Freedom Trail to Respite Conference: Research Findings Concerning Impacts of Changes in Policy

Luncheon Research Plenary Panel
Joan Hyde, PhD

Senior Fellow, Gerontology Institute, University of Massachusetts/Boston
And CEO, Ivy Hall Senior Living
Overview of this talk

- History of respite in Massachusetts
- Typology of policy barriers to provisions of respite
- Drivers of policy change
Joan Hyde, PhD was the founding Executive Director of the Massachusetts Alzheimer’s Association (1981–1986) after her experience as a family caregiver.

She has served as a Research Fellow at the Gerontology Institute, UMass/Boston since 1986, where most of her research is concerned with the impacts of regulation on provision of services for people with dementia and other chronic disabling conditions.

She received “Top 100 Women-Led Business” awards for her work in founding an assisted living company specializing in dementia care. She is currently the CEO of Ivy Hall Senior Living which consults to and manages Assisted Living and Seniors Housing programs. Recent research includes: “Housing and Service Needs for Adults with MS,” “Evaluation of the JCHE dementia support initiative” and “The use of interactive PERS in transitions in care.”
References

- Massachusetts Alzheimer’s Disease State Plan, 2012
- “Respite Care” The Massachusetts Executive Office of Elder Affairs, 1973
- Alzheimer’s Disease: Is the Massachusetts Respite System Ready? Silverstein and Hyde, 1987
- Home and Community-Based 1915(c) Medicaid Waivers for Respite Support (ARCH, 2012)
- Selected Caregiver Assessment Measures: A Resource inventory for practitioners
65.7 million caregivers (29% of the adult population of the United States) provide care to someone who is ill, disabled or aged. On average these informal caregivers provide about 20 hours of care a week, with those who live with the person receiving care averaging over 40 hours a week.
Caregiving: A Uniquely Human Attribute

Providing care to children, the infirm and the elderly is a distinctive characteristic of human beings. While most other animals only care for their young for a limited time, human “childhood” – even among hunter-gatherers and early agrarian societies – extends a decade or more into sexual maturity. And no other animals provide ongoing care to those who cannot care for themselves due to illness or infirmity.
My 94 year old mom and her aging caregivers
The Convergence of Aging and Disability

Improved survival of infants, children and young adults with developmental disability and other impairments

Aging of those with disability

Longevity of people with age-related disabilities
Convergence of Aging and Chronic Disabilities

People with developmental disabilities are aging at unprecedented rates and have unique health and service needs. Adults with developmental disabilities have a higher risk of developing chronic health conditions at younger ages than other adults, due to the confluence of biological factors related to syndromes and associated disabilities. They also may face poor access to adequate health care, as well as lifestyle and environmental issues. These unique service needs of this population pose new challenges for existing service networks. Traditionally the aging and developmental disabilities services systems have run on parallel tracks. Large-scale legislative changes that target long-term care services and supports will require greater communication and coordination between the two systems. In this time of great transformation, it is critical for the two systems to work together as their populations face similar needs including managed long-term, integrated care for people who are dually eligible for Medicaid and Medicare, and rebalancing initiatives that promote community living.

--- US Department of Health and Human Services, 2013
Policy Issues Impacting Respite Services

- Defining “need” when informal caregivers are involved
- Maintaining a system that is budget neutral or reduces public expense
- Caregiving costs shared across silos
- Perceived lack of control and oversight
- Costs of oversight and regulation disproportionately heavy for ongoing care
- Poor coordination among different disability groups
Evolution of Government Systems and Programs

- Administration on Aging
- Supplemental Security Income (SSI) and the Keys Amendment
- Medicare
- Medicaid
- Nursing Home Regulation and Reimbursement
Funding silos for healthcare, LTC and related expenses
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Congressional Budget Office Memorandum, March 1999
Measuring Level of Need

- Context of Caregiving
- Caregiver’s perception of health and functional status of care recipients
- Caregiver values and preferences
- Consequences of caregiving
- Skills abilities and knowledge
- Potential resources
Un-Siloed Costs of LTC in Home and Nursing Home
Caregiving Is a Marathon

The father and son team of Dick and Rick Hoyt, have been running the Boston Marathon together for 31 years. Now 72 and 51 years old, they are poster “children” for the fact that caregiving is a marathon.