

Session Sponsor:



Lessons from the Disability Community

Robert L. Kane, MD
University of Minnesota
School of Public Health

Administration for Community Living

- 2012 Merger of the Administration on Aging, the Administration on Intellectual and Developmental Disabilities, and the HHS Office on Disability
- Mission: Promote strategies that enable people to live in their communities.
- Combines two groups with different
 - Values
 - Histories

Definition of Disability

“People with disabilities are those with physical, sensory, and/or mental health conditions that can be associated with a decrease in functioning in such day-to-day activities as bathing, walking, doing everyday chores, and/or engaging in work or social activities.”

Iezzoni, 2010, AHRQ National Health Disparities Report

Constituents

Aging

- Healthy (Vital Aging)
- Chronically ill
- Frail

Disability

- Congenital/developmental (intellectual and physical)
- Acquired (trauma and disease)
- Mental
- Aging

Tenets

Aging

- Disability is disease based
- Medical care is central

Disability

- Disability is not basically medical
- Access to medical care is needed
- Cultural competence is appropriate

Philosophies

Aging (medical model)

- Disease/impairment → disability
- Coverage for impact of disease
- Care is remedial

Disability (access model)

- Disability → environmental modification
- Coverage is civil rights issue
 - Discrimination

Differences in Situation & Attitudes

Aging

- Limited expectations about what is normal
- Children have mixed relationships to parents; history, obligation
Importance of leaving a legacy
- Limited numbers of dependency years
- Decline viewed as inevitable
- Focus on past
- Short duration of problem makes it hard to sustain advocates

Disability

- Mainstreaming
- Parents feel guilty about children
- Parents of children with MR/DD want to protect them
- Long period of dependency
- Some hope that active intervention can change course
- Focus on future
- Parents are in for the long haul, as are young disabled

Premises about Goals

Aging

- Coping
- Preventing complications
- Getting needed care
- Limited social participation

Disability (access model)

- Social integration
- Normal participation
- Access

Outcomes

Disability Type	Example	Outcomes
Developmental Disability	Autism Cerebral palsy	Living independently Going to school Doing paid work Raising family
Acquired Disability	Spinal fracture/ quadriplegia	Living independently Going to school Doing paid work Raising family
Aging	Stroke Dementia	Slowing decline in ADLs/IADLs Reduced use of hospital/ER

Health Care Goals by Subgroup

Subgroup	Priority Concerns	Goals for Health Care
Healthy	Longevity, by preventing accidents, illness, and progression of early stages of disease	Staying healthy
Chronic conditions with normal function	Longevity, limiting disease progression, accommodating environment	Living with illness or disability
Significant but relatively stable disability	Autonomy, rehabilitation, limiting progression, accommodating environment, caregiver support	Living with illness or disability

Health Care Goals by Subgroup 2

Subgroup	Priority Concerns	Goals for Health Care
Limited reserve and serious exacerbations	Avoiding exacerbations, maintaining function, and specific advance planning	Coping with illness at the end of life
Long course of decline from dementia and/or frailty	Support for caregivers, maintaining function, skin integrity, mobility, and specific advance planning	Coping with illness at end of life

Lynn et al., Milbank Quarterly, 2007

Disability as a Model System

- Treat everyone with respect
- Respond to whole person
- Provide appropriate care
- Empower patients
- Common language to articulate problem, goals, expectations and roles
- Facilitate autonomy

Improving Patient-Clinician Encounters

Patient

- More proactive care management
- Prepare for office visits
- Focus visit on their agenda

Clinician

- Share information
- Value patient's insights about condition
- Involve patients in decision making
- Listen

Disability Policy Framework

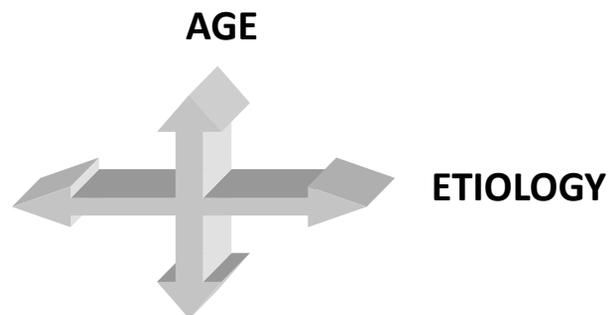
- Core precept: disability is a natural and normal part of the human experience
 - Does not diminish a person's right to fully participate in all aspects of society
- Focus on fixing physical and social environment, not on persons with disabilities

ADA Policy Goals

- Equality of opportunity
- Full participation
- Independent living
- Economic self-sufficiency

- Attained varies by etiology and age
 - Young/old
 - Physical/mental

Disability Disparities Operate
in Several Directions



Disparities

- By age
 - Children
 - Adults
 - Elders
- By diagnosis
 - DD vs. dementia
 - Blindness vs. deafness

Politics

- Differential advocacy
 - Sustained for young
 - Limited for old
- Ageism
 - Shared by young and old
 - Different standards for what is acceptable
- Merger of aging and disability programs
 - ID/DD