

# Critical Issues in Independent Living



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AARP Public Policy Institute  
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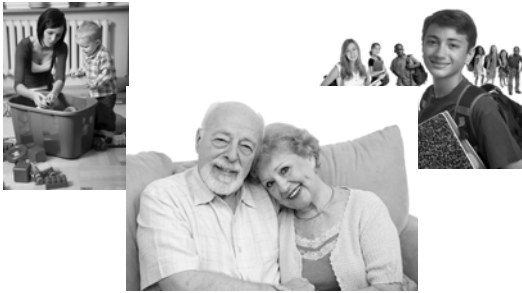
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## Independent Living: Important to People of ALL Ages



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## Overall Goal

An affordable, consumer and caregiver-focused system providing coverage for, and access to, high quality long-term services and supports for independent living.

**“Independent living is not doing things by yourself, it is being in control of how things are done.”**

Judith E. Heumann, Co-Founder,  
World Institute on Disability



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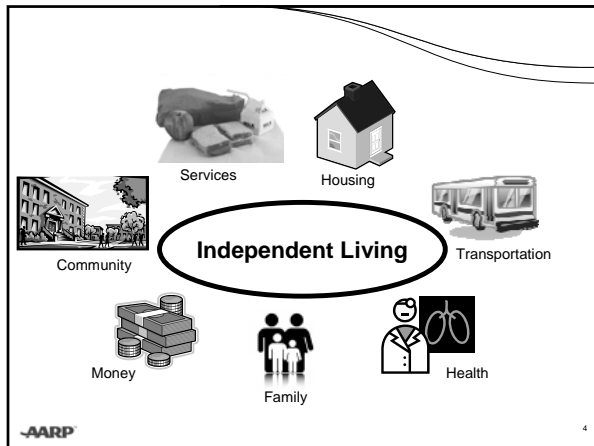
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### Aging in Place

People overwhelmingly prefer to remain in their home or community

- Most people age 50+ want to "age in place" (84%)
- People with disabilities want to live in their own homes (87%)

AARP logo in the bottom left corner.

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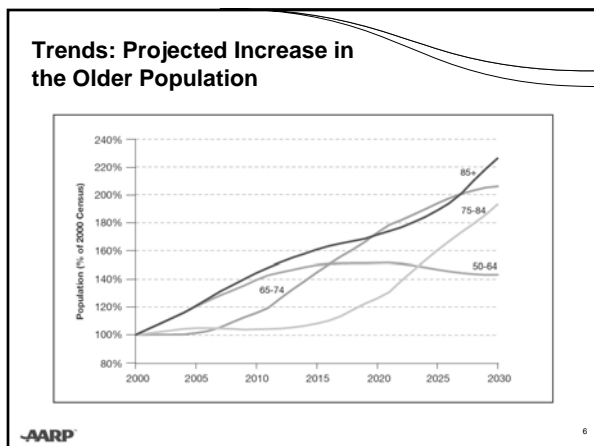
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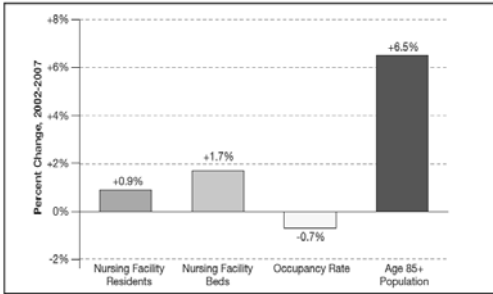
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### Older Population Growing But Nursing Home Beds Remain Mostly Constant



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### Livable Communities

The real question is not "where will people move" but rather "as we grow older, will our community be ready for us?"

Can we age successfully in our community?

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### Our Communities Are Unprepared

- 54% of American communities do not have the policies, program or services in place to promote quality of life, community engagement, and independent living of older adults
- 2/3 of planners and engineers have not yet begun considering the needs of older users in the multi-modal planning

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## Older Adults (Age 50+) Report Inhospitable Roads

- 40% say they do not have adequate sidewalks in their neighborhoods
- 47% say they cannot cross their main roads safely

AARP Source: International Communications Research Poll for AARP, 1,000 adults age 50+, July 2008

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## Major Findings

- More than one in five (21%) Americans age 65 and older do not drive.
- More than 50% of non-drivers age 65 and older - or 3.6 million Americans - stay home on any given day partially because they lack transportation options.
- Non-drivers take 15% fewer trips to the doctor than drivers.



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## Major Findings

- The following populations are more heavily affected:
  - Rural communities and sprawling suburbs;
  - Households with no car;
  - Older African-Americans, Latinos and Asian-Americans.
- Where public transportation is available, older Americans make regular use of it.

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## Rural Issues

- Persons age 60 and older account for nearly one-third of rural riders— far more than their 19% share of the rural population.
- Nearly 75% of households in rural areas do not have access to public transportation.
- Medical trips are a particular problem.

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## Demand for Specialized Transportation Outweighs Supply

- In 2008, 85% of state aging agencies reported an increase in requests for transportation services – more than for any other service.
- Nearly half (45%) had their waiting lists for transportation services.

NASUA, *The Economic Crisis and Its Impact on State Aging Programs*, 12/8/2008.

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## Affordable Housing

- 50+ Americans represent about 28% of all delinquencies and foreclosures in the current crisis.
- For every senior in rent-assisted housing, there are 6 with unmet housing needs.

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Sources: Alison Shelton, AARP Public Policy Institute. 2008. "A First Look at Older Americans and the Mortgage Crisis" HUD 2007 Assessment of Housing Needs Commission on Affordable Housing and Health Facility Needs for Seniors in the 21st Century. 2002. "A Quiet Crisis in America"

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### Accessible Housing

Easy reach cabinets

Easy to reach and operate appliances

Grab bars, roll under sink, lever handles etc.

Low threshold shower

Reinforced bathroom walls

No-step entry

Wide entry doors (min. 32" + net opening)

Wide doors (min. 32" + net opening)

Flexible room layout/design

Maneuverability

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### Visitability

3 Main Features:

Step-less entrance

Bathroom access

Accessible circulation

- One zero step entrance, located at the front, back, or side of the house, on an accessible path of travel
- 32 inch clear opening at doorways and accessible circulation throughout the floor plan
- Basic access to at least one bath or half bath on the ground floor

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### Housing & Transportation

#### Cleveland, Ohio: AARP Study (forthcoming)

- Long waiting lists for housing
- Safety and perception of safety were issues
- Lack of access to train station limits the use by residents
- Good bus service on main avenues, problems getting elsewhere

Cleveland Region Interview Locations

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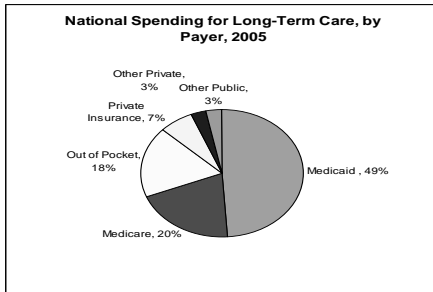
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## Medicaid - Primary Payer of LTC Services and Supports



Source: Georgetown University Long-Term Care Financing Project, "National Spending for Long-Term Care" fact sheet, February 2007.

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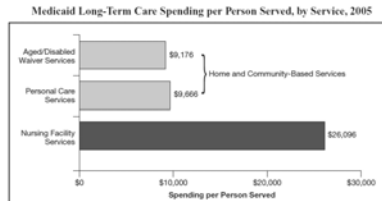
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## HCBS Can Serve More People

- On average, Medicaid dollars can support nearly 3 older people or adults with physical disabilities in Home and Community-Based Services for every person in a nursing home



Sources: Home and Community-Based Services from Ng, T., Harrington, C., and O'Malley, M. (2008). Medicaid Home and Community-Based Service Programs: Data Update. Kaiser Commission on Medicaid and the Uninsured, Nursing Homes from Center for Medicare & Medicaid Services (CMS), Medicare & Medicaid Statistical Supplement, 2008 edition.

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## Taking a Long View: HCBS Can Slow LTC Cost Growth

- New research evidence: States that invest in Home and Community-Based Services programs experience slower expenditure growth than states with low Home and Community-Based Services spending.
- States can realize savings over time if they concurrently decrease reliance on nursing home use.

[http://assets.aarp.org/rqcenter/il/i26\\_hcbs.pdf](http://assets.aarp.org/rqcenter/il/i26_hcbs.pdf)

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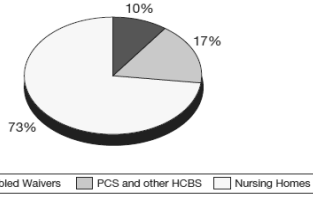
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## Bad News: Almost Three-Fourths of Medicaid Long Term Care \$\$ Go to Nursing Homes

Medicaid Long-Term Care Spending for Older People and Adults with Physical Disabilities in the United States, 2007



Sources: AARP Public Policy Institute calculations based on: Burwell, B., Sredl, K., and Eiken, S. (2008) Medicaid Long-Term Care Expenditures in FY 2007. Cambridge, MA: Thomson Reuters

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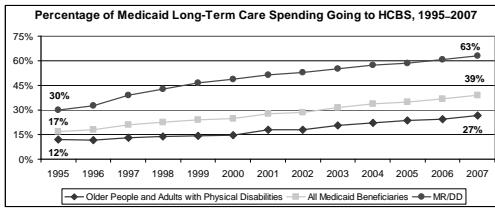
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## Good News: Home and Community-Based Services (HCBS) Going Up



Sources: AARP Public Policy Institute calculations based on: Burwell, B., Sredl, K., and Eiken, S. (2008) Medicaid Long-Term Care Expenditures in FY 2007. Cambridge, MA: Thomson Reuters; Burwell, B. (2002) Medicaid Home and Community-Based Services Waiver Expenditures, FY 1995-2001. Cambridge, MA: Thomson Reuters.

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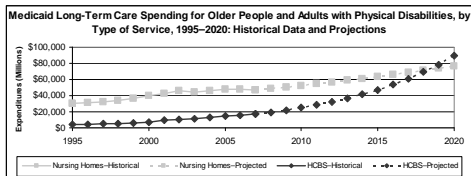
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## At This Rate: Good News Over Time

Current trends in balancing =  
50/50 spending balance achieved in 2019



Sources: AARP Public Policy Institute calculations based on: Burwell, B., Sredl, K., and Eiken, S. (2008) Medicaid Long-Term Care Expenditures in FY 2007. Cambridge, MA: Thomson Reuters (historical); AARP Public Policy Institute (projections).

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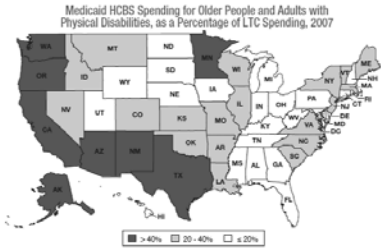
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### But - We Can Do A Lot Better

Nearly half of all states spend less than 1 in 5 Medicaid Long Term Services and Supports (LTSS) dollars for older people and adults with physical disabilities on HCBS. Only 8 states spend more than 2 in 5 Medicaid dollars.



Sources: AARP Public Policy Institute calculations based on: Burwell, B., Siedl, K., and Elken, S. (2008) *Medicaid Long-Term Care Expenditures in FY 2007*. Cambridge, MA: Thomson Reuters



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### Why Some States Are Doing Better Than Others?

- Philosophy and Leadership
- Single state agency to oversee state's long-term services and support system
- Single point of entry
- Single appropriation or coordinated funding sources
- Standardized assessment tool
- Comprehensive array of services



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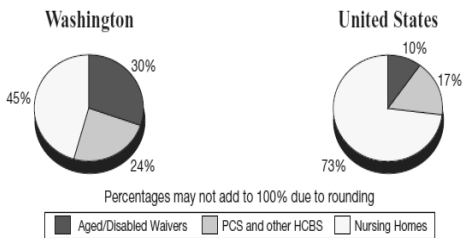
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### Medicaid LTC Spending in Washington is Balanced, 2007



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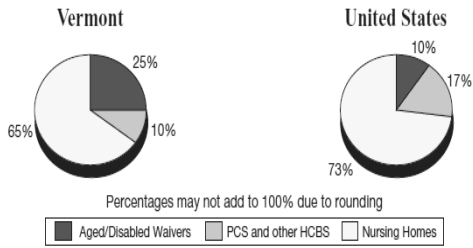
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### Medicaid LTC Spending in Vermont is Making Progress, 2007



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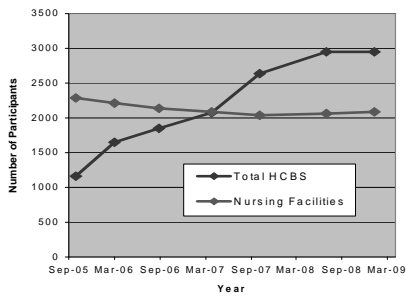
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### Vermont Choices for Care Participants, 2005–2008



Source: J. Senecal, Commissioner, Vermont Department of Disabilities, Aging and Independent Living, presentation at the 2009 Money Follows the Person conference

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### Health Transitions

- Intersection between people with chronic health conditions and LTC needs
- People with multiple, serious chronic conditions major cost driver in health system
- Most at risk during transitions

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### Planning for us – not “them”

- Boomers feel younger than their age...but are still getting older
- Can we develop pathways to support independence, or will disability be our path to invisibility?
- Example – Dotty and Brad

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### Can we get there from here?

- Barrier-laden housing
- Dependence on cars
- Driving alone
- Isolated families – becoming invisible
- Dependence on caregivers or low-wage workers
- Fragmented system
- Accessible, visitable housing
- Delivery services & livable communities
- Transit on demand
- Social networks, community engagement
- Shared services, good wages
- Comprehensive, coordinated services

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### Solutions

#### More Consumer Choice

- Offer a range of residential choices: consumers choose setting of their choice
- More consumer direction

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## Solutions

### Facilitate Balancing

- Establish state unified global budgets for funding Long Term Care
- Adopt nursing home diversion programs
- Consider financial incentives to states to shift more Medicaid spending to HCBS

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## Solutions

### Focus on Direct-Care Workers/Caregivers

- Improve recruitment, retention, and quality of direct care workforce
- Support family caregivers

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## Family Caregivers: The Backbone of the LTC System



Economic Value of Family Caregiving in 2007: \$375 billion



Medicaid LTC Spending in 2007 (Largest payer of formal LTC): \$97 billion

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**Solutions**

Community Engagement

- Promote social involvement in:
  - Organization memberships
  - Volunteer service
  - Community & facility planning

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**Solutions**

Affordable, Accessible Housing

- Promote design and modification of housing to meet physical needs of older people
- Ensure an adequate supply of diverse, affordable housing environments

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## Solutions

### Increased Mobility Options

- Improve the travel environment and support life-long driver education to ensure safer driving for all ages
- Take positive steps now to enhance mobility options for people with differing functional abilities
  - Public transportation
  - Organized private transportation
  - Walking and bicycling
  - Specialized transportation

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## Start spreading the word...

- Raise awareness
- Publicize and quantify the problems
- Bridge the silos – develop partners
- Find champions
- Use the right words: long term living, independence, choice
- Capitalize on policy opportunities

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