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

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Acknowledgements

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

The 30,000 foot view...
The ICF Framework on Disability

World Health Organization, 2002
Advantages to the ICF Framework

- Moves away from the medical model, incorporates social models of disablement
- “Mainstreams” experience of disability; ability is seen as a continuum
- Standardizes measurement and language, allowing for international, epi and policy level analysis
- Emphasizes level of function and participation over medical diagnosis
Diagnosis doesn’t matter. Timing matters.

- Age at onset of impairment/disability
- Position in the life course at onset
- Duration of impairment/disability
- Course/trajectory of impairment/disability
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 3 (Friday):
Healthcare policy implications for adults aging with long-term disability
Day 3 Presenters

Margaret Campbell
*Campbell & Associates*

Tamar Heller
*University of Illinois, Chicago*

Michelle Putnam
*Simmons College*
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.
Drivers of Improved Health Policy and Programs for Adults
Aging with Long-Term Disabilities:
What’s In Place, What’s Missing & What’s Needed

Margaret L. Campbell, PhD
Campbell & Associates Consulting –
Bridging Aging and Disability Research & Policy

Presented as part of the University of Washington, RRTC on Healthy Aging with Physical Disability State of the Science Webinar Series,
Sponsored by NIDILRR & NCOA
October 20, 2017
What’s in Place: Drivers of Recent Progress in Health Policy & Programs for Aging with Disability:
• Emerging consensus in research literature re: definition, size & timing of AwD
• Increased national data sources & knowledge of disability demographics
• Passage of the Affordable Care Act (ACA) & Creation of ACL
• Increased awareness and understanding of the health risks of AwD
• Emerging models of “successful aging with disability”

What’s Missing: Barriers to Improved Health Policy and Programs:
• Lack of nationally representative health surveys & large-scale predictive models of AwD
• Lack of inclusion of disability in major health promotion/disease prevention initiatives
• Lack of interventions research and EB programs to improve health outcomes
• Insufficient coordination between aging and disability agencies and networks
• Lack of cross-training in aging and disability for researchers and service providers

What’s Needed: Narrowing the Gaps in Health Policy and Programs:
• Expansion of “Community Living” policies and regulations to incorporate health
• Greater investment in national epidemiological & longitudinal data on AwD
• Greater investment in intervention studies and translational research and dissemination
• Greater investment in implementation and scale-up evaluations

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What’s In Place: Drivers of Recent Progress

Emerging Consensus re: Definition, Size & Timing of AwD:

- **Definition of Aging with Disability**: While there is no empirical standard for defining who is aging with disability, general consensus is that the term refers to people living with the long-term effects of disabilities acquired from birth to early middle-age who are now surviving into mid- and later life (Verbrugge & Yang, 2002; Molton et al., 2012; Iezzoni et al., 2014).

- **Size of Aging with Disability Population**: Although precise statistics are not available due to variations in definitions of disability and gaps in national data systems, the most recent inference for the U.S. suggests that between 12-13 million adults 18 years and older are living with an activity limitation acquired before age 40 (Verbrugge & Yang, 2002; LaPlante, 2014).

- **When Does Aging with Disability Begin, Ages 45-55**: Despite the lack of national statistics, emerging research indicates that with increasing age people with early onset of disability start to report greater difficulty associated with their main condition, beginning at ages 45-55 during the peak of their working careers (Verbrugge & Yang, 2002; Molton et al., 2012; Verbrugge et al., 2007).
What’s In Place: Drivers of Recent Progress

- **Increased National Data Sources Using the 6-Item Measure of Disability** (Sensory, Physical health, Mental health, Self-Care, Independent living, and Employment disabilities).
  - *American Community Survey (ACS)*: a continuous data collection effort conducted by the U.S. Census Bureau and used to produce annual estimates at the national, state and local level on population characteristics. Replaces the decennial Census long form.
  - *Current Population Survey (CPS)*: survey of about 50,000 households in the U.S., conducted on behalf of the Bureau of Labor Statistics. Primary source of labor force and income statistics, and used by government agencies, researchers, policy makers, and journalists to evaluate employment, government programs, and economic well-being and behavior of individuals, families and households.
  - *Survey of Income and Program Participation (SIPP)* – a longitudinal survey conducted over 3 to 5 years. During “wave” supplemental “topical modules (TM)” touch on different topics (i.e., Work History Disability, Child and Adult Functional Limitations). In the 2008 SIPP, the six disability questions were added to the Medical Expenses and Utilization of Health Care TM (waves 4/7/10).

- **Increased Disability Statistics Resources:**
  - *2016 Annual Disability Statistics Compendium* - a web-based tool that pools disability statistics published by various federal agencies together in one place.
  - *Cornell University Online Resource for Disability Statistics*
  - *Campbell & Associates Consulting – Bridging Aging and Disability Research and Policy*
What’s In Place: Drivers of Recent Progress

- **Increased Knowledge re: Demographics of Disability & Aging**
  - **Overall prevalence**: In 2014, 39.9 million or 12.6% of the community living population 5 years or older reported having a disability (Ward et al., 2014).
  - **Increased prevalence**: total # of non-institutionalized civilians 18 and older reporting disability increased by 2 million between 2005 & 2010 (Brault, 2010).
  - **Disability prevalence increases by age**: from 10.7% for persons age 21–64 years to 25.4% for age 65–74 years and 49.8% for ages 75 and over (Groah et al., 2012).
  - **Intersection of Disability & Aging**: 30% of individuals with disabilities report experiencing onset at age 44 or younger; 13% of 15–64 yr. olds reported disability onset at birth; and half of all persons age ≥65 reported having activity limitations before age 65 (Brault, 2010; Verbrugge, 2017).
  - **Potential Increases in Life Expectancy**: Clinical research studies and observations indicate that persons with early and mid-life significant disability may have increased life expectancy, with individuals with physical disability approaching nearly normal life spans (Brault, 2010; Groah et al., 2012) and those with I/DD now routinely live beyond 50 (Klingbeil et al., 2004).
What’s In Place: Drivers of Recent Progress

- Improved Awareness & Understanding of Health Risks of AwD:
  - **Secondary conditions,** “any additional physical or mental health conditions resulting directly or indirectly from a primary disabling condition that may threaten independence and community living, but that are not a diagnostic feature of that condition” (IOM, 1991; Field & Jette, 2007).
  
  - **Relationship to Age-Related Chronic Conditions:** “Indirect secondary conditions” experienced by people living with long-term disability, which are due in part to duration of the initial impairment, overuse, sedentary life styles, environmental barriers, and poor health behaviors, are frequently the same as the age-related chronic conditions experienced by the aging population at large. (Molton et al., 2012; Jensen et al., 2013).
  
  - **Timing of Onset of Secondary Conditions:** While precise data are not available, clinical and small-scale survey research indicate that the high rates of secondary and age-related chronic conditions experienced by people with long-term disability typically occur in middle-age, between 45- and 55, or about 20-25 years sooner compared to peers without disabilities (Field & Jette, 2007; Kemp & Mosqueda, 2012; Jensen et al., 2013).
What’s In Place: Drivers of Recent Progress

-- Improved Awareness & Knowledge of Health Risks

Common Disability-Related Secondary Conditions:
- Chronic pain & fatigue
- Bowel or bladder problems
- Pressure sores or ulcers
- Respiratory disorders
- Depression
- Osteoporosis
- Arthritis
- Diabetes
- Hypertension/Heart Disease
- Falls & fractures
- New mobility limitations
- Sensory Impairment
- Cognitive impairment

Shared Conditions:
- Joint pain/Arthritis
- Hypertension
- Diabetes
- Mobility limitations (gait & balance)
- Falls & fractures
- Skin Breakdowns
- Depression
- Vision/hearing impairments
- Cognitive limitations

Common Age-Related Chronic Conditions:
- Hypertension
- High Cholesterol
- Diabetes
- Arthritis
- Heart Disease
- Gait & balance problems
- Falls
- Respiratory infections/COPD
- Urinary incontinence
- Osteoporosis
- Skin breakdowns
- Vision Loss
- Hearing Loss
- Dementia
What’s In Place: Drivers of Recent Progress

Passage of the 2010 Affordable Care Act (ACA):

- The ACA Stipulates Improved Data Collection on People with Disabilities: Although non-funded, this provision requires the collection of data on “disability status for all applicants, recipients, or participants, regardless of age, by any federally conducted or supported health care or public health program, activity or survey;” and, thus serves as an incentive to inform improved health policies and programs for people with disabilities of all ages.

- The ACA established the Prevention and Public Health Fund (PPHF) – a grant program to support transformational investments in promoting wellness, preventing disease, and supporting the delivery of evidence-based and community-based prevention services for older adults and individuals with disabilities (e.g., Chronic Disease Self-Management Program).

- Implementing regulations associated with the ACA,

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What’s In Place: Drivers of Recent Progress

❑ Passage of the 2010 Affordable Care Act (ACA):

- Title IV of the ACA established ‘Prevention of Chronic Disease and Improving Public Health’ as a primary goal the nation’s health care system by:
  - removing financial barriers and increasing access to preventative healthcare services;
  - creating the Prevention and Public Health Fund (PPHF) to support transformational investments in promoting wellness, preventing disease, and supporting the delivery of evidence-based and community-based prevention services for older adults and individuals with disabilities; and
  - requiring development of a stronger evidence based on effective prevention programming.
- While there are ongoing calls for revisions and the repeal of the ACA, which may reduce funding or eliminate these provisions, the costs of chronic disease at the state and federal level are well documented (Trogdon et al., 2015) and may be persuasive in continuing the emphasis on the health promotion program regardless of any political discord.

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What’s In Place: Drivers of Recent Progress

- Creation of the Administration for Community Living (ACL):
  - **ACL was established in 2012** within the U.S. Department of Health and Human Services (HHS) and initially brought together the Administration on Aging (AoA), the Administration on Intellectual/DD, and the Office on Disability to serve as the federal agency responsible for increasing access to community supports for older Americans and people with disabilities.
  - **The mission was strengthen** in 2014 with the Passage of the Workforce Innovation and Opportunity Act (WIOA), which moved NIDRR to ACL under the changed name of the National Institute on Disability, Independent Living and Rehabilitation Research (NIDILRR). Thus, giving ACL a “research arm” to advance knowledge of the lived experience of aging with disability and “what works” to improve community living and health and wellness outcomes for this population.
  - **Since 2014**, a number of other federal programs and offices (e.g., Centers for Independent Living, Assistive Technology Act Program, Paralysis Resource Center, Protection & Advocacy Systems) have joined ACL further strengthening the agency’s ability to protect the rights of older adults and people with disabilities and provide a broad range of community based supports and services to both target populations.
What’s In Place: Drivers of Recent Progress

Examples of Health & Wellness Programs Funded by ACL:

- **Chronic Disease Self-Management** (CDSMP) - provides people with disabilities and older adults with education and tools to help them manage chronic condition.
- **Aging and Disability Evidence-Based Programs and Practices** (ADEPP) – purpose is to provide information that helps the public learn more about available evidence-based programs and practices in the areas of aging and disability and determine which of these may best meet their needs and reduce the lag time between creation of scientific knowledge and its practical application in the field.
- **Disease Prevention and Health Promotion Services** – under Title III-D of the Older Americans Act (OAA) provides formula grants to states and territories for evidence-based programs – required by the 2012 Congressional appropriations law -- to promote healthy behaviors & lifestyles of older adults only.
- **Falls Prevention** -- Financed by the Prevention and Public Health Fund, provides grants to public and private nonprofit entities, including state agencies and community organizations, to use evidence-based community programs to reduce falls -- a leading cause of injury -- for older adults only.

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What’s In Place: Drivers of Recent Progress

- **Emerging Models of “Successful Aging with Disability”:**
  - Using both qualitative and quantitative data from in-depth interviews and pilot intervention studies, the RRTC on Healthy Aging with Physical Disability is modifying the concept of “successful aging” to reflect what it means for adults aging with long-term disabilities.
  - Instead of emphasizing the “avoidance of chronic disease and disability”, key components of the original model of successful aging (Rowe & Kahn, 200) findings from the RRTC stress the following (Molton & Yorkston, 2017):
    - Psychology resilience and flexibility
    - Autonomy & choice
    - Health as necessary for community living
    - Maintenance of current health status in the context of secondary and age-related chronic conditions
    - Effective compensation for functional impairment
    - Access to primary healthcare and rehabilitation services that is accessible, appropriate, tailored to people with disabilities, and provided by knowledgeable providers, and
    - Social connectedness.
What’s Missing: Barriers to Improved Health Policy & Programs for AwD

☐ Gaps in Available Data:

- **Lack of national health surveillance surveys & longitudinal data systems** that extend across the life course and include measures of disability that allow us to more accurately estimate the prevalence of U.S. population aging with and aging into disability and to monitor changes in health and function, participation, and needs for services and supports.

- **Lack of questions on the temporal structure** of disability (e.g., age of onset and/or duration of primary disability) which limits our understanding of the Lived experience: of aging with and aging into disability (LaPlante, 2014; Freedman, 2014).

- **Lack of validated measures of secondary conditions** and age-related to chronic conditions that would allow us to estimate the prevalence of health problems within and between disability groups as well as across the life span and in comparison to non-disabled counterparts.
What’s Missing: Barriers to Improved Health Policy & Programs for AwD

Q Gaps in Research Investments:
   • Historic lack of federal funding for intervention development and efficacy studies for disability.
   • Lack of priority on translational/implementation research for disability to create new or adapt existing EB health interventions for adults with long-term disabilities that are ready to be tested in community based settings.

Q What is Translational Research? – No Agreed Upon Definition
   • The NIH Roadmap: Defines two types of TR:
     o Type 1: translational research is scientific research that helps to make evidence from basic and clinical science useful for practical applications that enhance human health and well-being (Khoury MJ. et al. (2007)).
     o Type 2, has received much less attention and funding, and is concerned with the adoption, implementation and sustainability of evidence-based interventions in community settings (Wolf, 2007; 2008).
What’s Missing: Barriers to Improved Health Policy & Programs for AwD

☐ What is Translational Research? (contd.)
  • *NIA-AoA 2014 Funding Opportunity Announcement*: Defines translational research in terms of “moving evidence-based findings” from one stage of research or one target population to another to encourage the “development of new EB interventions, programs, policies, practices, and tools that can be used by community-based organizations to help older adults remain healthy and independent, and living in the community” (*PA-11-123, 2011 & PA-14-161*).

☐ Why is TR Important? – Response to the “17 year Problem”
  • Provides methods and strategies to accelerate “the time it takes for research evidence to reach clinical practice” (Balas & Boren, 2000).

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What’s Missing: Barriers to Improved Health Policy & Programs for AwD

- Gaps in Evidence-Based Programs:
  - Supply and Demand Problem: Despite significant progress on both legislative and policy fronts, a significant gap exists between the “demand” or requirements for EB health and wellness programs and their “supply” in community settings where people with disabilities and older adults want to live.
  - Most Significant Gaps: While this imbalance exists for both older adults and people with disabilities, the gap is more pronounced for middle aged individuals with long-term disabilities, who tend to fall through the cracks in service delivery systems, than it is for their older counterparts with and without disabilities.

- Examples of Gaps in EB Programs:
  - A scoping review of the National Council on Aging (NCOA) Center for Healthy Aging database, containing all the health promotion programs that meet the ACL criteria for evidence-based found that only 2 of the 150 randomized controlled trials listed included middle-aged adults with LT disabilities (Molton et al, 2014).
  - Of 12 health promotion interventions listed on ACL’s Aging and Disability Evidence-Based Programs (ADEPP) website none have been tested and demonstrated to be effective for adults aging with LT disabilities.
What’s Missing: Existing Barriers to Improving Health Policy for AwD

- Consequences of Gaps in Supply and Demand for EBP:
  - Despite ACL’s mission to maximize the “... well-being and health of older adults and people with disabilities across the lifespan,” people aging with long-term disabilities are less likely to receive EB health promotion programs in community settings compared to their older adults with and without activity limitations.
  - The Resulting paradox, new polices requirement for EB programming associated with the ACA are nullified without the availability of EB health promotion interventions for adults aging with disability and without evidence on how to translate and implement these interventions in community settings.
    - This is particularly true for middle-aged individuals with disabilities, between the ages of 45 and 55, who tend to fall through the divide in aging and disability service systems.

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What’s Needed to Narrow the Gaps & Improve Health Policy and Programs for AwD:
Conclusions: Changes Needed to Narrow Gaps

- Changes in Federal Infrastructure Priorities & Investments:
  - *Create* or improve interagency mechanisms to:
    - support increased awareness and coordination of disability research across the life cycle and at the intersection of aging and disability
    - encourage the iterative progression of research on aging with disability from intervention development and efficacy studies to translation and implementation
  - *Establish* support (funding, infrastructure, incentives) for adoption of EB programs and practices and long-term evaluations
  - *Seek and develop partnerships and collaborations* that provide the resources and platforms necessary to support community based research and implementation of EB health promotion programs for individuals aging with disabilities across the life cycle.
  - *Focus* training and mentoring of emerging disability scholars and senior researchers alike to become interventionists and knowledgeable in the application of translational and implementation science.

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Conclusions: Changes Needed to Narrow Gaps

- Changes in Federal Data & Research Priorities and Investments
  - Expand the number of existing national health surveys that include measures of disability status and characteristics.
  - Expand the age range of longitudinal data systems to support the examination of disability across the life span and encourage development of predictive models of “healthy aging with disability” (e.g., Health and Retirement Survey (HRS) and the National Health and Aging Trends Survey (NHATS)).
  - Create incentives to expand sample sizes for health intervention research to strengthen effect size.
  - Increase the priority on funding efficacy studies to expand the supply of EB health interventions appropriate for adults aging with long-term disability.
  - Increase the priority on funding translational research studies aimed at adapting new or existing EB health interventions and testing efficacy for adults aging with long-term disabilities in home and community settings.
  - Increase the priority on funding implementation studies and scale-up evaluations of EB health programs demonstrated to be effective for aging with disability populations in community settings.
THANK YOU!

For comments & questions please contact:

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Campbell & Associates Consulting
Email: Margaret@Campbell.Associates
Key References


• Kassner, E. (2011). AARP Fact Sheet 222: Home and Community -Based Long -Term Services and Supports for Older People. AARP Public Policy Institute,. Available at: https://assets.aarp.org/rgcenter/ppi/ltc/fs222-health.pdf (accessed October 13, 2017)

Key References (contd.)

- Trogdon, J.G.; Murphy, L.B.; Khavjou, O.A.; Li, R.; Maylahn, C.M.; Tangka, F.K.; Orenstein, D. Costs of chronic diseases at the state level: The chronic disease cost calculator. Prev. Chronic Dis. 2015, 12, 150131. [CrossRef] [PubMed]
Aging with a Physical Disability in Medicaid Managed Healthcare

Tamar Heller, PhD, Randall Owen, PhD, & Caitlin Crabb, MPH
Department of Disability and Human Development, University of Illinois at Chicago
Introduction

• Many states transitioning adults with disabilities on Medicaid from Fee-for-Service (FFS) to Managed Care (MMC) for health and long-term services and supports (LTSS)
• Most states initially focused on families and children for enrollment in MMC; expanded to focus on aged, blind, and chronically ill
• Little research on adults with disabilities, specifically aging adults with physical disabilities transitioning to MMC
• 2010: 47 states implemented managed care covering 71% of Medicaid enrollees
Managed Care Triple Aim

- Reducing Medicaid expenditures
- Improving enrollee experiences with their care
- Improving the health of the population

Key methods:
- Capitation
- Emphasis on care coordination and primary care
Integrated Care Program (ICP)

• Mandatory managed care for Medicaid-only seniors and people with disabilities
• Began in 2011 with 40,000 people in Chicago suburbs
• Service Package 2 (managed LTSS) included in 2014
• Expanded in 2014 to include Chicago (with another 60,000 enrollees)
Evaluation Overview

- Solicits input from stakeholders / participatory process
- Uses quantitative and qualitative data
- Process evaluation
  - MCO capacity
  - Capacity building framework & focus groups
- Outcome evaluation
  - Encounter data
  - Quality of care
  - Consumer Survey
Evaluation Components

**Data Sources**
- Consumer Surveys
- Encounter Data
- Focus Groups
- MCO Data

**Stakeholders**
- Consumers & Families
- Advocates
- MCOs
- Providers
- State Agencies

**Evaluation Types**
- Process
- Outcomes
- Economic Impact

Advisory Board
Data Sources

• Consumer Survey
• FFS claims
• Managed Care Organization (MCO) claims
• MCO reports to Medicaid Agency (Health and Family Services)
• Health Services Advisory Group (HSAG) external reviews
• MCO special datasets to research team
• Capitated payments to MCOs
• Stakeholder meeting feedback
• Focus groups in first year of transition to ICP
Consumer Experiences
Research Questions: Consumer Experience

• Among adults aged 50 or over with physical disabilities, does enrollment in MMC versus FFS relate to enrollees’ health services appraisal (HSA) and perceived unmet health-care needs?

• Within MMC, which aspects of MMC health-care processes (continuity of care, PCP attitudes and knowledge, and attitudes of care coordinators) relate to HSA and perceived unmet health-care needs of adults aged 50 or over with physical disabilities?
Methods: Consumer Survey

- Surveys: 309 in MMC and 349 in FFS two years after MMC began
- Independent Measures:
  - Demographics (gender, race, health status, age)
  - Group status (MMC, FFS)
  - MMC processes (only for MMC enrollees)
    - Continuity of care (whether could see the same doctors after MMC)
    - Experience with care coordinators (CC) (input in care plan, whether wishes taken into account, knowledge of CC)
    - Experience with PCPs (whether up-to-date about services from specialists, knowledge of PCP about disability, whether wishes taken into account)

(Heller, et al., 2015)
Outcome Measures

• Unmet healthcare needs
  • Count of unmet healthcare needs out of 18
  • E.g. allergist, physical therapist, optometrist
• Healthcare services appraisal (HSA)
  • Scale of 6 items
  • Satisfaction with: overall healthcare, PCP, specialists, care coordination, medical/specialty care, and quality of healthcare

(Owen, Heller, & Bowers, 2016)
Table 1. Respondent Demographics

<table>
<thead>
<tr>
<th>Demographic</th>
<th>MMC (n=309)</th>
<th>FFS (n=349)</th>
<th>Significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>106 (34.3%)</td>
<td>141 (40.6%)</td>
<td>$\chi^2=2.790;$ df=1; $p=.095$</td>
</tr>
<tr>
<td>Female</td>
<td>203 (65.7%)</td>
<td>206 (59.4%)</td>
<td></td>
</tr>
<tr>
<td>Race</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>120 (38.8%)</td>
<td>35 (10.0%)</td>
<td>$\chi^2=75.524;$ df=1; $p=.000^{**}$</td>
</tr>
<tr>
<td>Health status</td>
<td>Mean=23.61; SD=6.10</td>
<td>Mean=24.47; SD=6.30</td>
<td>$p=.082$</td>
</tr>
<tr>
<td>Age</td>
<td>Mean=60.11; SD=7.75</td>
<td>Mean=59.05; SD=6.38</td>
<td>$t=-1.915; df=656; p=.056$</td>
</tr>
</tbody>
</table>

Note. n = 658. MMC = Medicaid managed care; FFS = fee for service.  
*p < .05. **p < .01.

(Heller, Owen, Bowers, & Gibbons, 2017)
Table 2. Health Services Appraisal and Unmet Needs Regressions for Aging People With Physical Disabilities (MMC and FFS)

<table>
<thead>
<tr>
<th>Variable</th>
<th>OLS Regression: HSA</th>
<th>Poisson Regression: Unmet Needs</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Beta</td>
<td>Significance</td>
</tr>
<tr>
<td>Age</td>
<td>-.001</td>
<td>.556</td>
</tr>
<tr>
<td>Gender (female vs. male)</td>
<td>-.003</td>
<td>.871</td>
</tr>
<tr>
<td>Race (minority vs. White)</td>
<td>-.033</td>
<td>.190</td>
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<tr>
<td><strong>Health status</strong></td>
<td><strong>.006</strong></td>
<td><strong>.000</strong>**</td>
</tr>
<tr>
<td>Enrollment in MMC</td>
<td>.027</td>
<td>.215</td>
</tr>
<tr>
<td>R²</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Note. HSA = health services appraisal; MMC = Medicaid managed care; FFS = fee for service. *p < .05. **p < .01

(Heller, Owen, Bowers, & Gibbons, 2017)
Table 3. Health Services Appraisal Regressions for Aging People With Physical Disabilities (MMC Only)

<table>
<thead>
<tr>
<th>Variable</th>
<th>HSA</th>
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<tr>
<td></td>
<td>β</td>
<td>Significance</td>
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<tr>
<td>Age</td>
<td>-.002</td>
<td>.395</td>
</tr>
<tr>
<td>Gender (female vs. male)</td>
<td>-.017</td>
<td>.548</td>
</tr>
<tr>
<td>Race (minority vs. White)</td>
<td>-.018</td>
<td>.536</td>
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<tr>
<td>Health status</td>
<td>.009</td>
<td>.001**</td>
</tr>
<tr>
<td>Continuity of Care&lt;sup&gt;a&lt;/sup&gt;</td>
<td>-.056</td>
<td>.001**</td>
</tr>
<tr>
<td>Experience with Care Coordinators</td>
<td>.031</td>
<td>.000**</td>
</tr>
<tr>
<td>Experience with PCPs</td>
<td>.021</td>
<td>.020*</td>
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<tr>
<td>R²</td>
<td></td>
<td>0.218</td>
</tr>
</tbody>
</table>

Note. HSA = health services appraisal; PCPs = primary care physicians.  
<sup>a</sup>Continuity of care is negatively coded.  
*p < .05. **p < .01.

(Heller, Owen, Bowers, & Gibbons, 2017)
Table 4. Poisson Regression: Unmet Health-Care Needs of Aging People With Physical Disabilities (MMC Only)

<table>
<thead>
<tr>
<th>Variable</th>
<th>Unmet Health-Care Needs</th>
<th>95% Confidence Interval</th>
<th>Significance</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Exp((\beta))</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>.973</td>
<td>[0.944 - 1.002]</td>
<td>.070</td>
</tr>
<tr>
<td>Gender (female vs. male)</td>
<td>1.185</td>
<td>[0.832 - 1.688]</td>
<td>.347</td>
</tr>
<tr>
<td>White (minority vs. White)</td>
<td>1.644</td>
<td>[1.164 - 2.320]</td>
<td><strong>.005</strong></td>
</tr>
<tr>
<td>Health status</td>
<td>.948</td>
<td>[0.922 - 0.974]</td>
<td><strong>.000</strong></td>
</tr>
<tr>
<td>Continuity of care(^a)</td>
<td>1.167</td>
<td>[0.937 - 1.453]</td>
<td>.167</td>
</tr>
<tr>
<td>Experience with care coordinators</td>
<td>.937</td>
<td>[0.880 - 0.999]</td>
<td>.046*</td>
</tr>
<tr>
<td>Experience with PCPs</td>
<td>.905</td>
<td>[0.810 - 1.010]</td>
<td>.075</td>
</tr>
</tbody>
</table>

Note. PCPs = primary care physicians. \(^a\)Continuity of care is negatively coded. *p < .05. **p < .01.

(Heller, Owen, Bowers, & Gibbons, 2017)
Table 5. Unmet Needs for Healthcare Services for 50+

<table>
<thead>
<tr>
<th>Category Items</th>
<th>MMC (n=309)</th>
<th>FFS (n=349)</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dental</td>
<td>121 (39.2%)</td>
<td>158 (45.3%)</td>
<td>.113</td>
</tr>
<tr>
<td>Physical Therapy</td>
<td>63 (20.4%)</td>
<td>72 (20.6%)</td>
<td>.939</td>
</tr>
<tr>
<td>Dietician*</td>
<td>53 (17.2%)</td>
<td>83 (23.8%)</td>
<td>.036*</td>
</tr>
<tr>
<td>Podiatrist</td>
<td>47 (15.2%)</td>
<td>69 (19.8%)</td>
<td>.126</td>
</tr>
<tr>
<td>Home Health Service*</td>
<td>34 (11.0%)</td>
<td>60 (17.2%)</td>
<td>.024*</td>
</tr>
<tr>
<td>Occupational Therapy*</td>
<td>32 (10.4%)</td>
<td>55 (15.8%)</td>
<td>.041*</td>
</tr>
<tr>
<td>Skin Doctor</td>
<td>30 (9.7%)</td>
<td>33 (9.5%)</td>
<td>.912</td>
</tr>
<tr>
<td>Allergist</td>
<td>29 (9.4%)</td>
<td>28 (8.0%)</td>
<td>.535</td>
</tr>
<tr>
<td>Neurologist</td>
<td>28 (9.1%)</td>
<td>32 (9.2%)</td>
<td>.962</td>
</tr>
<tr>
<td>Psychiatrist</td>
<td>27 (8.7%)</td>
<td>21 (6.0%)</td>
<td>.180</td>
</tr>
<tr>
<td>Cardiologist</td>
<td>26 (8.4%)</td>
<td>20 (5.7%)</td>
<td>.178</td>
</tr>
<tr>
<td>Psychologist</td>
<td>24 (7.8%)</td>
<td>20 (5.7%)</td>
<td>.297</td>
</tr>
<tr>
<td>Behavioral Health Counseling</td>
<td>22 (7.1%)</td>
<td>37 (10.6%)</td>
<td>.119</td>
</tr>
<tr>
<td>Surgeon</td>
<td>13 (4.2%)</td>
<td>13 (3.7%)</td>
<td>.751</td>
</tr>
<tr>
<td>Speech Therapy</td>
<td>11 (3.6%)</td>
<td>21 (6.0%)</td>
<td>.144</td>
</tr>
<tr>
<td>Non-Residential Substance Abuse Treatment</td>
<td>11 (3.6%)</td>
<td>20 (5.7%)</td>
<td>.190</td>
</tr>
<tr>
<td>Oncologist</td>
<td>9 (2.9%)</td>
<td>15 (4.3%)</td>
<td>.344</td>
</tr>
<tr>
<td>Residential Substance Abuse Treatment</td>
<td>8 (2.6%)</td>
<td>14 (4.0%)</td>
<td>.311</td>
</tr>
</tbody>
</table>

Note. MMC = Medicaid managed care; FFS = fee for service.
*p < .05. **p < .01

(Heller, Owen, Bowers, & Gibbons, 2017)
Results

• The transition from FFS to MMC did not significantly impact HSA or unmet healthcare needs

• Health status, experience with care coordinators, experience with PCPs, and continuity of care significantly impacted HSA for people aging with a PD in MMC

• Race, health status, and experience with care coordinators significantly impacted unmet healthcare needs

(Heller, Owen, Bowers, & Gibbons, 2017)
Qualitative Results

• Positive aspects
  • “Excellent services. I received periodic calls from my health care social worker.”
  • “They are very helpful in serving me.”

• Negative aspects
  • “My health is very poor and getting no better because of insurance, some doctors will help.”
  • “The most recent transportation companies either did not show up or were late.”
  • “Dental service poor – quality dentures and service.”
Summary of Consumer Experience

- Disparities for non-white racial minorities
- Importance of respectful and knowledgeable care coordinators and PCPs
- Need for continuity of care
Expenditures and Utilization
Research Questions: Costs and Health Service Use

• What are the differences in cost and service utilization (emergency room, in-patient hospitalization, outpatient visits) for adults with physical disabilities in MMC versus in FFS?

• Are there differential effects for older (age 46 and above) versus younger adults in MMC versus FFS in regard to costs and service utilization?
<table>
<thead>
<tr>
<th>Condition</th>
<th>Suburban Group (n = 719)</th>
<th>Comparison Group (n=1,036)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender (Female)</td>
<td>53%</td>
<td>48%</td>
</tr>
<tr>
<td>White</td>
<td>40</td>
<td>14</td>
</tr>
<tr>
<td>Black</td>
<td>36</td>
<td>60</td>
</tr>
<tr>
<td>Age = 46+</td>
<td>24</td>
<td>27</td>
</tr>
<tr>
<td>Cerebral palsy</td>
<td>57</td>
<td>47</td>
</tr>
<tr>
<td>Multiple Sclerosis</td>
<td>20</td>
<td>23</td>
</tr>
<tr>
<td>Spinal Cord Injury</td>
<td>7</td>
<td>11</td>
</tr>
<tr>
<td>Muscular dystrophy</td>
<td>6</td>
<td>4</td>
</tr>
<tr>
<td>Spina bifida</td>
<td>5</td>
<td>5</td>
</tr>
<tr>
<td>Polio</td>
<td>2</td>
<td>3</td>
</tr>
</tbody>
</table>
Table 7. Impact of Managed Care

<table>
<thead>
<tr>
<th></th>
<th>Pre-ICP Period (July 2010 – March 2011)</th>
<th>Post-ICP Period (Jan 2012 – Dec 2013)</th>
<th>ICP Impact</th>
</tr>
</thead>
<tbody>
<tr>
<td>State Expenditure</td>
<td>$2431&lt;sup&gt;a&lt;/sup&gt;</td>
<td>$2610&lt;sup&gt;b&lt;/sup&gt;</td>
<td>$179</td>
</tr>
<tr>
<td>Health Service Utilization&lt;sup&gt;c&lt;/sup&gt;</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Emergency Dept.</td>
<td>9.5%</td>
<td>4.7%</td>
<td>-4.7%*</td>
</tr>
<tr>
<td>Inpatient Hospitalization</td>
<td>4.6%</td>
<td>4.2%</td>
<td>-0.4%</td>
</tr>
<tr>
<td>Primary Care Physician</td>
<td>21.6%</td>
<td>24.8%</td>
<td>3.2%</td>
</tr>
</tbody>
</table>

*<sup>p</sup> < .01.

<sup>a</sup> Average per member per month state fee-for-service expenditure for acute healthcare and LLTSS except the one for HCBS Developmental Disabilities waiver program

<sup>b</sup> Average per member per month state’s capitation payment amount to MCOs

<sup>c</sup> Average per member per month % of member who accessed the service
<table>
<thead>
<tr>
<th></th>
<th>ICP Impact&lt;sup&gt;a&lt;/sup&gt;</th>
<th>Difference between two age groups (B) – (A)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age &lt;= 45 (A)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age &gt;= 46 (B)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>State Expenditure&lt;sup&gt;b&lt;/sup&gt;</td>
<td>$406</td>
<td>-$526</td>
</tr>
<tr>
<td>Health Service Utilization&lt;sup&gt;c&lt;/sup&gt;</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Emergency Dept.</td>
<td>-4.2%</td>
<td>-6.5%</td>
</tr>
<tr>
<td>Inpatient Hospitalization</td>
<td>0.6%</td>
<td>-3.4%</td>
</tr>
<tr>
<td>Primary Care Physician</td>
<td>2.5%</td>
<td>5.2%</td>
</tr>
</tbody>
</table>

* p < .05. ** p < .01.

<sup>a</sup> Average per member per month difference relative to propensity score matched comparison group in the same age group
<sup>b</sup> Average per member per month state’s expenditure
<sup>c</sup> Average per member per month % of member who accessed the service
Summary of Costs and Health Services

• For adults with physical disabilities MMC versus FFS resulted in fewer average monthly emergency room visits over a two year period compared to 9 months before.

• Older adults with physical disabilities were more likely to experience lowered costs over 24 months (in comparison with previous 9 months) due to managed care than younger adults.
Implications and Recommendations

• It’s important to consider the perspectives of people aging with disabilities in MMC to better serve their needs

• MMC programs need to facilitate continuity of care and provide training to care coordinators in person-centered approaches

• PCPs need to receive more training on working with older people with physical disabilities and using person-centered approaches that are respectful of the wishes of people with disabilities

• MMC programs may be more likely to see cost savings for older versus younger adults as they cost more to start with and capitation can suppress the costs of higher users.
Implications and Recommendations (2)

• Need to continue to study and evaluate managed care for older adults with physical disabilities who may have complex health needs
  • To what extent does MC results in better preventive healthcare and health promotion?
  • How can MCOs better serve people of diverse racial ethnic backgrounds?
  • What are experiences of other states?
  • What are promising and best practices in managed healthcare?
  • To what extent is there integration between healthcare and LTSS?
Citations


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- We have no disclosures.
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Aging in Place vs. Independent Living: Disability Rights, Ageism and Frameworks for Long-term Services and Supports Policy

Michelle Putnam, Ph.D.
School of Social Work, Simmons College
Boston, Massachusetts, USA
October 20, 2017
## U.S. Demographic snapshot: Disability

### Older adults
- 44.9 million adults age 65 and older in the U.S. in 2014. *(Kraus, 2015)*
  - 36% report experiencing disability.
  - 9% report cognitive disability.
- 25.6% of persons 65-74 (6.7 million) reported experiencing disability. *(Erickson et al, 2016)*
- 50.3% of persons ages 75 and older (9.4 million) reported disability. *(Erickson et al, 2016)*

### Adults 21-64
- 10.5% of persons ages 18-64 (20.4 million) reported experiencing disability in 2014. *(Kraus, 2015)*
- 4.4% (8.6 million) report experiencing cognitive disability.
- 1.2 million adults as having an intellectual disability and 944,000 as having developmental disability. *(Brault, 2012)*
- **Estimated 12.3% of population is aging with long-term disability.** *(Clark & Latham, 2014)*
Within long-term care, over a 15 period, marked shift from focus on institutional to home and community-based long-term care.

- Even a shift in professional terminology – from long-term care to long-term services and supports.
  - A compromise between care (dependency) and independent living (independence)?

- U.S. Legislature: American with Disabilities Act, 1990
- Supreme Court: Olmsted Decision, 1999
Figure 1. Medicaid HCBS Expenditures as a Percentage of Total Medicaid LTSS Expenditures, FY 1995–2013


At core, *desire to remain in community*
- Aspiration

Focus of gerontology has been on cultural attitude change

Successful?
- To some degree, coincides with baby boom.
Independent Living Model

- At core, *right to remain in community*
- Focus of disability rights has been on legal change
- Successful?
  - Shift from institutional to community-based care
Civil rights has had more policy power.

- The civil right argument has had substantial power related to long-term care, long-term services and supports.
- It is a human rights argument.
- It advances issues such as choice, decision-making, self-direction, consumer-control, opportunities, etc.
- It is historically more powerful in leveraging policy change than the aging in place – particularly for Medicaid policy.
Disability rights should take a stronger place in arguments for aging in place.

- Independent living should be operationalized for older adults.
  - Is this any different for older adults? Has historically been defined as distinct, but is this limiting its power?

- Where is the social model of disability in aging in place?
  - In Age-Friendly communities?

- Ageism related to disability should be directly confronted.

- Disability advocacy – a rights agenda - should be incorporated into aging policy work.
What matters most in the current policy environment?

- Instability in health care policy in general – suggests that advocates use all available models to help sustain coverage for long-term services and supports through Medicaid.
  - Loss of funds, loss of coverage puts individuals with disabilities of all ages at risk of institutionalization, poor quality of care, worse health, and greater mortality risk.

- Instability offers opportunities for partnerships, coalitions, and collective advocacy for broader populations – as well as perhaps the less noticed aging with disability population.
  - Avoid regression to the mean – back to stereotypes, policies that marginalize adults with disabilities rather than support independent living and positive aging.
THANK YOU

References available on request