

Advocating for Good Community Care: Long-term Care Systems Change Opportunities

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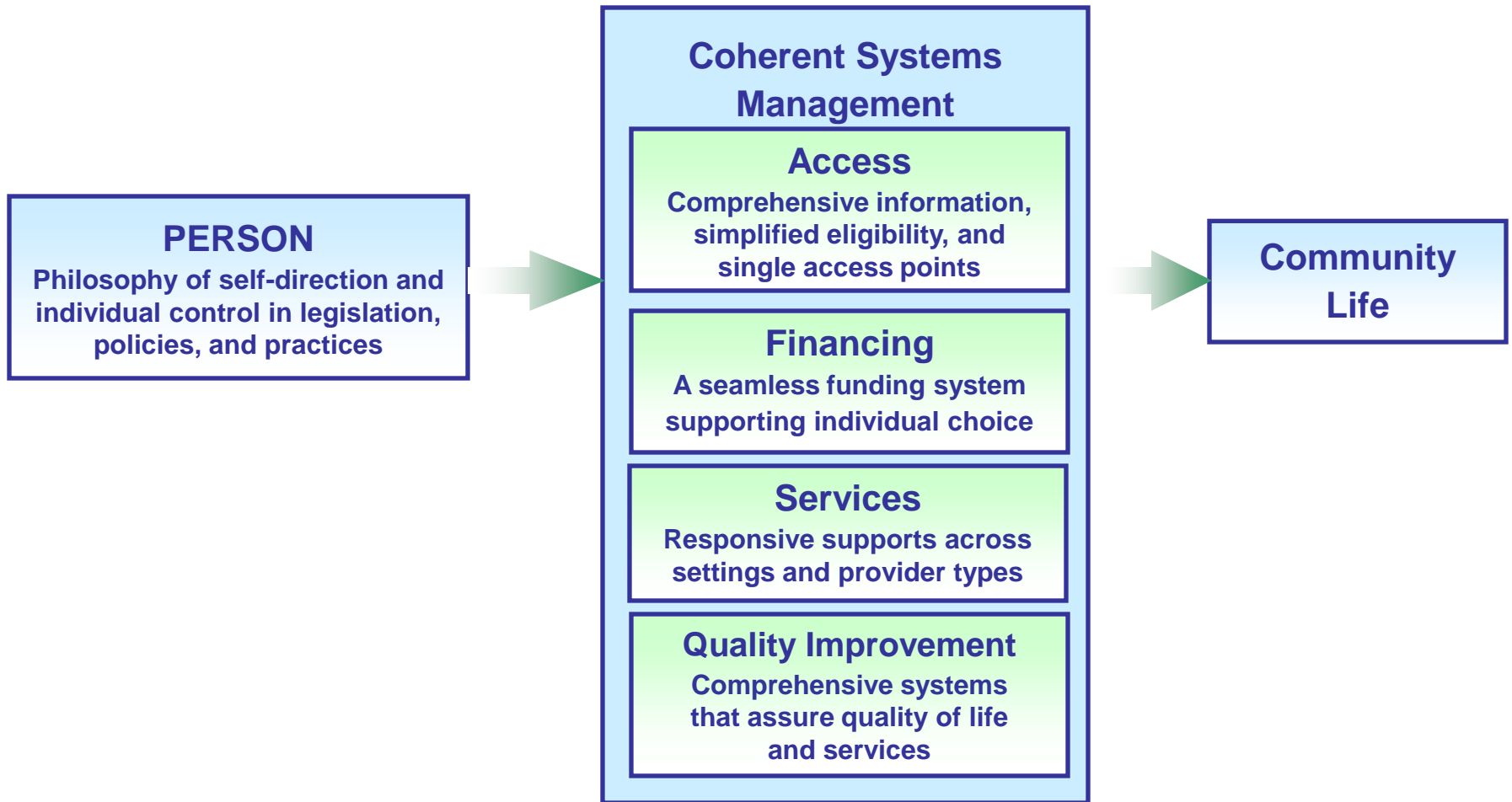
Rutgers Center for
State Health Policy

**Alzheimer's Association
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Objectives

- Overview of new and ongoing Systems Change Initiatives
- Where do your interests fit in this agenda for change?
- Opportunities for advocates to ensure initiatives address the needs of people with dementia

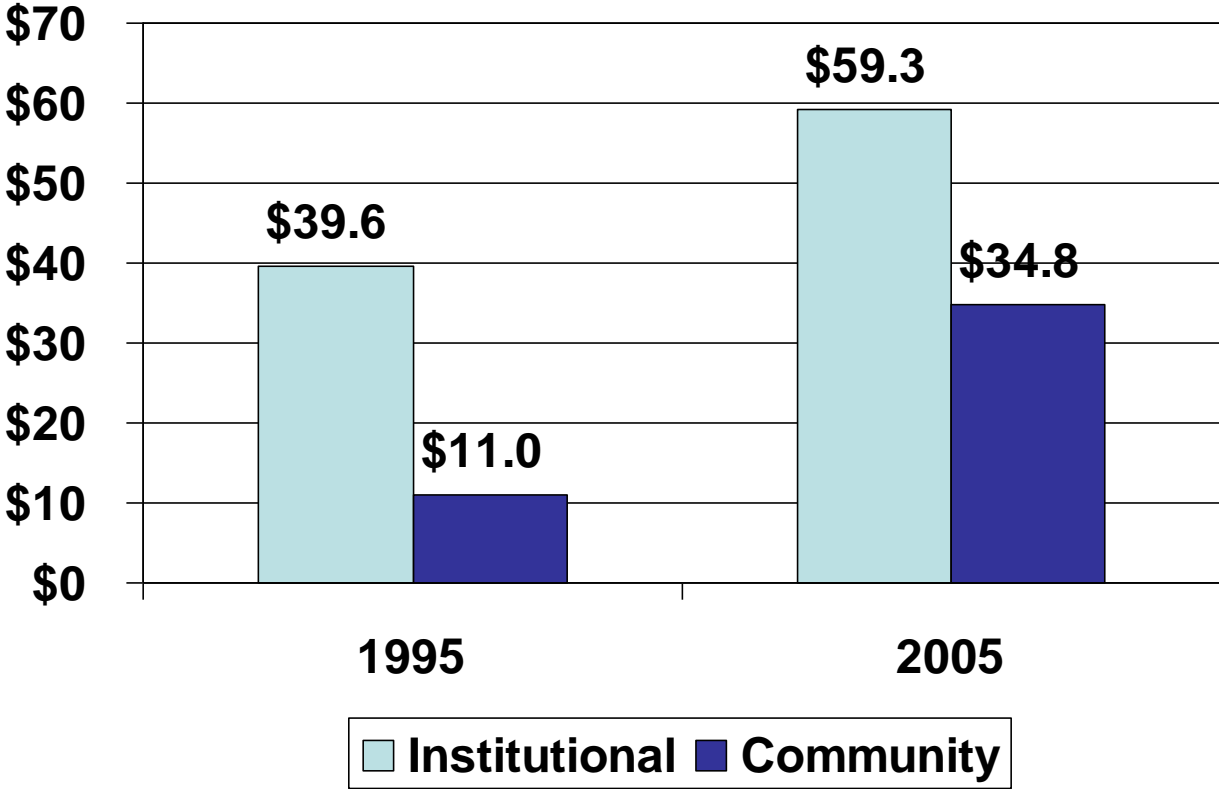
Agenda for Change: Key Building Blocks for Reform



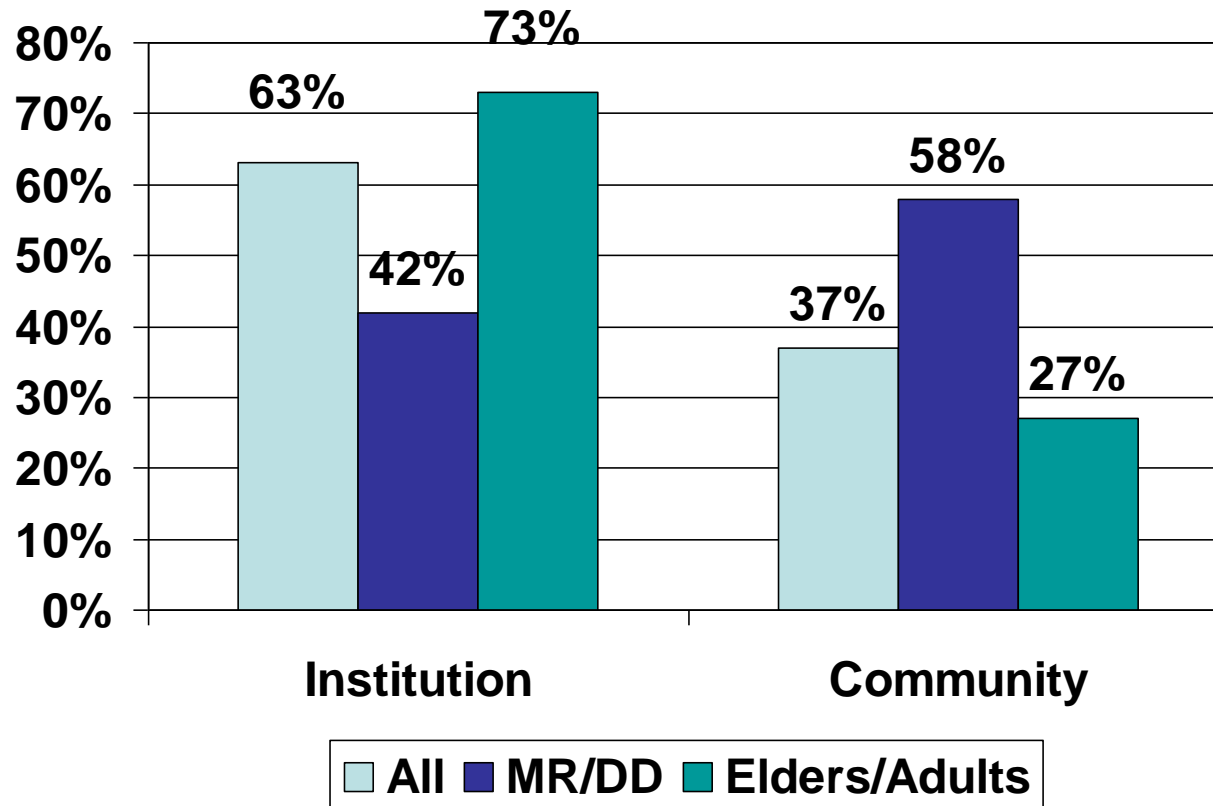
Balancing Services and Supports

- Major theme of Systems Reform
- Promote choices and funding mechanisms to support those choices
- National progress, but far to go

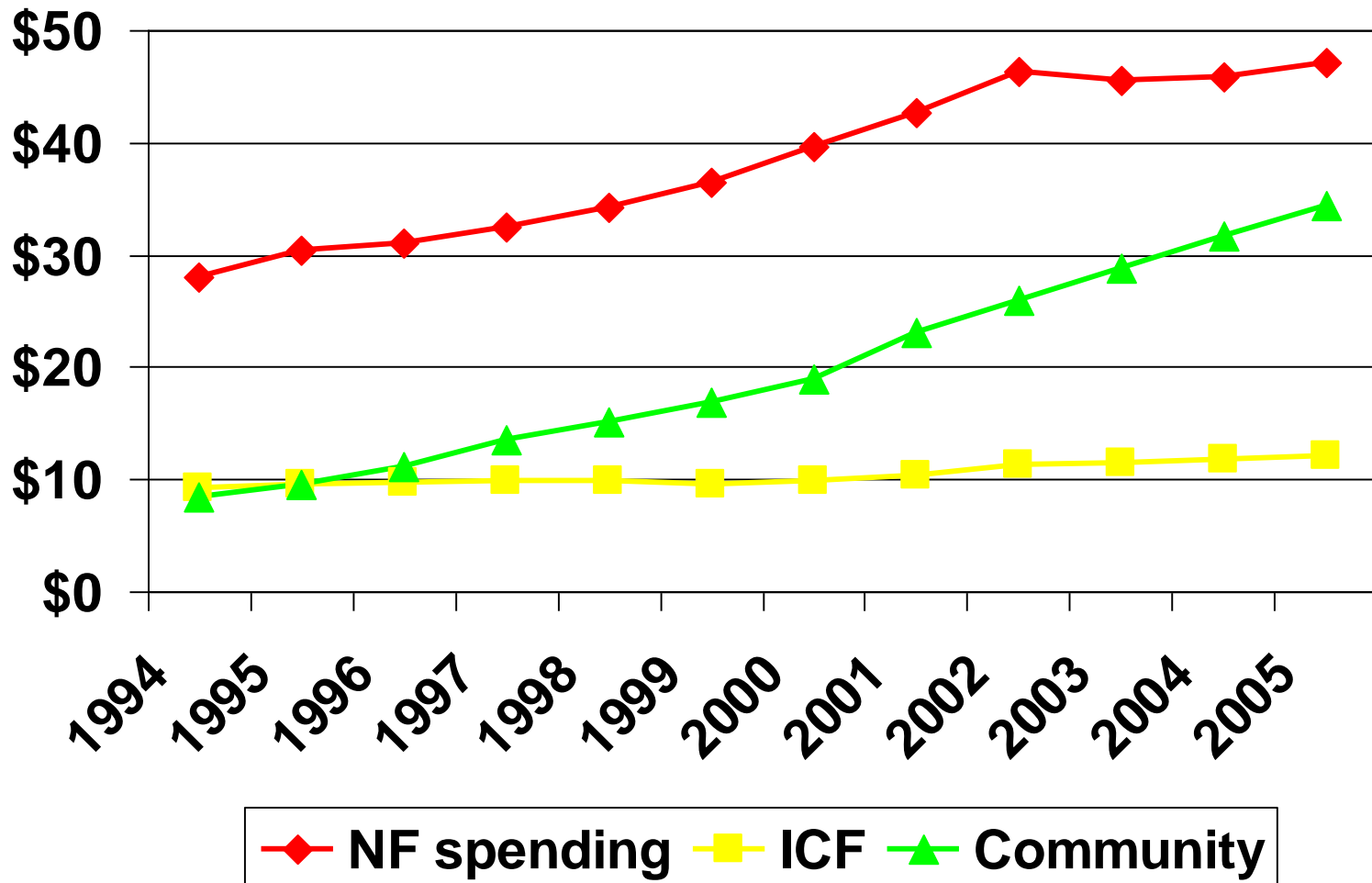
Medicaid spending balance (billions)



Percent by population group



LTC spending trends (billions)



Community: HCBS, state plan personal care, and home health

National Movement: Emphasis on the Individual

- Need array of choices for long term living - supports and services
- Consumer choice and control should be promoted
- Funding should be centered more on the individual than on providers

Consumer Direction, Managing Own Care Includes

- Having greater control, flexibility and choice
- Choosing preferred services
- Designing services to meet your own schedule
- Purchasing equipment, making home modifications

Managing Own Care Includes

- Hiring people that you want to help you with personal care -
 - including relatives, friends, neighbors

Consumer Direction is Not New

- Harrington (2000): 60% of HCBS waivers in 45 states
- 2001 inventory found 139 consumer directed service programs operating in almost every part of the country
- California's program is more than 30 years old

Consumer Direction is Not Only for Younger Adults

- Programs with high percentage of older adults show they like having control over services, schedules, and worker selection
- California serves 200,000 people and 77% are over 65 years
- Arkansas similar--72% older adults, with 41% surrogates

National Policy

For the first time, the Centers for Medicare & Medicaid Services (CMS) and the Administration on Aging (AOA) are partnering...

and providing grants and technical assistance to the states to do more to help people live in their homes and communities.

New Era, New Freedom

“We are about to enter a new era of personal control, of New Freedom, in the Medicaid program. With a concerted effort, every state can rebalance its Medicaid program. With the tools we have now, it is time to end the institutional bias....” Administrator of the Centers for Medicare & Medicaid Services, 2006

Josefina Carbonell, Assistant Secretary for Aging

“This is an exciting time to be involved in long-term care. It is clear we are witnessing a fundamental change in federal policy that is guided by the New Freedom Initiative and directed at giving people more control over their care, as well as providing more support for community living.”

Centers for Medicare & Medicaid (CMS) Investment

- Since 2001, CMS has awarded 306 Real Choices grants
- Vast majority of these grants were for small amounts, but total is \$237 million to 50 states, Guam, Northern Mariana Islands, and DC
- Many different types of grants

Centers for Medicare & Medicaid (CMS) Investment

- At first, a mix of interests
 - Nursing home transitions, housing, workforce, person-centered planning
- Then more focused
 - Aging and Disability Resource Centers
 - Quality, Money Follows the Person
- Now more about “infrastructure”

Infrastructure

- Means fundamental philosophies, processes, policies, working relationships, and funding that affect services for people with disabilities of all ages
- Six areas (access, self-direction, quality, information technology, financing, housing)

Centers for Medicare & Medicaid (CMS) Investment

- The Systems Transformation grants reflect serious investment in states that made the best case major changes
- 18 states selected for this multi-million dollar investment in systems transformation in 2005 (10) and 2006 (8)
- Consumer and family involvement mandated

Money Follows the Person

- Demonstration program
- \$1.75 billion over 5 years
- Focus on helping people leave institutions and give support in community
- 17 states awarded, 22 in pipeline
- Consumer and family input mandated

Your Interests in this Agenda for Change

- Long-term care options
- Information and assistance to find options
- Choice and control over services
- Flexible financing
- Family caregiver support
- Housing with services
- Well trained workforce
- Quality oversight

Assessment of Family Caregivers' Needs?

*Are family members seen merely as
“resources”, or as people with needs
and rights of their own?*

Lynn Friss Feinberg

Family Caregiver Alliance

Assessment of Family Caregivers' Needs

- We need to consider not only how the family caregiver can help the consumer, *but how we can help the family caregiver*
- Assessment is important for developing an individualized plan when the consumer chooses to seek family caregiver support in order to live in the community

Why Assessment?

- What is the “emergency back up” or “contingency planning” for a family caregiver who cannot provide the care that is assumed or stated in the “individualized care plan”? How would the state know unless there is a caregiver assessment?
- **“Caregiver as client”** and **“Caregiver as provider”** ...we should consider both.

Why Assessment?

- If the State is paying for the individual's care (state funded or Medicaid), and the plan for the individual relies on support from the family caregiver, the state should require and fund a caregiver assessment.
- Should be part of the “health and safety” review and “risk mitigation” that CMS requires.

Change Strategies

Conduct demo projects to develop & test caregiver assessment practices & protocols

Incorporate caregiver assessment & support needs in Medicaid home & community-based services

Caregiver as Client

- Need to talk to the caregiver to assess these needs.
 - Should be part of the policy implementation protocols
 - Should be part of the assessor training
- Assessment should lead to interventions.
 - Referrals to support groups
 - Counseling
 - Respite

Caregiver as Provider

- Often need help to learn how to become competent, safe “workers” who can better support the individual and protect them from harm, such as a falling between the bed and the wheelchair
- Need to assess the caregiver’s learning needs for caregiver training
- How to interact with the individual and professionals involved

Opportunities for Advocacy

- Strategic planning and updates in the 18 states: Get involved
- Money Follows the Person planning period: Get involved
- Advocate for family caregiver assessment and support—perhaps next round of CMS grants?

Selected Change Strategies

Build support for family caregivers among the public, policymakers, government officials, practitioners, insurers, employers & funders

- Example, add a question on caregiving to the U.S. Census

Change Strategies

- Adopt a caregiver policy at CMS to acknowledge role and contributions of caregivers in the Medicare & Medicaid programs
- Develop professional education and training curricula that include caregiver assessment

Summary

- Federal policy, state leadership, and consumer activism are fueling historic, fundamental change in long-term living
- Lessons learned: Not Easy, Not Fast, BUT Worth it, Possible
- Your Voice Must Be Heard

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