

What We Know and What We Need to Know  
About Aging with a Disability:  
Social and demographic factors

Vicki A. Freedman  
University of Michigan  
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# What We Know (IOM 2007)

- 40-50 million people in the United States report some kind of disability
  - Substantial numbers acquire disability before late life
- The number is projected to grow substantially between now and 2030
- Policy and programmatic interventions will undoubtedly play an important role in shaping the future of disability in America

# Overarching Themes

- What we know depends on available data
  - Creative use of existing data
  - Most non-national, not population based samples or cross-sections
  - Existing cross-sectional and panel studies have limitations (measures)

# Overarching Themes

- Also depends on how questions framed
  - Description and comparison vs. life course lens
  - Is the “disablement process” the right framework?
    - Alternative: Maximizing the population’s ability to carry out activities and participate in daily life, regardless of age or where they are on the functioning continuum—from the onset of health conditions through the end of life

- The Facts As we Know Them...and...
  - What We Still Don't Know

1. 13-16 million adults in 2010 living with disability due to a condition that occurred before age 45

- What proportion have (1) early-onset fatal conditions, where survival has increased vs. (2) early-onset non-fatal disabling conditions that appear to be increasing
- How is the composition of this group changing?
- If it is growing, why is it growing ?
- How much do environmental components contribute to this figure? How much can be reduced through environmental interventions?

2. Survival rates appear to have increased more for some groups with disabilities than for the general population
  - Rates are not typically population-based but compare clinical samples to national norms
    - Still often disease specific
  - How much has life expectancy for adults and children with disabilities increased?
  - In the future, what proportion will live until late life?
  - What will be the effect on late-life disability and long term care needs?

3. On the national level, the prevalence of limitations has been increasing among non-elderly adults and this appears to be linked in part to upward shifts in the BMI distribution
  - Implications for services needed in the future by older adults remain unclear because underlying processes (incidence, recovery, mortality) unknown
  - How much can environmental changes and other accommodations (AT, service environments, physical environments) compensate for changes in capacity?
  - How much of the change is increased survival of individuals with life long or early onset disabilities?

4. The duration of the longest-lasting causal condition has increased for <65 (to 18 years at 40) and 65+ with activity limitations (to 17 years for 85+)
  - Pattern of limitations within individuals over time less clear
  - Which factors allow people with potentially disabling conditions to avoid limitations?
  - How do individuals who reach late life having had a disability for decades differ in their daily life (time use and experienced wellbeing) from those who develop limitations later in life?

5. Symptoms of sleep disturbance, depression, pain, fatigue etc. and other secondary conditions among persons aging with a disability peak during middle age and contribute to changes in capacity
  - Most estimates are from non-national age-specific cross-sections; What happens as individuals age?
  - How do trajectories unfold? How do they look different than trajectories that start later in life?
  - At what point do conditions manifest and begin to necessitate changes and/or influence daily life?
  - Which approach or combination of approaches yields long-run benefits? “Use it or lose it” versus “conserve it and preserve it”

6. Adults aging with disability are more vulnerable than others with respect to their health and independence as they age; vulnerability related to lower SES and disparities in health behaviors
  - Long-term panel data measures limited (e.g. work limitations to identify individuals aging with disability; generalizability)
  - Do the health conditions that account for differences between adults aging with/without work limitations in health give rise to the work limitations in the first place?
  - How are late-life limitations of individuals different for those who reach later life with and without disabilities?

7. Adults aging with disability may be at an even greater risk of depression and poorer mental health in later life due to the potential synergistic nature of disability and depression over the life course
  - Panel data long but measures limited and biases related to who responds
  - How do trajectories differ for individuals who experience disabilities with onset in childhood vs. adulthood?
  - How does type and severity of disability influence trajectories?
  - What factors buffer these influences? SES? Social Supports? Role of attitudes? Environment?

8. Because disability onset, recovery , and mortality are linked to early life experiences, active life expectancy is strongly associated with early life measures of health and socioeconomic context.
  - Active life expectancy is a synthetic summary measure of average years remaining in a particular circumstance
    - How much can active life expectancy be altered under different intervention scenarios?
  - What should we be measuring? Independent functioning? Participation? Services?
  - How many person years of “care” will today’s adults need in the future? How is that different than the package available today?

# Taking Aim at Data Gaps

- Long-term panel studies accumulating valuable information and can answer some questions
- New panel study that allows understanding of intersection of capacity, accommodations, participation, but focuses on 65+ (NHATS)
- New, disease specific panels / registries
- No national disability surveillance system (IOM 2007)

# Aging with a Disability: Policy Perspectives

Lisa I. Iezzoni

Massachusetts General Hospital

Harvard Medical School

# GOAL IS INDEPENDENCE

- SHARED GOAL: Individuals in older and younger generations with disabilities typically seek independent living in communities rather than dependence, institutionalization
- But word “INDEPENDENT” has different meanings to different generations
- Different meanings have policy and programmatic implications

# INDEPENDENCE DEFINED

- Simplifying for brevity and clarity
- Older generation (WWII, Depression era)
  - Disability = functional impairments preventing “normal” participation in daily activities
  - Requires individuals to compensate or readjust expectations
  - Accommodations represent dependence
- Younger generations
  - Disability = functional impairments confronting environmental barriers to participation
  - Accommodations facilitate independence

# IMPACT OF DIFFERING DEFINITIONS

- Differing perspectives on independence dictate differing directions of aging and disability programs, policies, research
  - Distinct age- and disability-based theories, conceptual frameworks, “philosophies”
  - Differing perspectives on health and social service interventions, innovations, programmatic silos
  - Different language; identical words with differing meanings → confusion and misunderstandings

# WHEELCHAIRS AND INDEPENDENCE

- Don't wheelchairs represent dependence?
  - You can't walk safely and independently
  - “I wouldn't be caught dead using a cane let alone a wheelchair.”
- No, wheelchairs represent independence!
  - Walking gets you from Point A to Point B
  - My wheelchair gets me from Point A to Point B
  - I no longer worry about falling, injuries, exhaustion
  - I direct where I go; no one pushes me
  - “Spring after a housebound winter – reopened world.”



Michael:

7,627 km (almost 5,000 mi) on  
wheelchair odometer on 5.15.12, after  
 $\approx$  4 years of active use

# PCAs AND INDEPENDENCE

- Don't personal care assistants (PCAs) represent dependence?
  - Human help with most intimate, basic needs (e.g., feeding, bathing, toileting, dressing, mobility)
- No, PCA's represent independence!
  - I hire PCAs
  - I direct what they do for me and when and how they do it
  - PCAs facilitate my ability to do what I wish to do: I DECIDE
  - (Yes, PCAs need a living wage, health insurance ...)



# REASONABLE ACCOMMODATIONS

- Critical policy context for disability is history of discrimination, stigmatization, failures of environments to accommodate needs, barriers to education and employment
- Americans with Disabilities Act, signed July 26, 1990 (almost 22 years ago)
- Proactive efforts to accommodate disability but not absolute
  - “Reasonable accommodations”
  - “Readily achievable”
  - Supreme Court restricting reach (despite Olmstead)





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# IMPLICATIONS

- Accommodating disability requires active recognition of specific accommodation needs
  - Disabilities are diverse
  - Multimorbidities, especially with diseases of aging and secondary conditions complicating disabilities
- Must develop technical and policy specifications for DIVERSE accommodation approaches
- Demands PROACTIVE THINKING, PLANNING, AND THUS RESOURCES: “disability in all policies”

# PERSISTENT DISADVANTAGES

- Multifactorial origins but persistent discrimination certainly contributes:
  - Higher poverty rates, lower SSDI monthly payments, fewer retirement assets
  - Lower educational attainment
  - Higher unemployment rates
  - Worse overall health, ↑er smoking, ↑er BMI
  - Health care disparities, e.g.
    - Lower cancer screening rates
    - Disparities in breast and lung cancer care

- Policy challenges as we know them...and...

- What we need to learn and understand

# 1. COSTS TO SUPPORT INDEPENDENCE

- Supporting independent living for individuals with disabilities will cost money
  - Individuals, families
  - Federal, state, and local programs
  - Broader societal costs
- Social programs currently confronting significant cuts from federal to local levels
- Setting priorities will require information

# QUESTIONS ABOUT COSTS

- What are most efficient ways to achieve goals of independent living of persons aging with disabilities?
- What are we purchasing for dollars spent?
- What expenses offset other expenses?
- How are costs distributed across different sectors, population subgroups?
- How much is society willing to pay?

## 2. QUALITY OF LIFE, PARTICIPATION

- Increasing participation in daily and community activities improves quality of life and overall sense of well being
  - Reduces depression, increases self-efficacy, etc.
  - Prevention of secondary conditions, chronic conditions of aging (e.g., hypertension, diabetes)
- Various accommodations facilitate this participation
  - Assistive technologies, including computer-based and information technologies
  - Home modifications (e.g., improving accessibility)
  - Personal care assistants (PCAs)

# QUESTIONS ABOUT QoL, PARTICIPATION

- What types of interventions are most effective at improving QoL, participation, prevention?
- What types of accommodations best facilitate QoL, participation, prevention?
- What approaches maximize the likelihood that persons with disabilities will participate in and benefit from these interventions?
- ANSWER EACH QUESTION ACROSS DISABILITY TYPES, subpopulations (e.g., by SES, culture)
- Is society willing to pay for QoL improvements or must there be other “returns on investment”?

# ASSISTIVE TECHNOLOGY FRONTIERS

- What are major areas requiring assistive technology research? e.g.,
  - Power wheelchair batteries; hearing aids; cochlear implants; limb prostheses; external stimulation devices; etc.
  - Voice activated equipment of all sorts, including “routine use” equipment (e.g., automated bank teller machines, machines dispensing subway tickets)
  - Full range of information technologies
  - “Smart homes,” computer controls within homes
- Who will pay for assistive technology?
  - Payment policies limit coverage to “medically necessary” items
  - AT and home environmental modifications typically not covered
  - Medicaid covers more than Medicare; state variations
  - Payment policies affect technological development (e.g., iBot)

# PARTICIPATION CHALLENGES

- Low employment among working-age persons with disabilities
- Recession exacerbates problems
- QUESTION: How are vocational rehabilitation and training programs benefitting persons with disabilities, in both short and long term?
- Implications for income, household resources
  - Ability to cover uncovered needs (e.g., PCAs, AT, home environmental accommodations)
  - Housing, food security, overall well being

### 3. PERFORMING ADLs, IADLs

- Persons might need human assistance for performing basic ADLs, IADLs
- (Robotic solutions not yet ready for widespread use – more research needed)
- Informal caregivers might not be available
- Concerns about physical, psychological abuse
- Medicare does not cover PCA care; Medicaid program coverage variable across states and at risk during budget cuts

# ADL, IADL QUESTIONS

- How are consumer-directed and other programs to provide PCA and home-based assistance working? From perspectives of:
  - Persons with disabilities, families
  - PCAs
  - Costs, programmatic support, workforce
- What other innovative models might support ADL, IADL needs?
- Over next several decades, what are projections of PCA needs across society?
- What workforce will supply those needs? And how should they be paid?

# 4. ROLE OF FAMILIES

- Family issues might be complicated
  - Younger persons with disabilities: parents' role
  - For some groups, higher rates of divorce, fewer children, more likely to live alone
- Concerns about abuse
  - Domestic violence rates relatively high, both for women AND men with disabilities
- Special issues relating to persons with intellectual disabilities
  - Questions about guardianships, self-determination

# QUESTIONS ABOUT FAMILIES

- What are demographic projections about family composition for persons with disabilities over next several decades?
- What approaches best meet support needs of persons with intellectual disabilities?
- What programs are needed to address domestic violence and other abuse of women and men with disabilities?
- How should HIPAA and other privacy and legal concerns be addressed for persons with disabilities in various different circumstances?

# 5. MEDICAL CARE

- “Medical care” (broadly defined) is necessary
  - Address underlying disabling condition
  - Address secondary conditions, chronic conditions
  - Prevent complications, secondary conditions
  - Wellness, rehabilitation, maximizing function
- Concerns relating to medical care
  - Medicalizing disability
  - Poor coordination across clinical specialties, with community-based services
  - Failure of clinicians to understand persons’ needs, preferences
  - Inaccessible facilities, offices, equipment
- Team-based models, innovations in care delivery
  - e.g., Nurse practitioners providing, coordinating care in homes
  - e.g., Self-management, collaborative care

# QUESTIONS ABOUT MEDICAL CARE

- Increasing and training clinical workforce
  - Primary care physicians: How to improve training relating to disability issues?
  - What should be roles and training for other health care professionals in delivering primary care (e.g., nurse practitioners, physician assistants, rehab therapists)?
- Changing payment policies
  - How to adjust payments to recognize time demands?
  - What policies should be tried to support new delivery models (e.g., global capitation), improve coordination?
- Methods for increasing accessibility of health care facilities, offices, including in rural communities?
- Quality measures

## 6. CONCERNS TRANSCEND SECTORS

- Disability concerns transcend health and human services sectors
  - Health insurance, income support, housing, transportation, food, labor, education, legal and civil rights, local and regional planning, etc.
- Environmental focus goes beyond physical environment to social and policy environments
- Disability is part of life – virtually everyone will experience some type of disability at some point as they age

# QUESTIONS: TRANSCENDING SECTORS

- How does society at large plan for growing numbers of persons aging with disabilities?
- What nations offer examples about doing this well?
- How do we introduce “disability in all policies”?
- What are societal costs of NOT planning ahead?
- How can we overcome human nature: inherent reluctance to discuss topics that feel uncomfortable?

