



Independent Living: The Changing Role of Consumers



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Independence and Disability



The Desire for Independence

- Is important to people of all ages:
 - Toddlers struggle to walk unaided
 - Teenagers rebel
 - Adults choose where they will live or work
- We want to be in charge of our lives



What Happens?

- When disabilities, early or late in life:
 - Threaten our independence?
 - Require us to rely on others for help?

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Facts About Disability

- The vast majority do NOT require long-term assistance at any one time
- Most people WILL require assistance at some point in their lives

How many need help?

- Nearly 10 million Americans need some help with daily activities:
 - About two-thirds are age 65+
 - The rest are children or adults with disabilities
 - More than 8 in 10 do *not* live in nursing homes
 - Most live in their own homes or community-based settings such as group homes or assisted living

Is this long-term care?

- Long-term care is defined as personal care and assistance that an individual might receive on a long-term basis because of a disability, chronic condition, or illness that limits his or her ability to function.
- Long-term services and supports (LTSS) is a preferred term because “care” may imply dependence and convey paternalism

Independent Living Philosophy

- Disability is not an individual characteristic or “problem” but a relationship between the individual and the entire environment in which he or she lives, including:
 - Physical surroundings
 - Family networks
 - Quality of health and supportive services
 - Public policies



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



Evolution of LTSS in the US





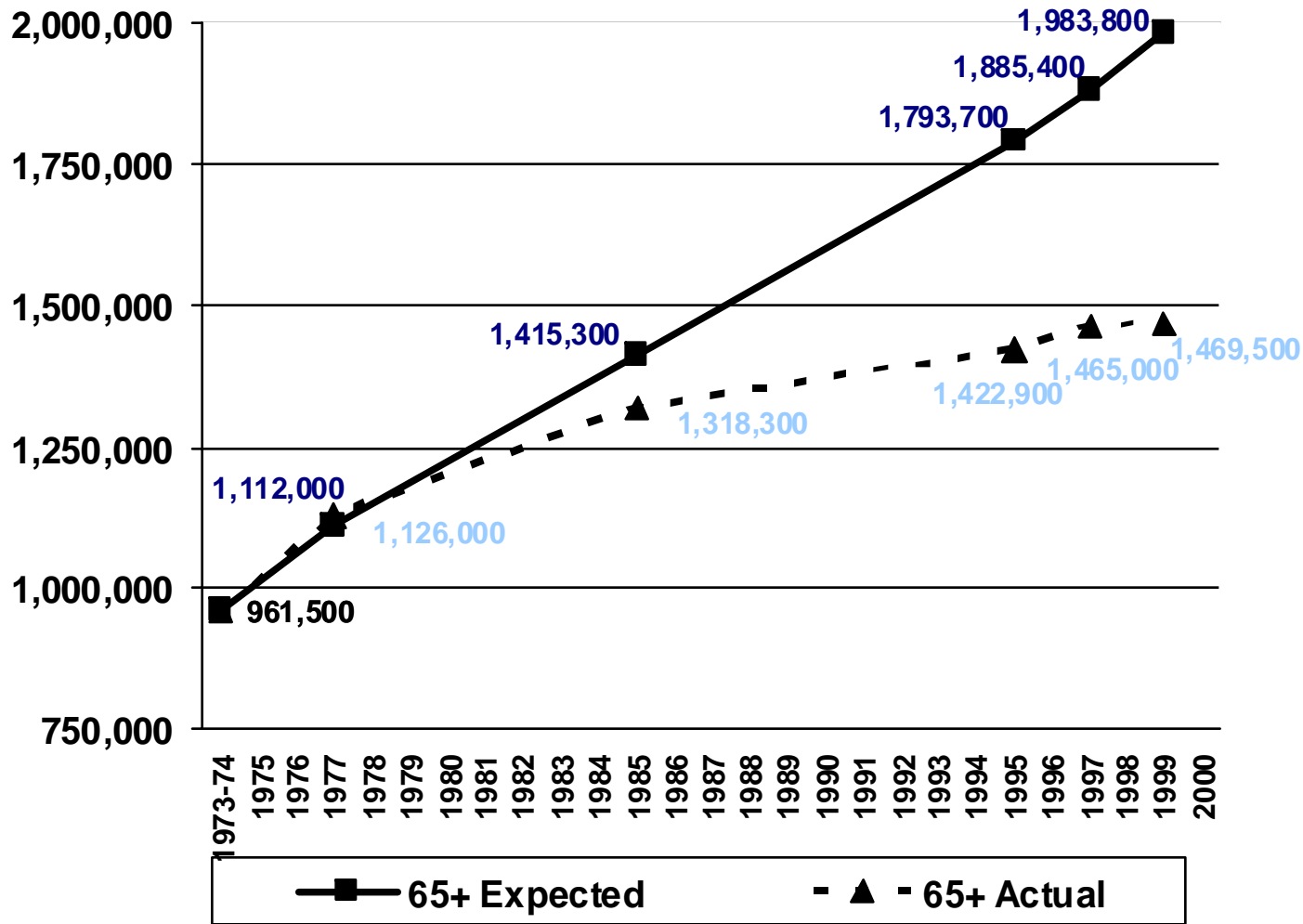
The “Bad” Old Days

- As recently as 25 years ago – the only option was nursing homes
- Medicaid HCBS waivers had just been enacted
- Assisted living was virtually nonexistent
- Board and care homes were generally a poor-quality community alternative for the nearly destitute

Nursing Home Trends

- The population age 75+ increased 23% from 1994 - 2004
- Over that period, the nursing home population *decreased* by 5%
- This trend reflects not only consumers' preferences, but a growth of alternatives

Nursing Home Population Age 65+ Has Seen Little Growth Since the Mid-1980s



Source: AARP Public Policy Institute Analysis of NNHS data, 2002.

Characteristics of Nursing Home Users

- Most nursing home stays are of relatively short duration: primarily post-hospital rehabilitation
- Among people with long nursing home stays:
 - Acuity levels have risen
 - Prevalence of cognitive impairments is high
- Only 5% of people will use more than 5 years of nursing home care after turning 65
 - 8% will use 2-5 years

Movement Toward HCBS

- People want to retain their independence and maximize their choices as they age
- Nearly 9 in 10 people age 50+ *with disabilities* strongly prefer independent living in their own homes to other alternatives
- They want more direct control over what services they receive and when they receive them

AARP: "Beyond 50.03: A Report to the Nation on Independent Living and Disability"

<http://www.aarp.org/research/housing-mobility/homecare/aresearch-import-752-D17817.html>

Medicaid: Primary Source of Financing

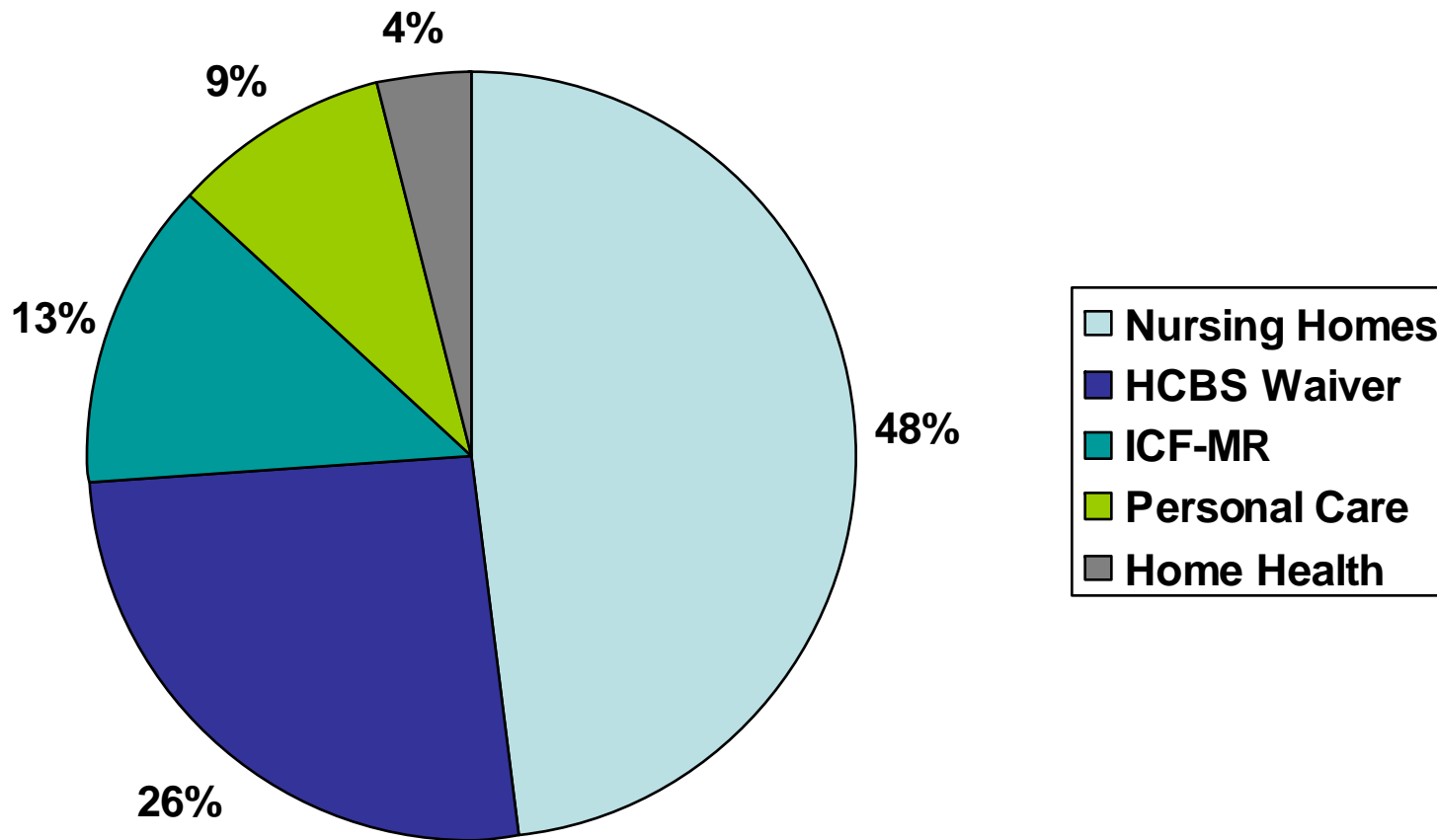
- Historically, Medicaid spending has favored nursing homes
- Consumers have demanded more emphasis on home and community-based services
- Supreme Court “Olmstead” decision supported right to “least restrictive” setting
- Federal and state initiatives call for “rebalancing” Medicaid spending to promote HCBS

Medicaid Rebalancing

- In 2006, Medicaid spending for HCBS rose to 39% of total Medicaid LTSS spending
- By comparison, in 1996, HCBS comprised just 21% of total Medicaid LTSS spending
- HCBS vs. institutional spending varies tremendously across the states
- Nine states now spend 50% or more of their Medicaid LTSS dollars on HCBS

Medicaid LTSS Spending – 2006

Total = \$99 billion





Traditional Model

- Early development of HCBS used agency model
- Care managers determined services
- Home care agencies delivered services
- Consumer role fairly limited

Roots of the Independence Movement

- Disability rights movement among adults with physical disabilities
- Deinstitutionalization of people with chronic mental illness
- Advocacy by parents of children with MR/DD



Slow Spread to Older Population

- Assumptions that older people preferred to have others “manage” their service delivery
- Paternalism about the capabilities of older people
- Concerns about safety and abuse

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Drivers of Change

- Advocacy
- Olmstead decision
- Cost
- Workforce shortages
- Changing perceptions

Consumer Direction

- Consumer-directed HCBS represents a philosophical approach to service delivery that maximizes consumers' ability to:
 - assess their own needs;
 - determine how and by whom they are met;
and
 - define what constitutes quality.

Consumer Choices

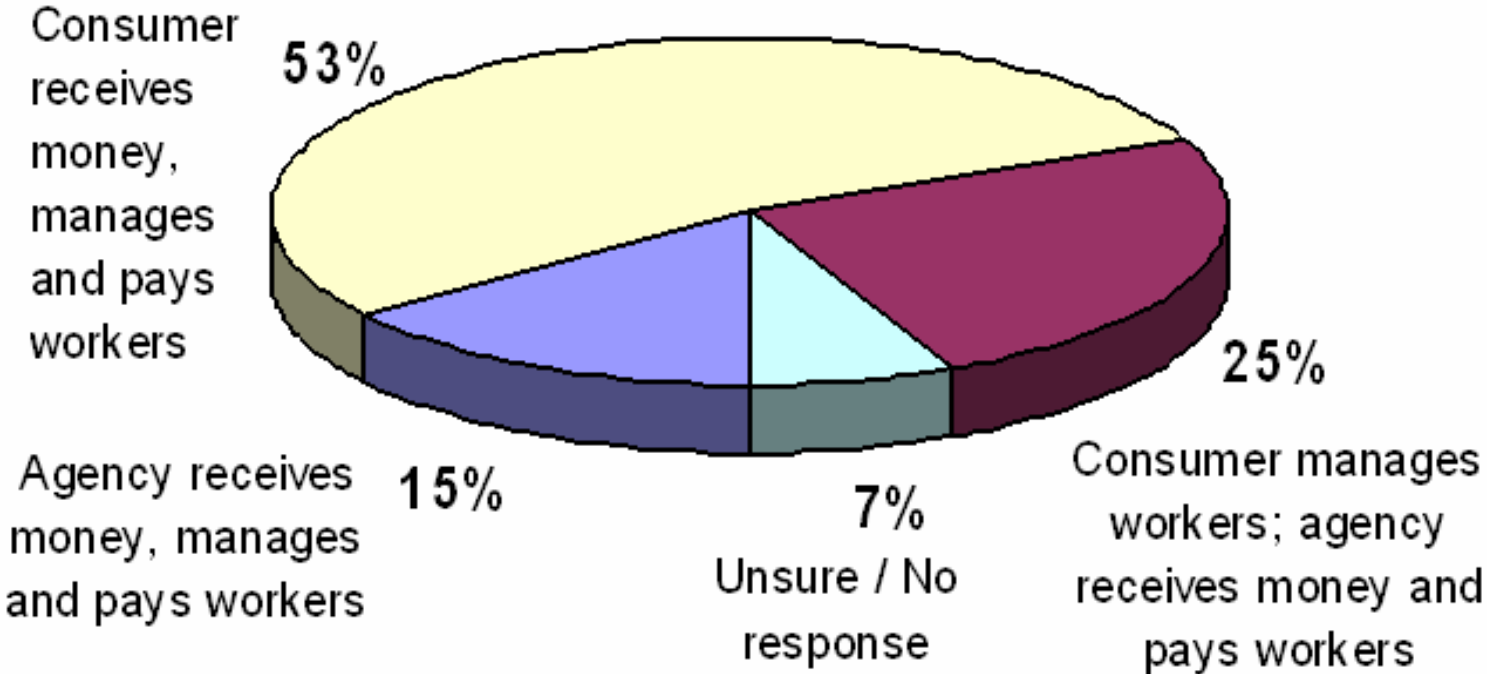
- Depending on the program, consumers may be able to:
 - choose which services to receive;
 - select the days and times for service delivery;
 - hire, manage, and terminate the workers of their choice, including family members; and
 - manage their budgets by setting wages and/or purchasing items that enhance their independence (such as home modifications or assistive devices).



AARP Survey Results

- More than three-fourths (76 percent) of people age 50 and older would prefer to manage their own home care services rather than receive services managed by an agency.
- Among people with disabilities age 50 and older, only 15 percent preferred agency-directed services.

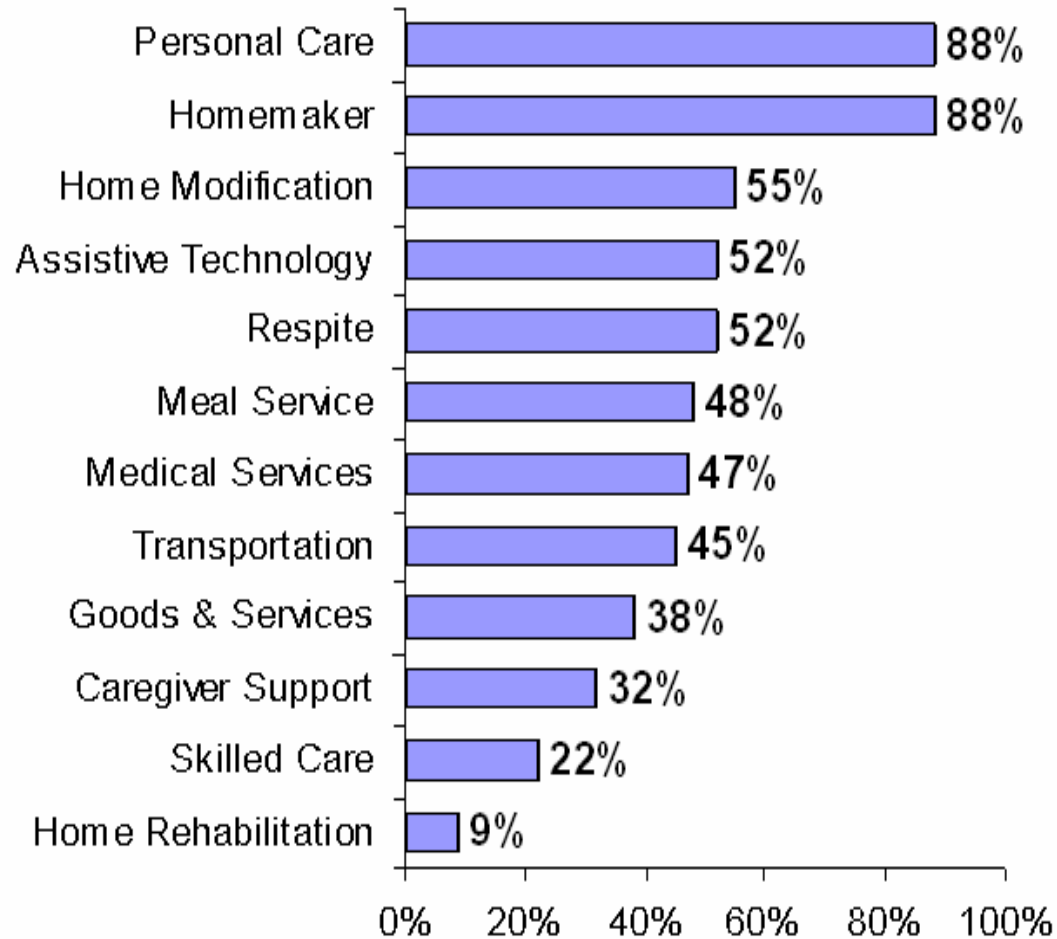
Consumer Preferences for Managing and Paying Home Care Workers



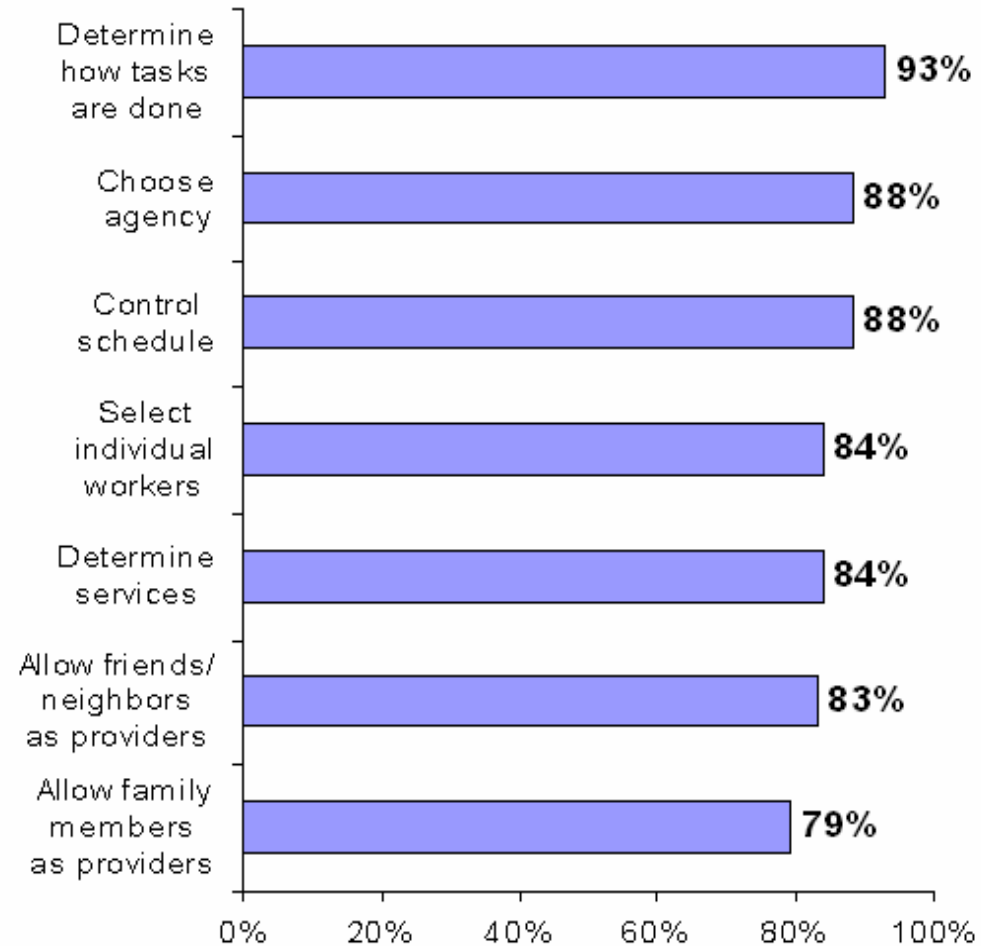
Characteristics of Consumer Directed Programs

- 2004 NASUA survey of programs serving older persons:
 - 40 states responding
 - 62 programs
 - 70,000 older persons served

Types of Services Provided



Types of Consumer Choices



High Satisfaction

- Over three-quarters (78 percent) of state aging directors indicated that older consumers are highly satisfied with consumer directed services.
- Rigorous evaluation of Cash & Counseling programs found participants:
 - expressed greater satisfaction with services received;
 - reported a higher quality of life;
 - reported fewer unmet needs; and
 - indicated they had received more paid care.
- No evidence of abuse found.



AARP's Vision

Components of LTC Reform

- Give people choices to live at home:
 - End Medicaid's institutional bias
 - Expand options for consumer directed services
- Help those who help others by supporting family caregivers
- Develop a system that helps everyone:
 - A universal LTC program based on principles of social insurance is desirable
 - Cash benefits offer maximum flexibility
- Public education and personal planning & responsibility are important:
 - Private insurance can enhance benefits for those who can afford it
 - Better regulation and consumer protections will make private insurance more appealing