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). This project was supported, in part by grant number 90CR2001-01-00, from the U.S. Administration for Community Living, Department of Health and Human Services. Grantees undertaking projects under government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official Administration for Community Living policy.
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
• **Emphasizes level of function and participation**
• “Mainstreams” experience of disability; ability is a continuum
• Standardizes measurement and language, allowing for international, epi and policy level analysis
For the ICF, diagnosis doesn’t matter

• UNIVERSALITY
  – “A classification of functioning and disability should be applicable to all people irrespective of health condition.”

• PARITY
  – “There should not be, explicitly or implicitly, a distinction between different health conditions... In other words, disability must not be differentiated by etiology.”

World Health Organization, 2002
Is this a sticking point?

• From Rehab/medical professionals…
  – “Someone born with cerebral palsy has a very different experience than someone who has a stroke in their 70’s; even if activity limitations and participation restrictions are the same on paper.”

• From some disability advocacy groups…
  – The framework does not acknowledge core aspects of disability identity; SCI (for example) is not seen as a “health condition”
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

Birth

Muscular Dystrophy
Cerebral Palsy
Spina Bifida

Multiple Sclerosis
ALS

Diabetic Complications
Heart Disease
Osteoarthritis

Fractures
Dementing conditions

Age 50

Traumatic amputation
SCI
TBI

Age 100
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, 3 speakers
  – The first speaker provides a large scale view of the field
  – The second 2 speakers focus on a particular related subject area

• Questions can be sent via the chat feature, and are addressed at the end of each talk
Day 1 (Monday):

Long-term services and supports and caregiving for adults aging with disability.
Day 1 Presenters

Lois Verbrugge
*Aging with disability for midlife and older adults*

Joe Caldwell
*Long term services and supports: Trends in policy and delivery system reforms*

Margaret Campbell & Debra Sheets
*Advancing independent living and caregiving outcomes for individuals aging with and aging into disability: Converging perspectives, policies and data*
Aging with Disability for Midlife and Older Adults

Lois M. Verbrugge, PhD
University of Michigan
Advances in Independent Living Knowledge and Outcomes for Aging and Disability: Part 1 – Diverse Perspectives & Converging Mandate, Policies & Programs

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

Presented as part of the RRTC on Healthy Aging with Physical Disability State of the Science Webinar Series, Sponsored by NIDILRR & NCOA
October 16, 2017
‘Independent Living’: Disability Perspective

• **Key Components of Independent Living (IL): (NCD Report, 2015)**
  – *IL as a philosophy* or way of looking at society and disability, where people with disabilities make the decisions that affect their own lives, are treated as consumers of services, and the environment is viewed as the first obstruction to independence.
  – *IL as a worldwide civil rights movement* that advocates for equal opportunities and participation in community life, self-determination, and self-respect.
  – *IL as a service system* made up of non-residential centers for independent living (CILs) run by and for people with disabilities.

• **Origins: 1960s – Disability Self Advocates**
  – IL movement coincides with the deinstitutionalization of people with significant disabilities, starting in the 1960s, which created an imperative to live free and independent lives.

• **Independence vs. Interdependence:**
  – Over time, the IL model evolved to embrace “interdependence,” or the reciprocal relationship between individuals involved in both peer support and the receipt of personal care services.
‘Independent Living’: Disability Perspective (contd.)

• **Independent Living (CILs) Program:**
  – *Definition:* “Centers for Independent Living" are consumer-controlled, cross-disability, nonresidential private nonprofit agencies designed and operated within a local community by people with disabilities that provide an array services (Source: [ILRU Directory of CILs](https://ilru.org/sites/default/files/resource_document/INDEPENDENT_LIVING_1.pdf))
  – *Funding:* CILs are found in every major city in the U.S., and are supported by the Administration for Community Living/DHHS, through funding authorized by the Rehabilitation Act of 1973, as amended.
  – *Target Population:* although there are no age restrictions, traditionally CILs have almost exclusively served people under 65 with disabilities of all types.

• **CIL Program Services/Outcomes:**
  – Information and referral services,
  – Consumer control,
  – Independent living skills training (e.g., self-determination/ self-advocacy)
  – Peer counseling, and,
  – More recently, de-institutionalization of people with disabilities in conjunction with implementation of the *Olmstead* decision.
‘Aging in Place’ Perspective on IL

• **Definition:** “the ability to live in one's own home and community safely, independently, and comfortably, regardless of age, income, or ability level” (Source: [U.S. Centers for Disease Control and Prevention](https://www.cdc.gov))

• **Origins: 1980s – Policy Makers & Professional Advocacy**
  – Started with policy makers and researchers and coincided with the emergence of ‘environmental gerontology,’ with a strong focus on the relationship between housing environments and the physical capabilities
  – Quickly embraced by ‘aging’ professional and advocacy organizations (e.g., AARP, National Association of Area Agency on Aging) and for-profit provider and trade associations (e.g., LeadingAge)

• **Meaning of Concept to Older Adults** (Wiles et al., 2011):
  – Term “aging in place” unknown to most respondents.
  – While many older adults distinguish between their physical homes and neighborhoods, they also stated that their physical homes bring a sense of identity, refuge and security.
  – But choice is key.
‘Aging in Place’: Aging Perspective (contd.)

• ‘Aging in Place’ Programs & Outcomes:
  – *Examples*: [Partners for Livable Communities, Aging in Place Initiative](http://www.aarp.org/livable-communities/about/): between 2007-2009 provided workshops and “JumpStart the Conversation” grants to local communities, funded by MetLife Foundation and National Association of Area Agencies on Aging (n4a)
  – *Traditional Outcomes*: Housing, Home modifications (i.e., wider doorways, entrances without steps, grab bars), Fall prevention, Personal Alert Systems, and Building standards.
  – *Target Population*: Traditionally ‘aging in place’ initiatives have been exclusively provided within the aging services network therefore serve primarily people 65 and over.

• Evolution of ‘Aging in Place’ Concept:
  – Shift to broader, more inclusive concepts of “Age-Friendly” and ‘Livable’ Communities, as reflected in The AARP Livable Initiative ([http://www.aarp.org/livable-communities/about/](http://www.aarp.org/livable-communities/about/)), that focuses on safe communities, walkable streets, housing and transportation, access to needed services; and opportunities for all ages to participate in community life.

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Common Goal for Community Living

- Despite different origins (self advocacy vs. professional advocacy) and diverse perspectives (IL in community as a right vs. as a preference):
  - survey after survey consistently indicates that when older persons and adults with long-term disabilities, 45 years and older, are asked where they prefer to live as they age, the overwhelming majority say they want to live in their communities and not institutions (Source: ARRP Home and Community Preferences of the 45+ Population. 2014)
Evolving Convergence: Shared Mandate for Community Living

More recently, through laws and court decisions ‘community living’ has been established as a legal right for people of all ages.

• **ADA: “It’s the Law”:**
  – In 1990 passage of The Americans with Disabilities Act (ADA) affirmed that people with disabilities have the same rights as all citizens: to live with their families and friends in local neighborhoods and towns, to be employed in regular jobs at competitive wages, and to participate in community affairs.

• **Olmstead: “Most Integrated Setting”**
  – In 1999, the U.S. Supreme Court ruled in *Olmstead v. L.C.* that people with disabilities must receive services in the most integrated settings possible.

• **Equal Protection- Unequal Awareness & Utilization:**
  – Although the ADA and landmark Olmstead decision are critical tools in protecting the rights of people with disabilities and older adults alike, awareness and utilization of these rights and protections is considerable less among the older population and to some degree the providers who serve them. This remains a barrier to bridging aging and disability services.

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Evolving Convergence: Shared Policies – ACA HCBS

• **ACA, Section 2402(a):** The 2010 passage of the Affordable Care Act, Section 2402(a) required the Secretary of the U.S. Department of Health and Human Services (HHS) to ensure all states receiving federal funds develop service systems that are:
  – responsive to the needs and choices of all beneficiaries receiving home and community-based long-term services (HCBS),
  – maximize independence and self-direction, and
  – provide coordination to assist with a community supported life.

• **Definition of HCBS:** refers to a broad range of paid and unpaid services that generally help *older adults and people with disabilities* remain living in the community in their own homes or in the least restrictive setting (Source: Reaves & Musumeci (2015)).

• **Administration for Community Living (ACL) HCBS Programs:**
  – **Aging and Disability Resource Centers (ADRCs)** -- serves as a gateway to a broad range of services and supports for older adults and people with disabilities.
  – **Americans with Disabilities Act National Network** -- funds regional centers to provide information, training, and technical assistance to individuals, businesses, and agencies regarding rights and responsibilities under the ADA.
  – **Centers for Independent Living (CILs)**
  – **Assistive Technology Act program** -- located in every state and charged with helping people with disabilities of all ages find, try and obtain AT devices and services.

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Evolving Convergence: Significance of HCBS Programs

• **Significance of Section 2402(a) for both Aging and Disability:**
  – Incorporates requirements that uphold the philosophies and priorities of both constituencies related to community living:
    ▪ *Person-Centered Planning* - a process directed by the person with long-term service and supports (LTSS) needs that starts with assessing strengths, goals, preferences, needs (medical and HCBS), and desired outcomes.
    ▪ *Self-Direction* -- allows the person maximum control over his or her HCBS including the amount, duration, and scope of services, as well as choice of providers, including family or friends).
  – Creates one, non-age based federal policy stream and set of implementing regulations for public programs that provide HCBS to older adults and people with disabilities; and
  – Provides a policy and regulatory structure to accelerate the integration of aging and disability services.

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Current Convergence between Aging and Disability
‘Independent Living’ Services & Programs
Conclusion: Lingering Gaps, Promising Developments

- **Lingering Gaps:** Despite significant progress on the legislative, policy and administrative fronts, numerous gaps remain in meeting the community living needs and preferences of older adults and people with disabilities. Examples include:
  - Insufficient coordination and integration between aging and disability HCBS programs (e.g., ADRCs, CILs, and Tech Act) which perpetuates traditional age-based silos and results in lack of access to key services, particularly for adults aging with disabilities who tend to fall through the divides.
  - Lack in inclusion of health promotion and wellness programs as required components of HCBS that go beyond assistance with daily activities to promoting healthy aging for all.

- **Promising Developments:**
  - Expansion of integrated models of care that incorporate both medical and home and community-based services into a coordinated delivery system.
  - Increased availability of technologies to support community living and caregiving by enabling communication and engagement, health and wellness, learning, and safety and security.
Key References


❖Campbell & Associates Consulting – Bridging Aging and Disability Research and Policy
Advancing Independent Living and Knowledge for Aging and Disability: Part 2- Carers & Care Receiving

Debra Sheets, Ph.D., MSN, FAAN  
Stuart MacDonald, Ph.D.  
University of Victoria

RRTC on Healthy Aging with Physical Disability State of the Science Webinar Series  
University of Washington

October 16, 2017
Carer Statistics

• Definition: someone who assists others with activities of daily living and/or medical tasks

• Statistics
  – 43.5 million caregivers provided unpaid care to an adult or child in the past year,
  – 15.7 million family caregivers are caring for someone with dementia.

• Demographics
  – Average age: 49.2 years
  – Gender: ¾ are female.
  – Time: about 24.4 hours per week providing care
  – Duration: average is 4 years; 1/3 spend 5 to 10 years
  – Relationship: 42% care for a parent

• Tasks
  – 46% perform medical and nursing tasks
Care Recipient Statistics

• Demographics
  – Average age: 69.4
  – Living arrangements
    • 48% reside in their own home
    • 35% reside in the caregivers home

• Care Needs
  – May be episodic, daily, occasional, short- or long-term
  – 6.3 million older adults receive a family caregiver’s help with household tasks or self-care because of health or functioning reasons

• Aging with Disability
  – an estimated 641,000 adults are aged 60+ with developmental and other disabilities (e.g., cerebral palsy, autism, epilepsy, traumatic brain injury).
  – Secondary conditions (new onset of comorbid condition) are common in midlife
The Canadian Longitudinal Study on Aging (CLSA)

- **Focus:** changes in health, function, and well-being of Canadians ages 45 to 85 years.
- Unique opportunity to study middle-aged (ages 45-64) and older individuals aging with disability as well as those aging into chronic disease or disabling conditions
  - U.S. longitudinal aging studies typically start at age 60 or 65
With over $90 million of funding from the government and partners, the CLSA has created one of the most comprehensive research platform in the world with longitudinal data and biospecimens from over 50,000 Canadians over the age of 45 that will span 20 years.

➢ The study collects data through telephone interviews, in-home interviews and physical assessments (including biospecimen collection), covering all disciplines from biological, medical, psychosocial, social, lifestyle to socioeconomic aspects of aging.

➢ Participants also take part in standardized, performance-based tests including memory and cognitive function.

➢ Participants in the CLSA are selected at random and the information collected is generalizable to the Canadian population.
The CLSA can answer important policy and program questions that no other data sources can address.

For example:

➢ Investigating how lifestyle factors (nutrition, exercise) can promote resilience against depression and healthy aging.

➢ Studying how hearing loss may interfere with social functioning and in turn contribute to disease and dementia.

➢ Evaluating the effects of longstanding disability on health, function and risk for secondary conditions on middle-aged and older adults.
Participants
(51,352)

Enrolled

Questionnaire Data (telephone and in person interviews)
(>50,000)

Physical Exam and Biological Specimen
(>30,000)

Active Follow-up
(F) Every 3 years
- Questionnaire
- Physical exam
- Biological samples

Maintaining Contact
(MC) mid-wave
- Update contact information & implement Retention strategies

Passive Follow-up
Every 3 years
- Health care utilization
- Disease registries
- Mortality databases

Data and Biological Sample Repositories
Data linkage with health care, mortality and disease registries

Researchers, governments, partners
The CLSA platform collects data and biospecimens from:

- 51,338 Canadians aged 45 – 85 years at baseline
  - Questionnaires by telephone interview on 21,241 participants
    - Randomly selected 10 provinces
  - Questionnaires by in-person interviews and physical assessments on 30,097 participants
    - Randomly selected 25-50 km of 11 sites in 7 provinces

- 20 year study: Follow up every 3 years, maintaining contact in between

- Data Linkage with health care, mortality and disease registries

- The CLSA is currently in Follow-up 1 of data and biospecimen collection
- Data from the Baseline are available and already used by the research community and governments
## Depth and Breadth of Baseline CLSA

### PHYSICAL & COGNITIVE MEASUREMENTS
- Height & weight
- Waist and hip measurements
- Blood Pressure
- Grip strength, timed up-and-go, chair raise, 4-m walk
  - Standing balance
- Vision (retinal imaging, Tonometer & visual acuity)
- Hearing (audiometer)
- Spirometry
- Body composition (DEXA)
- Bone density (DEXA)
- Aortic calcification (DEXA)
- ECG
- Carotid Plaque sweep (ultrasound)
- Carotid intima-media thickness (ultrasound)
- Cognitive assessment (30 min. battery)

### HEALTH INFORMATION
- Chronic disease symptoms (disease algorithm)
- Medication and supplements intake
- Women’s health
- Self-reported health service use
- Oral health
- Preventative health
- Administrative data linkage health services & drugs & other administrative databases

### PSYCHOSOCIAL
- Social participation
- Social networks and support
- Caregiving and care receiving
- Mood, psychological distress
- Veteran’s Identifier & PTSD
- Coping, adaptation
- Injuries and consumer products
- Work-to-retirement transitions
- Retirement planning
- Social inequalities
- Mobility-life space
- Transportation
- Built environments & Contextual Factors
- Air Pollution
- Income, Wealth and Assets

### LIFESTYLE & SOCIODEMOGRAPHIC
- Smoking
- Alcohol consumption
- Physical activity (PASE)
- Nutrition (nutritional risk and food frequency)
- Birth location
- Ethnicity/race/gender
- Marital status
- Education
Canadian Longitudinal Study on Aging (CLSA)
Carers, Care receivers and Disability

- Identify carers and care receivers: duration, intensity, and needs
- Identify selected disabilities in mid-life and follow individuals for 20 years
- Describe health, secondary conditions, functional limitations and use of assistive technologies
- Explore social participation, social networks and life satisfaction
## Care receivers aging with disability

### Demographics

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<tr>
<th>Age (yrs)</th>
<th>Any of 4 conditions (n=1404) %</th>
<th>Multiple Sclerosis (n=82) %</th>
<th>Polio (n=70) %</th>
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## Care receivers aging with disability

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<td>0.6</td>
</tr>
</tbody>
</table>
## Care receivers aging with disability

### Informal Care

<table>
<thead>
<tr>
<th>Types of help</th>
<th>Any of 4 conditions (n=1404)</th>
<th>Multiple Sclerosis (n=82)</th>
<th>Polio (n=70) \</th>
<th>Rheumatoid Arthritis (n=248)</th>
<th>TBI (n=114)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(%)</td>
<td>(%)</td>
<td>(%)</td>
<td>(%)</td>
<td>(%)</td>
</tr>
<tr>
<td>Personal care</td>
<td>18.1</td>
<td>17.1</td>
<td>10.0</td>
<td>17.7</td>
<td>18.5</td>
</tr>
<tr>
<td>Medical Care</td>
<td>14.4</td>
<td>11.0</td>
<td>2.9</td>
<td>13.7</td>
<td>14.6</td>
</tr>
<tr>
<td>Managing Care</td>
<td>10</td>
<td>15.9</td>
<td>4.3</td>
<td>10.1</td>
<td>10.0</td>
</tr>
<tr>
<td>Housework</td>
<td>59.1</td>
<td>68.3</td>
<td>54.3</td>
<td>61.7</td>
<td>59.0</td>
</tr>
<tr>
<td>Transportation</td>
<td>50.7</td>
<td>47.6</td>
<td>31.4</td>
<td>51.6</td>
<td>51.1</td>
</tr>
<tr>
<td>Meal Prep</td>
<td>37.6</td>
<td>36.6</td>
<td>18.6</td>
<td>36.3</td>
<td>38.4</td>
</tr>
<tr>
<td>None</td>
<td>16.6</td>
<td>15.9</td>
<td>28.6</td>
<td>15.7</td>
<td>16.0</td>
</tr>
<tr>
<td>People helping (M)</td>
<td>2.79</td>
<td>2.48</td>
<td>1.6</td>
<td>2.89</td>
<td>2.81</td>
</tr>
<tr>
<td>Duration (# wks)</td>
<td>19.0</td>
<td>34.3</td>
<td>29.4</td>
<td>21.1</td>
<td>17.6</td>
</tr>
<tr>
<td>Hours per week</td>
<td>9.9</td>
<td>10.9</td>
<td>7.1</td>
<td>9.5</td>
<td>10.0</td>
</tr>
</tbody>
</table>
### Care receivers aging with disability

#### Secondary conditions

<table>
<thead>
<tr>
<th>Condition</th>
<th>Any of 4 conditions (n=1404) %</th>
<th>Multiple Sclerosis (n=82) %</th>
<th>Polio (n=70) %</th>
<th>Rheumatoid Arthritis (n=248) %</th>
<th>TBI (n=114) %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Depression (clinical)</td>
<td>32.3</td>
<td>29.3</td>
<td>20.0</td>
<td>33.9</td>
<td>33.4</td>
</tr>
<tr>
<td>Osteoarthritis</td>
<td>25.7</td>
<td>12.2</td>
<td>24.3</td>
<td>41.1</td>
<td>25.0</td>
</tr>
<tr>
<td>Osteoporosis</td>
<td>14.7</td>
<td>22.0</td>
<td>14.3</td>
<td>23.4</td>
<td>13.2</td>
</tr>
<tr>
<td>Urinary incont.</td>
<td>20.2</td>
<td>52.4</td>
<td>10.0</td>
<td>18.5</td>
<td>18.7</td>
</tr>
<tr>
<td>Bowel incont.</td>
<td>6.5</td>
<td>26.8</td>
<td>5.7</td>
<td>4.4</td>
<td>5.8</td>
</tr>
<tr>
<td>Parkinson’s</td>
<td>1.1</td>
<td>0</td>
<td>0.0</td>
<td>0.8</td>
<td>1.2</td>
</tr>
<tr>
<td>Dementia/Memory Problems</td>
<td>0.7</td>
<td>0</td>
<td>0.0</td>
<td>0.8</td>
<td>0.8</td>
</tr>
</tbody>
</table>
## Care receivers aging with disability

### Chronic conditions by age

<table>
<thead>
<tr>
<th>Chronic conditions</th>
<th>Age 45-64 N=767 (%)</th>
<th>Age 65+ N= 637 (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Heart disease</td>
<td>12.8</td>
<td>30.0</td>
</tr>
<tr>
<td>Pulmonary disease</td>
<td>12.6</td>
<td>14.9</td>
</tr>
<tr>
<td>Diabetes</td>
<td>23.1</td>
<td>30.1</td>
</tr>
<tr>
<td>Cancer</td>
<td>15.9</td>
<td>27.6</td>
</tr>
<tr>
<td>Stroke</td>
<td>3.5</td>
<td>5.8</td>
</tr>
<tr>
<td>Dementia</td>
<td>0.3</td>
<td>1.3</td>
</tr>
<tr>
<td>Depression</td>
<td>40.9</td>
<td><strong>25.9</strong></td>
</tr>
</tbody>
</table>
Discussion

• **Health:** about 3 in 4 persons with disability report good, v. good or excellent health.

• **Function:** ADLs and IADLs vary by disability.
  – Persons with MS have significantly more ADLs and IADLs than the other 3 types of disability

• **Type of help:** most common were housework, transportation and meal preparation
  – Duration:

• **Secondary conditions:** vary by disability and remain a significant health concern.

• **Chronic Conditions:**
  – Heart disease, diabetes and cancer increase with age.
  – Depression decreases with age but affects 1 in 4 persons aging with disability.
Limitations and Future Directions

• **Limitations**
  – Only descriptive data are presented
  – Duration of disability may not be possible to determine
  – Data on a limited number of disabilities is being collected
  – Only cross-sectional data is available until 2018

• **Future Directions**
  – Additional analyses to explore differences by age and sex (e.g., examine the combination of chronic conditions, secondary conditions and disability on function).
  – Explore additional secondary conditions (e.g. pain)
  – Multivariate modeling to explore relationships and predict outcomes of interest.
Conclusion

- As the age of populations around the world continues to increase, the population of those aging with disability is also growing.
- There is a urgent need for high quality, longitudinal, population-based information to advance our understanding of aging with disability.
- The CLSA offers a unique opportunity to look at aging with disability from a longitudinal perspective (i.e. 20 years)
- It is a rich resource that allows us to move beyond describing change over time to actually studying the dynamic determinants of change within and between individuals with different disabilities over time.
  - It will become increasingly valuable to scientists and policymakers in the years ahead as repeated, longitudinal data become available.
References


• National Alliance for Caregiving and AARP. (2015). Caregiving in the U.S.


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Ine Wauben (Managing Director): wauben@mcmaster.ca

CLSA funded by the Government of Canada through CIHR and CFI, and provincial governments and universities

www.clsa-elcv.ca
Long Term Services and Supports: Trends in Policy and Delivery System Reforms

Joe Caldwell, Director, Long-Term Services and Supports Policy

October 16, 2017
Our Mission:
Improve the lives of millions of older adults, especially those who are struggling

NCOA leads the Disability & Aging Collaborative

- Informal coalition of more than 40 national aging and disability groups working together to advance LTSS policy
- One of the first successful efforts to bring together aging and disability organizations
Disability and Aging Collaborative

- American Association on Health and Disability
- American Association of People with Disabilities
- AARP
- ACLU
- ADAPT
- Alliance for Retired Americans
- Altarum institute
- AFSCME
- ANCOR
- The Arc of the United States
- Association of University Centers on Disabilities
- Alzheimer’s Association
- Bazelon Center for Mental Health Law
- Caring Across Generations
- Center for Medicare Advocacy
- Community Catalyst
- Dana & Christopher Reeve Foundation
- Direct Care Alliance
- Disability Rights Education & Defense Fund
- Easter Seals
- Families USA
- Health and Disability Advocates
- Leading Age
- Lutheran Services in America
- National Association of Area Agencies on Aging
- National Association of Councils on Developmental Disabilities
- National Academy of Elder Law Attorneys
- National Association for Home Care and Hospice
- National Committee to Preserve Social Security and Medicare
- National Council on Aging
- National Council on Independent Living
- National Consumer Voice for Quality Long-Term Care
- National Disability Rights Network
- National Health Law Program
- National PACE Association
- National Senior Citizens Law Center
- Paralyzed Veterans of America
- Paraprofessional Healthcare Institute
- SEIU
- United Cerebral Palsy
- United Spinal Association
- VNAA – Visiting Nurse Associations of America
Overview

- Highlight trends in two key areas:
  - Access to Home and Community Based Services
    - Rebalancing
    - Unmet Needs
  - Integrated Models of Care
    - Movement to MLTSS and Integration
    - HCBS Quality
    - Business Acumen

- Identify research opportunities related to individuals aging with disabilities
Progress on Rebalancing

- States have made significant progress on “rebalancing,” moving away from institutional service to HCBS.
- However, major gaps remain and the work continues:
  - Bipartisan support to extend Money Follows the Person Demonstration
  - Rebalancing occurring through MLTSS and integration
  - States adopting Community First Choice 1915(k) option
  - States implementing HCBS settings rule
Rebalancing Progress: Percentage of Medicaid LTSS Expenditures on HCBS

Gaps by State:
Percentage of Medicaid LTSS Expenditures on HCBS

Gaps by Population

- Percentage of Medicaid LTSS expenditures for HCBS:
  - 76% for people with I/DD
  - 44% for older adults and adults with physical disabilities
  - 42% for people with mental health and substance use disorders

- While rebalancing is occurring the population of younger individuals in nursing homes seems to be rising.
Population Under 65 in Nursing Homes

Figure 3.3. Percentage of Nursing Home Residents by Age: United States, 2011-2014

Source: CMS Nursing Home Compendium 2015
Excellent Research on Quality of Life: Money Follows the Person Evaluation

Quality of life of MFP participants pre- and post-transition

Source: Mathematica’s analysis of MFP Quality-of-Life surveys and program participation data submitted to CMS through May 2016.
Growing Unmet Needs and Waiting Lists

- Vast majority of individuals who need LTSS reply on unpaid assistance and do not receive formal services
  - All individuals needing LTSS in US (Kaye, Harrington, & LaPlante, 2010)
    - Approximately 10.9 community residents, half of them nonelderly
    - 92% received unpaid help
    - Only 13% received paid help
  - Individuals with I/DD (Larson et al., 2017)
    - Estimated 4.7 million people with I/DD
    - Only 1.37 million (30%) received formal services and of those 57% lived at home with family.

- Waiting lists for HCBS have doubled over past decade
  - In 2015, more than 640,000 people were on 1915 (c) waiver waiting lists, and the average waiting time exceeded two years (Ng et al., 2016).
Integrated Care

• Majority of individuals with disabilities receive their health and long-term services and supports (LTSS) in fee-for-service Medicaid with very little care coordination or integration of acute, LTSS, and behavioral health services.

• Over the past decade there has been a seismic move towards delivery system reforms to better integrate, coordinate care, and address the “social determinants” of health
  - Medicaid Managed LTSS
  - Financial alignment demonstrations (Duals demos)
  - Accountable Care Organizations (ACOs), Health Homes, other delivery and payment reform initiatives
Growth of MLTSS Programs

Source: NASUAD (2017) Medicaid Integration Tracker
PACE Demonstrations for Under 65

- Program for All-Inclusive Care for Elderly (PACE)
  - Provider-based model that integrates Medicare-Medicaid for individuals age 55 and older
  - As of 2016, 118 PACE organizations in 32 states
- PACE Innovation Act (enacted November 2015)
  - Provides authority to extend PACE to new population
  - Disability community worked with National PACE Association to develop recommendations
- RFPs likely on the horizon to test PACE demonstrations for individuals under 65
HCBS Quality and Performance Measures

- Quality and performance measures are a key tool in making MLTSS and other delivery system reforms work:
  - Ensure consumer protections
  - Provide information so individuals and their families can choose health plans
  - Help plans to improve outcomes
  - Align payments, incentives, and penalties to drive desired goals

- Void of HCBS quality measures that have been endorsed by the National Quality Forum
HCBS Quality and Performance Measures

- Significant work occurring in this area at national and state level:
  - National Quality Forum Workgroup on HCBS Quality
  - CMS/Mathematica
  - RTC on HCBS Outcome Measures (University of Minnesota)
  - National Core Indicators (NCI) and National Core indicators –Aging and Disability (NCI-AD)
Aging and Disability Business Acumen

- ACL have invested in projects to assist aging and disability community-based organizations develop “business acumen skills” to be able to contract with health care entities
- NASUAD Disability Business Acumen
  - Learning collaborative with 5 states
State of the Science: Opportunities for Research Concerning Individuals Aging with Disabilities

1) Access to Home and Community-Based Services as Individuals with Disabilities Age
   - Unmet needs as individuals age
   - Connection to aging service system
   - Transitions in and out of institutional settings
   - Supporting family caregivers, particularly aging caregivers

2) Development and Evaluation of New Models to Support Individuals Aging with Disabilities
   - Collaborations with managed care entities and providers
     - MLTSS, PACE demos, initiatives
   - Participatory research with community-based organizations assist with designing and documenting the value of packages of services and supports addressing needs of individuals aging with disabilities
Questions?
Join us for the next session!

- **Wednesday, October 18th, 12-2 p.m. EST/9-11 a.m. PST** ([Register](#))

- **Focus:** Autonomy and access for adults aging with disability.

- **Presenters:**
  - Ivan Molton (University of Washington)
  - Sarah Ruiz (National Institute on Disability, Independent Living and Rehabilitation Research)
  - Lisa Iezzoni (Harvard University)
  - Philippa Clarke (University of Michigan)