2021)



Rapid, Relevant, Rigorous Research that includes the voices of stakeholders



Time for a National LTSS Policy

- Incremental changes to today's strategy will not work, can we create a hybrid model building on state experiences but creating national standards?
- Consumers, their friends & family at the heart of the model of care
- Financing and Equity must be addressed
- Proactive vs. Reactive Need for expanded social care
- Workforce support both formal and informal
- Using Technology Humanely
- Research informed



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THANK YOU!

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