State of the Science:
Advances at the Intersection of Aging & Long-term Disability

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Acknowledgements

• This webinar series was developed under a grant from National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR grant number 90RT5023-01-00). NIDILRR is a Center within the Administration for Community Living (ACL), in the Department of Health and Human Services (HHS). The contents of this webinar series do not necessarily represent the policy of NIDILRR, ACL, HHS, and you should not assume endorsement by the Federal Government.

• This series is hosted by the National Council on Aging (NCOA)
Why this webinar series?

The 30,000 foot view...
Goals for the webinar series

• Much work has described new onset impairments or disability in older adults

• We will highlight recent research in individuals who are
  – 1) Growing older, and
  – 2) Live with “disability” (restrictions + environment), that is
  – 3) due to health conditions acquired from birth through early adulthood (i.e., “long-term” or “lifelong” conditions)

• We also wish to discuss the intersection of the Aging and Rehab/Disability fields in research and policy formation
Structure

• Three days (10/16; 10/18; 10/20)

• Each day:
  – The first speaker provides a large scale view of the field
  – The next speakers focus on a particular related subject area

• Questions posed by moderator between speakers

• Each webinar is between 90-120 min
Day 2 (Wednesday): Autonomy and access issues for adult aging with disability
Day 2 Presenters

Sarah Ruiz
*NIDILRR perspective on research at the intersection of aging and disability*

Ivan Molton
“Successful aging” and long-term physical disability

Lisa Iezzoni
*Dignity of risk*

Philippa Clarke
*The role of the built environment for successful aging with long term physical disability*
Housekeeping...

• Captioning is available (click the link in the “chat” box to view captioning)
• Questions can be sent via the chat feature, and are addressed at the end of each talk
• The slides and recording will be sent to everyone that attended the webinar today. They will also be archived on the National Council on Aging website.
Research on Aging with Disability: History and Opportunity

Sarah Ruiz, PhD, Senior Scientist
National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR)
History

• NIDILRR has pioneered the area of aging with disability research for more than 35 years
• In the 1980s, the first centers on aging with physical and intellectual disability began
• ...Early efforts generated little traction
• Policy suggest a more supportive environment for aging with disability
History of NIDLRR Investments
1980-2016
~$160m

• Total number of grants funded between 1986 and 2016 across all program mechanism based on the content of the title, abstract, and/or key words on NARIC
  – 113 grants on “aging” (19 current)
  – 80 grants on “secondary conditions” (15 current)
  – 20 grants on “older adults” (5 current)
  – 52 grants on “aging with disability” (15 current)
  – 11 grants on “aging and secondary conditions” (3 current)
Opportunity

• Now under ACL, NIDILRR has a vehicle to disseminate evidence-based programs and strategies to millions of people with disabilities across the U.S.
• Many of programs scaled through the ACL network are currently available to people with disabilities.
• Each program is ready to scale under the right circumstances.
• NIDILRR funding in this area could open up a whole array of evidence-based programs that could be considered for inclusion in alternative payment models in large health systems.
“Successful” aging with early-acquired disability

Ivan Molton, PhD
University of Washington School of Medicine
Seattle, WA
What do we mean when we say “Disability?”

• A biopsychosocial experience in which impairments interact with the environment and personal factors to limit participation.

• But in practice, the context for this term often varies...
  – in Geriatrics and Gerontology:
    • Due to impairments often associated with age-related health conditions (osteoarthritis, osteoporosis, stroke, CVD, COPD)
  – In Rehabilitation Medicine:
    • Due to impairments often associated with conditions that appear from birth to midlife (SCI, MS, CP, TBI, PPS, MD)
This distinction often comes down to timing, onset and course

• Able-bodied older adults may develop impairments as they age. This is typically a linear or stepwise process, and disability is a new and gradual experience.

• People with early-onset, impairing health conditions age “with” impairments. They are experienced in managing disability. Any new impairments are due to disease progression, or to developing “secondary conditions”.
Timing matters

- Age at onset of impairment/disability
- Position in the life course at onset
- Duration of impairment/disability
- Trajectory of impairment/disability
A growing and aging population

- People aging with long-term impairing conditions represent a large and underserved population
  - An estimated 27-39% of adults with disabilities experienced onset prior to age 44, constituting approximately 12 million individuals in the US

- The average age of people aging with certain early-acquired, impairing health conditions is increasing
  - In the U.S. and Europe, the average age of people with multiple sclerosis is now between 45 and 50
  - More than half of individuals with spinal cord injury are over age 50 (age at onset has increased 10 years since 1970)
Successful aging and the Disability Criterion

• “Low probability of disease and disease-related disability” and “a high level of physical and cognitive function”.
  – 90% of empirical studies on successful aging include some version of this criterion (Depp & Jeste, 2006)

• In people aging “with” long-term disability, the criterion is problematic
• Seen as ableist
• Does not include adaptations/accommodations
• Does not allow for successful aging with impairments
Different perspectives

“For the disabilities system, aging is a success; for the aging network, disability is a failure.”
(Ansello, 2004)
Qualitative Analysis Methods

- Nine focus groups conducted from 2009 to 2014, n = 49
- All participants were at least 45, and reported restrictions in activities associated with diagnosis of multiple sclerosis, spinal cord injury, post-polio syndrome or neuromuscular disease
- Participants were recruited nationally and represented rural and urban locations in 13 states
- Some groups conducted in person, some over telephone
Qualitative Analysis Methods

- A discussion guide included questions such as: What does it mean to you to age successfully with long-term physical disability? What resources do you have now that help you age well?
- Data were analyzed using steps recommended for qualitative research (Benner, 1994), including creation of a formal codebook using indexing software (Dedoose) and a constant comparative method through independent coders.
Demographics of Focus Group Members

- 20 men, 29 women
- $\overline{M} \text{ age} = 62$ (range 45-80)
- Mean time with the health condition/diagnosis was 21 years; 55% had lived with the condition >20 years
- 73% College graduates
- 62% married/living with partner
Results: Theme 1, Resilience and Adaptation

• “Resilience” meant the ability to experience pleasure, contentment, and reward from daily life, and avoidance of chronic low mood.

• “Life is what you make it, and it can be a very beautiful thing if you just look for the beauty that is in your life, present every day, as opposed to looking for the problems,” (M/SCI/62).
Results: *Theme 1, Resilience and Adaptation*

- “Adaptation” meant shifting or re-structuring goals based on changes in function, and was seen as an inevitable and necessary:
- “When I think about thriving, it's not necessarily the way that I was before, and so it's not so much removal of everything but a replacement, so it's like, Okay, MS has caused this vacuum or this void in my life, but what else am I going to fill it with? (M/MS/51).”
Results: *Theme 2, Assisted Autonomy*

- “Assisted Autonomy” meant the ability to maintain a sense of personal agency, self-efficacy and choice as one aged. This was not the same as “independence.”

- Many examples focused on the ability to make choices regarding how one directed caregivers, or how one selected adaptive equipment in order to participate in valued activities.

- “The goal is definitely to be able to do what you want to do. Not necessarily what you have to do.” (F/MS/57).”
Results: *Theme 3, Social Connectedness*

• This domain included the degree to which one is interacting with ones’ friends, family and social environment.

• Included general social support, practical support, and disability-specific information

• “If it weren't for my wife I wouldn't want to be here, period.” (M/MD/68)
Results: *Theme 3, Social Connectedness*

- This included contact with 3 groups (for different reasons):
  - Friends without disability
  - Friends with disability
  - Friends with the same medical diagnosis

- “Growing up, the goal for... polio survivors was to be normal and to hide the handicap... As I've gotten much older over the last 10 years, I've become a little more open to attending support groups...”.
  (F/PPS/67)
Results: *Theme 4, Physical Health*

- Reflected an individual’s current symptoms, wellness, and access to services to promote or maintain physical health.
- Included 2 subthemes:
  - Maintenance of current physical health
  - Access to healthcare
- These descriptions tended to map most closely onto descriptions of “avoidance of disability” from the larger gerontology literature.
Maintenance of Current Health

• The focus was not on the primary health condition, but rather on management of common “secondary” conditions
  – Especially pain, fatigue, and spasticity, which worsen with age
• Health was seen as necessary to community participation, including employment:
  – “With such limited eyesight and the loss of cognition, ...when I lost my sense in my fingers... I said I had to retire from being a nurse.” (F/MS/51).
  – “I really tried to do that for three years, and it was the hardest three years of my life. I mean... I was on so many medications that I had to detox... and then I lost the job anyways.” (M/MS/56).
Access to Healthcare Included:

- Availability (of primary and rehabilitation care, as well as community wellness and exercise programs)
- Accessibility (in terms of environmental and transportation barriers, as well as appropriate medical equipment in physician offices)
- Appropriateness (including providers who are knowledgeable about “disability conditions”, and community programs that were adapted or tailored for people with disability).
Access to Healthcare

“Most general practitioners don't know where to send people and for what services there are. I have a general practitioner that I like and have gone to for years, but he says, ‘I am too busy to research polio. You research it and I'll be glad to send you.’” (F/PPS/80)
Are these themes any different than in older adults in general?

• These themes map onto previously discussed aspects of successful aging, including
  – Biomedically based approaches (e.g., maintaining ones’ physical health, Rowe & Kahn 1997; Seeman et al., 1994)
  – Psychologically based approaches (e.g., maintaining social connectedness; Bowling & Dieppe, 2005).
  – Adaptation based approaches (e.g., loss-based selection; selective optimization & compensation; Baltes & Baltes, 1990).
Participants Referred Openly to this Overlap

“...that's the thing about MS. It's like most people will get all the symptoms of MS eventually. It's just that we get it much, much earlier. And, you know, in some ways the same things that work with the geriatric population probably would work with MS as well,”

(M/MS/58).
However, the Context for Successful Aging Differs

• Disability occurs earlier in the trajectory of the lifespan, and this affects a number of factors that are increasingly important in later life
  – Less likely to marry, less likely to have children = smaller social networks in aging
  – More likely to retire early and involuntarily due to worsening health = poorer financial trajectories in aging

• Assisted autonomy, not “independence”
  – These individuals may see autonomy as an ongoing negotiation with care providers, family and caregivers
Differences in context

• Caregiving is uniquely fused with social support
  – Many people with early-acquired physical disability rely solely on partners and family to meet most caregiving needs (especially true in SCI)

• Geography and local resources are especially tied to meaningful participation
  – Participation requires availability of specialty clinics, adapted buses, curb cuts, resources for driving and computer access, community wellness programs that can accommodate different levels of function.
Perhaps an Inoculating Effect?

- Participants emphasized their unique perspective on aging.
- A lifetime of experience with disability, ableism, adaptation and resilience may have an inoculating effect in terms of distress associated with new limitations:

  “You are used to adversity. It’s how you grow up” (F: PPS: 67).

You have “a certain resilience of view” and have experienced disability when “you’re young, able to adapt,” (M: SCI: 56).
Based on these interviews, successful aging with disability includes:

• **Psychological resilience**, including the absence of negative mood states and the ability to experience pleasure, contentment, and reward from daily life
• **Psychological adaptability and flexibility**, including an openness to selection, optimization and compensation, and to changes brought about by the disability condition
• **Autonomy and choice** in decision making, including a high degree of personal efficacy in directing one’s care and choosing activities (distinct from “independence”)
• **Social and community participation** and positive connection to others, both with and without disability
• **Medical care that is accessible, available and appropriate**, with an emphasis on management of secondary health conditions
• **Effective compensation for functional impairments**, within an individual’s particular abilities, and based on their own goals and expectations for activity
Questions?
Dignity of Risk

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Mongan Institute Health Policy Center,
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October 18, 2017
DIGNITY OF RISK

Individuals are “worthy of honor and respect” even when they make decisions that may increase “the possibility that something bad or unpleasant will happen.”

D. Mukherjee, Hastings Center Report, 2015
People should be allowed to make their own decisions about how they live their lives, even if their choices carry risks.
Mandatory evacuation ordered for Florida Keys
“Like war that was happening out here is the best way I know how to describe it. … Always listen to your officials.”
EXCEPTIONS TO DIGNITY OF RISK PRINCIPLE

- Where actions clearly put other persons involuntarily at risk

- Hurricane context
  - First responders deployed to rescue persons in dangerous situations
  - Decisions affect dependents, such as children

- Other situations affecting children, although complicated – what is truly reckless disregard for child’s wellbeing?

- COMMON EXAMPLE: person with various impairments driving without appropriate accommodations
  - Aging parent conundrum
The Car Key Conversation

BY JANE GROSS  JULY 3, 2008 12:31 PM

Many caregivers dread the moment they must ask an elderly parent to surrender the car keys. (Max Whittaker for The New York Times)
Persons with disability are especially likely to have others around them – family members, friends, and clinicians – question whether they should be permitted to live their lives as they wish.

These attitudes of others reflect complex factors, including:
- Stigmatized attitudes about disability
- Paternalism
- “Safety” considerations, with seeming legitimacy depending on perspective

With clinicians, questions about dignity of risk often arise at times of transition, such as:
- After hospitalization for acute event, such as pneumonia
- Occurrence of secondary condition, like pressure ulcer or injury from fall
AGING, DISABILITY, AND DIGNITY OF RISK: TOPICS

1. Implication of demographic trends
2. Principles of independent living
3. Countervailing forces
   - Stigmatization
   - Paternalism
   - "Safety" considerations
4. Case study: Michael
5. Conclusions
1. DEMOGRAPHIC TRENDS
57 million persons and numbers growing
GROWING NUMBERS AGING WITH DISABILITY

- Many factors contribute to increasing numbers, including persons with early onset disability living into middle and older ages.
- Medical advances since the mid-20th century, starting with antibiotics, have extended longevity of persons with even significant functional impairments.
- Aging with disability increases risks of secondary conditions: “any additional physical or mental health condition that occurs as a result of having a primary disabling condition” (Institute of Medicine, 1991).
- Persons also risk developing comorbidities: “health conditions that develop independent of the primary condition” (Institute of Medicine, 2007).
Accumulating evidence suggests that persons aging with disability, either congenital or acquired by mid-life, show physiological signs of more rapid aging than nondisabled persons, although reasons for this are unknown.
IMPLICATIONS

- Functional impairments and health conditions that challenge independent living increase with aging
  - Underlying disability
  - Secondary conditions
  - Comorbid conditions

- Successful independent living in communities requires more complex and multi-faceted accommodations, for example to:
  - Address progressive functional impairments from underlying disability
  - Prevent or treat secondary conditions, such as pressure ulcers, falls, urinary tract infections, and depression
  - Treat comorbid conditions, including use of oral and injection medications (e.g., insulin), monitoring for comorbidity complications and treating side effects
2. INDEPENDENT LIVING PRINCIPLES
INDEPENDENT LIVING PRINCIPLES (4 OF 10)

1. “Civil Rights – equal rights and opportunities for all; no segregation by disability type or stereotype.”
2. “Consumerism – a person (‘consumer’ or ‘customer’) using or buying a service or product decides what is best for him/herself.”
3. “De-institutionalization – no person should be institutionalized (formally by a building, program, or family) on the basis of a disability.”
4. “De-medicalization – individuals with disabilities are not ‘sick’, as prescribed by the assumptions of the medical model and do not require help from certified medical professionals for daily living.”
INDEPENDENT LIVING PRINCIPLES

1. Persons with disability have equal rights as do other people and should not be stereotyped.
2. Persons with disability decide what is best for themselves.
3. Persons should not be institutionalized because of disability.
4. Disability does not equal sickness and does not require medical professionals to direct daily lives.
3. COUNTERVAILING FORCES
COUNTERVAILING FORCES

- Stigmatization
- Paternalism
- “Safety” considerations
INDEPENDENT LIVING PRINCIPLES

1. Persons with disability have equal rights as do other people and should not be stereotyped. ←STIGMATIZATION
2. Persons with disability decide what is best for themselves. ←PATERNALISM
3. Persons should not be institutionalized because of disability. ←← STIGMATIZATION, PATERNALISM, AND “SAFETY” RISKS
4. Disability does not equal sickness and does not require medical professionals to direct daily lives. ←“SAFETY” RISKS
Disabilities are diverse. Nonetheless, they share one common element: persons with disabilities perform basic human functions – such as seeing, hearing, speaking, moving, thinking, and emoting – in different ways than do other persons. In the public’s mind, these basic functions crystallize the essence of what it means to be “human.” These differences distance persons with disability from the “normative” human, implicitly raising questions about their core humanity.
History of disability stigmatization and isolation reaches back millennia, as “normals” feared contamination or taint from interacting with disabled persons who were often held morally culpable for their impairments. Eugenics movement in late 19th and early 20th century America aimed to prevent persons with disability from having children.
Despite the 1990 Americans with Disabilities Act (ADA), compared with nondisabled persons, individuals with disability continue to have greater disadvantages in education, employment, income, housing, transportation, and other eco-social determinants of health. They also often experience disparities in their health care services, which research suggests is linked – at least partially – to stigmatization.
RESULTS OF STIGMATIZATION

- Views of persons with disability are devalued, delegitimized
- Extent to which persons with disability value their own lives is underestimated
- People impose their own views: e.g., “I wouldn’t want to live like you.”
- Erroneous assumptions are made about how people with disability should live their lives, without asking about or respecting their views
PATERNALISM

- Stigmatization supports paternalism
- "Broadly defined, paternalism is an action performed with the intent of promoting another's good but occurring against the other's will or without the other's consent. In medicine, it refers to acts of authority by the physician in directing care and distribution of resources to patients." (AMA Journal of Ethics, 2012)
- "Policy or practice on the part of people in positions of authority of restricting the freedom and responsibilities of those subordinate to them in the subordinates' supposed best interest" (general definition)
- Persons with disability are assumed to need protection, with others making decisions for them
DIVERSITY OF DISABILITY

- Subgroups of persons with certain types of disability raise special considerations for dignity of risk and paternalistic views
- Persons with organic brain syndromes and dementia
- Persons with serious mental illness, although this is complicated
- Persons with substance use disorders, although this is also complicated
- Persons with intellectual disability, although growing evidence base supports efforts to enhance self-determination for these individuals
Welcome

Welcome to the National Gateway to Self-Determination Web Portal, a clearinghouse for resources, training, and information on promoting self-determination. This site provides a single access for self-advocates, professionals, policy-makers, families, and the general public on the current best practices in promoting self-determination.
SAFETY

“Condition of being protected from or unlikely to cause danger, risk, or injury” (general definition)

Synonyms: welfare, well-being protection, security

Safety is never absolute: everything people do daily carries risks, large and small

Who decides what environment is “safe” and what risks are acceptable to achieve a person’s specific life goals

Growing area of contention for persons aging with early-onset disability, who are used to living independently in communities, and clinicians, especially those unfamiliar with independent living principles
CONTROVERSY: Putting persons with significant physical disability used to living independently in the community into a nursing home ostensibly for their safety
SUPREME COURT OF THE UNITED STATES

No. 98–536

TOMMY OLMSHEAD, COMMISSIONER, GEORGIA DEPARTMENT OF HUMAN RESOURCES, ET AL., PETITIONERS v. L. C., BY JONATHAN ZIRMING, GUARDIAN AD LITEM AND NEXT FRIEND, ET AL.

ON WRIT OF CERTIORARI TO THE UNITED STATES COURT OF APPEALS FOR THE ELEVENTH CIRCUIT

[June 22, 1999]

JUSTICE GINSBURG announced the judgment of the Court and delivered the opinion of the Court with respect to Parts I, II, and III–A, and an opinion with respect to Part III–B, in which O'CONNOR, SOUTER, and BREYER, JJ., joined.

This case concerns the proper construction of the anti-
4. CASE STUDY: MICHAEL
MICHAEL: with permission ...
MICHAEL

- 63 years old, 21 year history of primary progressive multiple sclerosis (PPMS)
- Born Birmingham, England; DPhil physics Oxford University
- Excellent physical health: high altitude, long distance cyclist; became avid speed skater and cross country skier after moving to North America in 1981
- Progressive lower limb weakness in early 40s
- Diagnosed with PPMS in 1996
PROGRESSION

- Within 5 years, needed to use wheelchair for all mobility needs; retired from work at age 50
- Cognitively entirely intact
- No eye symptoms
- Major functional deficits:
  - Lower limb function: almost like transected spinal cord (no volitional foot or leg movement)
  - Urinary incontinence: suprapubic tube inserted
  - Spasticity and fixed contractures of both arms and hands
  - Chin-operated joystick controls wheelchair and iPad
Michael confronted his progressive disability head on, adapting his environment within his resources
Pump needs to be turned off if Michael is not sitting on the cushion.

Pump needs to be off at night.
Michael researched and obtained a high-tech seat cushion that has circulating air cells and helps prevent pressure ulcers
INSURANCE COVERAGE

- Primarily to obtain essential PCA services and cover the 20% Medicare copays, Michael enrolled in a PACE program
  - Nursing home-certifiable, Medicare, ≥ age 55
- Some PACE leaders did not want him because he lives alone; they thought he should be in nursing home
- Worked well: PCA coverage, home nursing
- PACE primarily enrolled population with high prevalence of Alzheimer’s disease, geriatricians
- Unlike other PACE members, Michael did not attend adult day care
4,020 km (≈ 2,498 miles) on wheelchair odometer on 7.24.17, after 3.5 years of active use
JULY

Michael’s high-tech seat cushion malfunctioned and was sent away for 3 days for repair; during that time he developed a pressure ulcer.

PACE nurses came daily to treat the ulcer, calling it a stage 2 and saying – over nearly a month – that is was getting slowly better.

But it was not.

On July 28, PACE geriatrician who served as Michael’s PCP told him she planned to admit him to a nursing home for bedrest and frequent turning to treat the pressure ulcer.

Michael agreed to go into the nursing home, thinking it would be short-term and only to treat the pressure ulcer.
On August 8, Michael was sent to a wound care nurse specialist at an academic medical center, who assessed the pressure ulcer as stage 3.

On August 18, wound care nurse specialist said the wound had improved dramatically and indicated to Michael that he could make plans for going home with continued bed rest on his circulating air mattress.

On August 23, PACE geriatrician came to see Michael in nursing home and indicated that she never planned to release him from the nursing home if he intended to continue his active lifestyle.

Geriatrician said Michael was not “safe” at home.
PACE gave Michael option to appeal their refusal to let him go home, which he did.

On September 1, results of appeal came down, stating Michael was “terminally ill”.

Decision gave Michael 3 choices:
1. Disenroll from PACE
2. Enter a different nursing home
3. Go home on “palliative care”

Document did not define “palliative care”

(Labor Day weekend)
Morning: PACE care team was to get together to come up with palliative care plan for Michael

2:00 p.m.: Michael received email from PACE saying they could not produce a “safe” care plan – partially blaming his desire to continue an active lifestyle

3:00 p.m.: PACE CEO came to Michael’s bedside in nursing home and told him:
- They would not release him from the nursing home
- They were initiating involuntary disenrollment proceedings against him
Michael contracted with local disability rights organization for legal representation

Filed appeal to Medicare’s adjudicating agency of PACE’s decision to keep him in the nursing home and not provide the same home-based services they had given him for 4 years

September 20, nursing home physician declared Michael’s pressure ulcer officially healed

Nursing home informed PACE Michael was ready for discharge, but PACE did not respond
October 2, Michael won his appeal but on October 6, PACE announced plans to contest this decision. The situation is still unfolding.
CONCLUSION

- Fundamental disconnect between how Michael lived and viewed his life – informed by independent living principles – and how geriatrician viewed his life – informed ostensibly by concerns about “safety” but also with strong hints of stigmatization and paternalism.

- Michael’s situation is increasingly common, as persons with significant disability age.

- Clinical community needs to become more aware of persons’ daily lives, their goals and preferences, and how they view safety.

- Dignity of risk principle essential to give persons with disability equal rights to determine the course of their lives as others can do.
THE ROLE OF THE BUILT ENVIRONMENT FOR SUCCESSFUL AGING WITH LONG TERM PHYSICAL DISABILITY

Philippa Clarke, PhD
Dr. E.A. Clarke, 1933-2016
Outline

• Health inequalities for people aging with a physical disability
• Conceptual models of disability
• The role of the built environment in the disablement process
• Methods to assess the demands of the built environment
Health Inequalities
Aging with Disability vs. Aging into Disability

- Increased longevity for individuals with disabilities
- Coupled with global aging
- Creates challenges for societies trying to meet the needs of both populations (Toronto Declaration, Bickenbach et al. 2012)

- Growing older with disability and growing into disability are likely to be two very different experiences
Disability and Health Data System
(CDC’s Division of Human Development and Disability)

• Compared to adults without disabilities…
  … those with disabilities are more likely to:
  • be obese
  • be sedentary
  • be current smokers
  • experience an unmet medical need due to cost

  … those with disabilities are less likely to:
  • have seen a dentist in the past year
  • have received cancer screening and other preventive services
Health Inequalities

• Over half of adults with disability do not engage in physical activity due to socio-environmental barriers:
  • equipment barriers in recreational facilities
  • negative attitudes by persons without disabilities at rec centers
  • inaccessible walking paths and sidewalks

(Rimmer, 2004)
Models of Disability
International Classification of Functioning, Disability and Health (ICF) (WHO, 2001)

- Health Condition (disease or disorder)
  - Body Functions and Structures / Impairment
  - Activity / Limitation
  - Social Participation / Restriction
International Classification of Functioning, Disability and Health (ICF)

Body Functions and Structures/Impairment

Environmental Factors
- Products & Technology
- Supports & Relationships
- Attitudes & Stereotypes
- Services & Policies
- Natural and Human-made Environments

Health Condition (disease or disorder)

Activity/Limitation

Social Participation/Restriction

Personal Factors
- Coping Styles
- Adaptation
- Activity Substitution
- Life Experiences

Inequalities

Models
“Disability is the expression of a physical or a mental limitation in a social context.”

Saad Nagi, 1965
ICF (WHO, 2001)

Health Condition (disease or disorder)

Body Functions and Structures/Impairment

Activity/Disability

Social Participation/Restriction

Environmental Factors

Built Physical Environment
The Role of the Built Environment in the Disablement Process
The Built Environment
Health Canada (2002)

“...all buildings, spaces, and products that are created or modified by people. It impacts indoor and outdoor physical environments..., as well as social environments..., and subsequently our health and quality of life.”
Mobility disability and the Urban Built Environment

Body Functions and Structures/
Lower Extremity Impairment

Activity
Outdoor Mobility

Built Physical Environment
Quality of Streets and Sidewalks

Social Participation
Survey Data

- Chicago Community Adult Health Study (CCAHS)
- Representative study of 3,105 individuals
  - aged 18 and over living in the city of Chicago
- Face-to-face interviews (72% response rate)
- Field period: May 2001 - March 2003
Measures of Socio-Environmental Context

• Systematic Social Observation (SSO) (Sampson & Raudenbush 1999)

• Direct observational method

• While walking through small respondent-centered neighborhoods, trained raters document characteristics using a standardized instrument

• E.g. presence of litter, heavy traffic, condition of buildings/streets

• SSO was conducted on 1,663 City Blocks
CHICAGO COMMUNITY ADULT HEALTH STUDY
Systematic Social Observation Coding Sheet

VERY IMPORTANT!!
On the diagram below, please circle the street numbers and write the street names to indicate the starting point of your observations. All of the block faces on the inside of the block will be coded “a” and all block faces on the outside will be coded “b.” If this diagram in no way resembles the block under observation, use the space at the bottom of the page to sketch a diagram, identifying streets with both a number and a name.

Street Name: __________________________
Street Number: 1 2 3 4

Street Name: __________________________
Street Number: 1 2 3 4

Street Name: __________________________
Street Number: 1 2 3 4

Street Name: __________________________
Street Number: 1 2 3 4

Block Face b

Block Face a

Block Face a

Block Face b

Block Face b

Block Face b
Quality of Streets and Sidewalks

2. Condition of the Street (CHECK ONE)

1) Very Poor (many sizeable cracks, potholes, or broken curbs)…
2) Fair
3) Moderately Good (no sizeable cracks, potholes, or broken curbs)
4) Very Good
Survey Measures of Impairment and Mobility Difficulty

- **Lower extremity physical impairment**
  - How much difficulty do you have... (stooping, kneeling, climbing stairs, getting up from a chair)
    - no difficulty
    - Some difficulty
    - a lot of difficulty/cannot do without help (severe)

- **Mobility Limitation**
  - “How much difficulty do you have walking 2-3 blocks by yourself?”
    - no difficulty
    - some difficulty
    - a lot of difficulty/cannot do without help (severe)
RESULTS: Odds Ratios of Risk for Severe Mobility Difficulty

* Predicted values are calculated for an African American male, age 70+, high school education, never married, living alone, with 3 chronic health problems, current smoker and economic hardship.
If street and sidewalk quality could be improved for those adults at greatest risk, disability could ostensibly be minimized or prevented.
Social Participation and the Built Environment
International Classification of Functioning, Disability and Health (ICF)
(WHO, 2001)

Health Condition
(disease or disorder)

Body Functions and Structures/Impairment → Activities/Limitations → Participation/Restriction

Urban Environment
Data: Chicago Community Adult Health Study

Survey Measures of Social Participation

• Social interaction ICFd9205
  • frequency of getting together with friends, neighbors, relatives (at least once/month vs. less)

• Voting ICFd950
  • voted in last federal and/or mayoral elections

• Obtaining preventive health care ICFd5702
  • physical exam, blood pressure check, and cholesterol check in past 2 years
Survey Measures of Impairment and Mobility Limitation

- **Lower Extremity Impairment**: difficulty stooping, kneeling, climbing stairs, getting up from a chair (movement-related activity limitations index)

- **Vision impairment**: Trouble reading or seeing over a distance (even with glasses)

- **Mobility Limitation**: Difficulty walking 2-3 blocks without help
Systematic Social Observation

- Quality of street conditions
- Residential security
- Volume of traffic
Odds Ratios for Social Interaction (Block Group Level)*
by Difficulty Walking 2-3 Blocks and Residential Security

*With controls for age, gender, race/ethnicity, marital status, education, income, chronic health conditions, smoking, BMI, vision, hearing, cognition
Odds Ratios for Obtaining Preventive Health Services (Block Group)* by Vision Impairment and Volume of Traffic

*With controls for age, gender, race/ethnicity, marital status, education, income, chronic health conditions, smoking, BMI, physical impairment, hearing, cognition, neighborhood security, neighborhood disorder, neighborhood decay, street conditions
Odds Ratios for Voting* (Tract Level) by Difficulty with Movement-Related Activities and Quality of Street Conditions

*With controls for age, gender, race/ethnicity, marital status, education, income, chronic health conditions, smoking, BMI, vision, hearing, cognition, neighborhood disorder, neighborhood decay
Summary and Implications

• Findings emphasize the importance of looking at the environment as one factor that can interact with a person’s underlying impairments or activity limitations to either limit or facilitate engagement in society.

• “Modern medicine can still not eliminate many activity limitations, but at least in theory, with the right assistive devices, personal assistance, social support, policies, and environment, people with disability can fully participate in society”.  
  Whiteneck and Dijkers (2009)
Methods to assess the demands of the built environment:
Using the Internet to conduct a Virtual Neighborhood Audit
Optimizing Mobility in Later Life: The Role of the Urban Built Environment for Older Adults Aging in Place

Philippa Clarke and Nancy Ambrose Gallagher
Purpose

• How do 15 month trajectories of outdoor mobility disability vary by built environment characteristics?

• Focus on 1188 vulnerable older adults (age 55+) in central Detroit:
  • Mean age = 77.0 years (±12.3)
  • 70.2% Female
  • 77.8% African American
  • 45.7% Living alone
  • On average, participants have over 3 (±1.8) chronic health conditions
  • 85% have unsteady gait
  • 56% report fear of falling outdoors
  • 23% have barriers at the entry to their home (e.g. unstable front stairs)
Built Environment Data

• Neighborhood audit of all 4 streets in each participant’s residential block

• SSO with Google Street View

  • Indicators of built physical and social environment can be reliably assessed with a virtual audit instrument (Clarke, 2010)

  Observed agreement = .60-.96 (Kappa=.11-.93)
### QUESTIONS ABOUT ENTIRE STREET

<table>
<thead>
<tr>
<th>Question</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>5. Is there a public transportation stop on the street?</strong></td>
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<td>(e.g. bus stop or rail station)</td>
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<tr>
<td>1) Yes</td>
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<tr>
<td>2) No</td>
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<td><strong>6. If yes, are there any amenities at the transportation stop?</strong></td>
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<tr>
<td>1) Benches</td>
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<tr>
<td>2) Shelter</td>
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<tr>
<td><strong>7. Quality of Sidewalks (CHECK ALL THAT APPLY)</strong></td>
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<tr>
<td>1) Sidewalks are in place on both sides of the street</td>
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<td>2) Sidewalks are continuous (no missing segments)</td>
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<td>3) Sidewalks are smooth/flat/unbroken</td>
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<td>4) Sidewalks are free from obstructions</td>
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<tr>
<td>(e.g. poles, signs, shrubs, tree roots, cars, etc.)</td>
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<tr>
<td>5) Sidewalks are wide enough for two people to pass comfortably</td>
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<tr>
<td><strong>8. Crossing Streets (CHECK ALL THAT APPLY)</strong></td>
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<tr>
<td>1) There are pedestrian crossing signals at intersections</td>
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<tr>
<td>2) Crosswalks are marked/striped</td>
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<tr>
<td>3) Crosswalks are visible</td>
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<tr>
<td>4) There are curb cuts/ramps</td>
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</tbody>
</table>
Built Environment Variable
(derived from the SWEAT-R, Michael, et al. 2009)

• Summary accessibility score:
  • Sidewalks in place on both sides of street
  • Sidewalks are continuous (no missing segments)
  • Sidewalks are smooth/flat/unbroken
  • Sidewalks are free from obstructions (poles, tree roots, etc.)
  • Wide enough for two people to pass (≥1.5m)
  • Public transportation stop on the street

• For each street, calculate summary score (range 0-6)
• Create mean across all (4) streets in the participant’s block (high score = more accessible built environment)
Results from Google Street View

• Summary Accessibility Score (range 0-6) = 3.52 ± 1.19
• Proportion of Streets with:
  - Sidewalks in place on both sides of street 83%
  - Continuous sidewalks 68%
  - Smooth/flat/unbroken sidewalks 54%
  - Sidewalks free from obstructions 64%
  - Sidewalk width ≥1.5m 68%
  - Public transportation stop on the block 31%
Dependent Variable: Outdoor Mobility

- Number of days a participant goes outdoors in a typical week (mean=$1.6 \pm 1.7$)
  - Every day 1.5%
  - 2-6 days 27.8%
  - Once 38.2%
  - Never 32.5%
Trajectories of Outdoor mobility

FIGURE 1. Predicted number of days outdoors based on two-class Poisson growth mixture model. Michigan Minimum Data Set for Home Care: Detroit residents age 55+ (n=1,188).
## Logistic Regression for Latent Class Membership:

<table>
<thead>
<tr>
<th>Latent Class 1† (Almost Never Goes Out)</th>
<th>Coefficient</th>
<th>OR (95% CI)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (years)</td>
<td>.03*</td>
<td>1.03 (1.01, 1.05)</td>
</tr>
<tr>
<td>Femalea</td>
<td>-.09</td>
<td>0.91 (0.55, 1.52)</td>
</tr>
<tr>
<td>African Americanb</td>
<td>-.18</td>
<td>0.84 (0.31, 2.28)</td>
</tr>
<tr>
<td>Self-Care Difficulty</td>
<td>.46***</td>
<td>1.58 (1.24, 2.01)</td>
</tr>
<tr>
<td>Mobility Impairment</td>
<td>.25**</td>
<td>1.29 (1.09, 1.51)</td>
</tr>
<tr>
<td>Chronic Health Conditions</td>
<td>-.06</td>
<td>0.95 (.82, 1.09)</td>
</tr>
<tr>
<td>Vision Impairment</td>
<td>.28*</td>
<td>1.32 (1.06, 1.66)</td>
</tr>
<tr>
<td>Barriers at Entry to Home</td>
<td>.40‡</td>
<td>1.49 (.93, 2.47)</td>
</tr>
<tr>
<td><strong>Urban Accessibility Score</strong></td>
<td>-.16*</td>
<td>0.85 (0.71, .99)</td>
</tr>
</tbody>
</table>

* p<.05  ** p<.01  *** p<.001  ‡ p<.10 (two-tailed tests)

Latent Class 2 (occasionally goes outdoors) is the reference class

Reference group is Male

Reference group is White
Summary and Implications

• Growing interest in developing interventions to help older adults remain in their own homes and out of long-term care institutions.

• Maintaining outdoor mobility is an important step in preventing disability and institutionalization.

• Older adults living on a block with accessible sidewalks and a public transit stop were significantly more likely to leave their home to go outside.

• Outdoor accessibility is meaningless if people cannot get out their front door.
Conclusions
Conclusions

• Need for an integrated approach to prevent disability at multiple levels:
  • Body
  • Person
  • Environment – with consideration of multiple barriers (street and sidewalk quality, safe communities, weather)
The Social Construction of Disability

“Disability is a function of the gap between a person’s capabilities and the demands created by the physical and social environment.”

Saad Nagi, 1965
Acknowledgements

UM Collaborators
James House, Jeff Morenoff, Neil Alexander, Nancy Gallagher

• K01 EH000286-01

• R01 AG018418-08A2
• R03 AG04366102
Thank you!

pjclarke@umich.edu
Join us for the final session!

- **Date**: Friday, October 20th, 12-2 p.m. EST/9-11 a.m. PST ([Register](#))

- **Focus**: Healthcare policy, and implications for adults aging with long-term disability.

- **Presenters**:
  - Margaret Campbell (Campbell & Associates)
  - Tamar Heller (University of Illinois Chicago)
  - Michelle Putnam (Simmons College)