ADA Audio Conference Series
April 19, 2017

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2:00pm Eastern Time

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ADA Audio Conference Series
Looking at Institutional and Community Living Through Data
April 19, 2017
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Customize Your View continued

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  2. **By Email** webinars@ada-audio.org ; or
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Looking at Institutional and Community Living
Through Data- An ADA Participatory Action
Research Consortium (ADA-PARC) Report

Principal Investigators: Lex Frieden, LL.D & Joy Hammel, PhD, OTR/L
Collaborating ADA Centers: Southwest ADA Center, Great Lakes ADA Center, Southeast ADA Center, Pacific ADA Center, Rocky Mountain ADA Center, Mid Atlantic ADA Center

Funding

• This research is funded by the National Institute on Disability, Independent Living, and Rehabilitation Research
  ▪ Award number 90DP0026-03-00; HHS award ED H133A120008-14
  ▪ Department of Health and Human Services, Administration For Community Living, NIDLRR - Disability and Rehabilitation Research Program (DRRP)
Acknowledgements

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- Joy Hammel (Co-PI)
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- Roxy Funchess
- Bob Gatis
- Jill Bazyik
- Rachael Stafford
- Scott Saboleta
- Lewis Kraus
- Terence Ng
- Marian Vessels

- Karen Goss
- Oce Harrison
- Ann Deschamps
- Christy Stuart
- Maynor Guillen
- Pam Williamson
- Barry Whaley
- Saly Weiss
- Robin Jones
- Peter Berg
- Candice Alder
- Erica Jones
- Michael Richardson
- Kafeh Matrone
- Kurt Johnson
- Pimjai Sudsawad (NIDILRR Project Officer)

Purpose of ADA-PARC

- To collaboratively examine participation disparities experienced by people with disabilities post ADA & Olmstead
- To identify & examine key environmental factors contributing to these disparities
- To benchmark participation disparities and highlight promising practices at state & city levels
- To action-plan strategies for dissemination and utilization of findings to be used by ADA Centers and others in community capacity building & systems change initiatives

Representative Cities

<table>
<thead>
<tr>
<th>ADA Center</th>
<th>States</th>
<th>Selected Cities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Southwest</td>
<td>Arkansas, Louisiana, New Mexico, Oklahoma, Texas</td>
<td>Houston, TX, Austin, TX, Little Rock, AR, Baton Rouge, LA</td>
</tr>
<tr>
<td>Great Lakes</td>
<td>Iowa, Indiana, Michigan, Minnesota, Ohio, Wisconsin</td>
<td>Chicago, IL, Detroit, MI, Columbus, OH</td>
</tr>
<tr>
<td>Southeast</td>
<td>Kentucky, Missouri, North Carolina, South Carolina, Tennessee</td>
<td>Raleigh, NC, Greensboro, NC, Asheville, NC, Gastonia, NC</td>
</tr>
<tr>
<td>Pacific</td>
<td>Arizona, California, Hawaii, Nevada, the Pacific Basin</td>
<td>Oakland, CA, San Francisco, CA, Santa Barbara, CA, Sacramento, CA</td>
</tr>
<tr>
<td>Rocky Mountain</td>
<td>Colorado, Montana, North Dakota, South Dakota, Utah, Wyoming</td>
<td>Denver, CO, Salt Lake City, UT, Missoula, MT</td>
</tr>
<tr>
<td>Mid-Atlantic</td>
<td>DC, Delaware, Maryland, Pennsylvania, Virginia, West Virginia</td>
<td>Baltimore, MD, Richmond, VA, Washington, DC, Pittsburgh, PA</td>
</tr>
<tr>
<td>Northwest</td>
<td>Alaska, Idaho, Oregon, Washington</td>
<td>Seattle, WA, Portland, OR, Boise, ID</td>
</tr>
</tbody>
</table>
Tracking 3 Major Participation Areas

- **Community living (CL)**
  Community vs. institution living, HCBS spending, Money Follows the Person Transitions

- **Community participation (CP)**
  Health insurance, affordable & accessible housing, access to community & disability resources, transportation, crime rates, livability indicators

- **Work/economic participation (WE)**
  Employment, economic status, poverty rates, cost of living

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Community Living

adaparc.org

Community Living Indicators

- A core goal of people with disabilities and an underlying concern of the Americans with Disabilities Act is
  Disability, Health insurance, Affordable & accessible housing, Community resources, Livability indicators

- People with disabilities live in the community
- People with disabilities living in an institution
- People with disabilities living in other, More quarters

Programs and Services for Community Living

1. Supports for Home and Community-Based Services (HCBS) Participants in Other Living: Term Support Services 6/2017
2. Supports for HCBS Expenditures FY 15/16
3. Number of Person with Didesability: Lives in HCBS Service Area
4. Number of People who Receive Social Security Disability Insurance

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Percentage of People with Disabilities Living in an Institution

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Percentage of People with Disabilities Living at Home

Percentage of People with Disabilities Living in Other Group Quarters

Benchmarking: Summarizing Community Living Participation at State Level (2013-15)

<table>
<thead>
<tr>
<th>Summary Score across Community Living Indicators</th>
<th>Best States</th>
<th>Worst States</th>
</tr>
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<tbody>
<tr>
<td>100: best opportunity</td>
<td>Alaska</td>
<td>Kansas</td>
</tr>
<tr>
<td>90</td>
<td>Oregon</td>
<td>Connecticut</td>
</tr>
<tr>
<td>89</td>
<td>Arizona</td>
<td>Iowa</td>
</tr>
<tr>
<td>87</td>
<td>Hawaii</td>
<td>North Dakota</td>
</tr>
<tr>
<td>85</td>
<td>Nevada</td>
<td>Utah</td>
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<tr>
<td>83</td>
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<td>Utah</td>
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<tr>
<td>83</td>
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</tbody>
</table>
Individual Community Living Perspective: Olmstead Interviews

- 104 interviews with people who have transitioned out of nursing homes/institutions to community via Olmstead initiatives
  - Compare participation levels, needs and issues in nursing home vs. community
  - Rate levels of participation in community (Kessler/NOD/Harris questions so can compare to random disability and general population samples)
  - Qualitatively describe transition & trajectory over time

Contact on Community Living for ADAPARC

- Lewis Kraus
  Co-Director, Pacific ADA Center
  lewisk@adapacific.org
  510-285-5600

Speakers

- Charlene Harrington
  Professor of Sociology and Nursing
  University of California San Francisco
Trends in Nursing Facilities, Staffing, Residents and Deficiencies in the U.S.

Charlene Harrington, Ph.D., RN Professor
University of California San Francisco, CA

Figure 26
Number of Nursing Facility Residents and Occupancy Rates, 2009-2015

Figure 27
Average Nursing Facility Occupancy Rates By States, 2015

SOURCE: Harrington, Carrillo, and Garfield, based on OSCAR/CAPR data.
Figure 28

Number of Nursing Facility Admissions Per Bed in 2015

![Map showing number of admissions per bed in 2015.](image)

Source: Brown University [LTC Focus](http://ltcfocus.org/map/#/average-acuity/col=0&dir=asc&pg=&lat=37.996162679728116&lng=-99.31640625&zoom=4)

Figure 29

Distribution of Nursing Facility Residents by Primary Payer, 2009-2015

![Bar chart showing distribution of nursing facility residents by primary payer.](image)

Source: Harrington, Carrillo, and Garfield, based on OSCAR/CASPER data.

Figure 30

Share of Nursing Facility Residents with Medicaid as Primary Payer by State, 2015

![Map showing share of residents with Medicaid as primary payer.](image)

Source: Harrington, Carrillo, and Garfield, based on OSCAR/CASPER data.
Figure 31
Percent of Nursing Facility Residents with Low Care Needs, 2010


Figure 32
Percent of Nursing Facility Residents Under Age 65 Years of Age, 2015


Figure 33
Percent of Nursing Facility Residents By Characteristics, 2010-2015

SOURCE: Harrington, Carrillo, and Garfield, based on OSCAR/CASPER data.
Figure 34: Distribution of Nursing Facilities by Ownership Type, 2009-2015

<table>
<thead>
<tr>
<th>Year</th>
<th>Government</th>
<th>Non-Profit</th>
<th>For Profit</th>
</tr>
</thead>
<tbody>
<tr>
<td>2009</td>
<td>26.3</td>
<td>58.8</td>
<td>15.9</td>
</tr>
<tr>
<td>2010</td>
<td>25.5</td>
<td>57.6</td>
<td>16.9</td>
</tr>
<tr>
<td>2011</td>
<td>25.1</td>
<td>58.8</td>
<td>16.1</td>
</tr>
<tr>
<td>2012</td>
<td>25.0</td>
<td>58.2</td>
<td>16.8</td>
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<tr>
<td>2013</td>
<td>24.4</td>
<td>58.4</td>
<td>17.2</td>
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<tr>
<td>2014</td>
<td>24.5</td>
<td>58.8</td>
<td>16.7</td>
</tr>
<tr>
<td>2015</td>
<td>23.3</td>
<td>58.4</td>
<td>18.3</td>
</tr>
</tbody>
</table>

SOURCE: Harrington, Carrillo, and Garfield, based on OSCAR/CASPER data.

Figure 35: Share of Nursing Facilities that are For-Profit by State, 2015

[Map showing distribution of for-profit nursing facilities by state, 2015]

SOURCE: Harrington, Carrillo, and Garfield, based on OSCAR/CASPER data.

Figure 36: Share of Nursing Facilities that are Chain-Owned by State, 2015

[Map showing distribution of chain-owned nursing facilities by state, 2015]

SOURCE: Harrington, Carrillo, and Garfield, based on OSCAR/CASPER data.
Figure 37
Average Nursing Facility Staffing Hours per Resident Day, 2009-2015

Total Nurse Hours Licensed Nurse Hours RN Hours
1.5 1.5 1.5 1.6 1.6 1.6 1.6
4.9 4.9 4.9 4.9 4.9 4.9 4.9

Note: Total Nurse Hours includes RNs, LPN/LVNs and Nursing Assistant. Licensed Nurse Hours includes RNs and LPN/LVN.
Source: Harrington, Carrillo, and Garfield, based on OSCAR/CASPER data.

Figure 38
Average Nursing Facility Staffing Hours per Resident Day
By State 2015

SOURCE: Harrington, Carrillo, and Garfield, based on OSCAR/CASPER data.

Figure 39
Nurse Staffing by Ownership Group 2003-2009 (hours per resident day)

Largest for-profit chains have significantly lower total staffing than all other ownership types.

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Summary

- Nursing home occupancy has declined while Medicare short-term rehabilitation use has increased steadily
- Medicaid continues to be the major payer for residents
- Some residents with light care needs, under age 65, and with special needs are living in nursing homes
- For-profit and chain ownership has increased – they have lower staffing & poorer quality
- Nurse staffing has improved but is still very low in half of nursing homes and many states
- Quality of care continues to be a problem throughout the states and enforcement varies widely across states
Speakers

• Steve Eiken, 
  Research Manager IBM Watson Health

IBM Watson Health

Balancing Long Term Services & Supports: History, Status and Strategies

Steve Eiken
April 19, 2017

Truven Health Analytics is now part of the IBM Watson Health business

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Looking at Institutional and Community Living Through Data
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Historically, most people were served, and most dollars were spent, on institutional services.

Balance has shifted significantly since 1981

Medicaid HCBS and Institutional Expenditures as a Percentage of Total Medicaid LTSS Expenditures, FY 1981–2014

Three Decades of Policy and Legislative Changes have Supported the Expansion of HCBS

Many statutory amendments and court decisions changed public policy related to Medicaid LTSS and Medicaid eligibility, including:

- 1981: Establishment of Section 1915(c) Waivers
- 1982: TEFRA option for states to cover children with disabilities living at home who qualify for institutional services
- 1987: Nursing Home Reform Act
- 1990: The Americans with Disabilities Act
- 1994: repeal of the “cold bed” regulation that required states to demonstrate a reduction in institutional capacity for each Section 1915(c) waiver enrollee
- 1997: Medicaid Buy-In program
- 1999: Olmstead versus L.C. Supreme Court decision
- 2005: The Deficit Reduction Act, which established Section 1915(i), Section 1915(j), and the Money Follows the Person Demonstration
- 2010: The Affordable Care Act, which created the Balancing Incentive Program and Community First Choice

Inflation-Adjusted Medicaid Institutional Expenditures have Stabilized, While HCBS Continued to Grow


HCBS Expenditures have Increased at a Faster Rate than Institutional Expenditures


A Majority of HCBS are Furnished Through Section 1915(c) Waivers

Distribution of HCBS Expenditures by Type of Service, FY 2014

Nursing Facility Expenditures Account for Most Institutional LTSS

Distribution of Institutional LTSS Expenditures by Type of Service, FY 2014

- Nursing Facilities: 77%
- ICF/IID: 7%
- Mental Health Facilities: 15%
- Institutional MLTSS – unspecified: 1%

Source: Eiken et al., 2016.

Two-thirds of Medicaid LTSS Beneficiaries Receive HCBS

Number and Percentage of Medicaid LTSS Beneficiaries Receiving Institutional Services and HCBS, 2012

- Institutional: 30%
- HCBS: 66%
- Both: 4%


A Majority of Medicaid LTSS Beneficiaries are Under Age 65

Distribution of Medicaid LTSS Beneficiaries by Age Group, 2012

- Under 21: 16%
- 65 and older: 45%
- 21 to 64: 39%

Source: Eiken, 2016.
Balance Varies by Subgroup


- A/D population
- People with DD
- People with SMI/SED
- All subgroups

Balance Varies by Age

Percentage of Medicaid LTSS Beneficiaries who Received HCBS and Institutional Services by Age Group, 2012

- HCBS Only
- Both
- Institutional Only

About Half the States Spent More than 50 Percent of Medicaid LTSS on HCBS in 2014

Medicaid HCBS Expenditures as a Percent of Total Medicaid LTSS Expenditures, by State, FY 2014

Source: Eiken, 2016.
Source: Eiken et al., 2016.
Seven of Ten States with the Greatest Percent Increase in HCBS Expenditures (FY 2012-14) were Balancing Incentive Program States

<table>
<thead>
<tr>
<th>State</th>
<th>2012 Expenditure</th>
<th>2014 Expenditure</th>
<th>Increase</th>
</tr>
</thead>
<tbody>
<tr>
<td>New Jersey</td>
<td>$13.2 billion</td>
<td>$14.3 billion</td>
<td>8.4%</td>
</tr>
<tr>
<td>Ohio</td>
<td>$12.4 billion</td>
<td>$14.0 billion</td>
<td>12.4%</td>
</tr>
<tr>
<td>Missouri</td>
<td>$11.7 billion</td>
<td>$13.0 billion</td>
<td>11.7%</td>
</tr>
<tr>
<td>Iowa</td>
<td>$7.2 billion</td>
<td>$7.8 billion</td>
<td>8.5%</td>
</tr>
<tr>
<td>Texas</td>
<td>$6.9 billion</td>
<td>$7.5 billion</td>
<td>8.5%</td>
</tr>
<tr>
<td>New York</td>
<td>$5.0 billion</td>
<td>$5.5 billion</td>
<td>10.0%</td>
</tr>
<tr>
<td>Arkansas</td>
<td>$4.8 billion</td>
<td>$5.3 billion</td>
<td>10.4%</td>
</tr>
<tr>
<td>Colorado</td>
<td>$5.1 billion</td>
<td>$5.6 billion</td>
<td>9.8%</td>
</tr>
<tr>
<td>Arizona</td>
<td>$7.1 billion</td>
<td>$7.6 billion</td>
<td>6.9%</td>
</tr>
</tbody>
</table>

Speakers

• Carol Irvin
  Mathematica Policy Research

Findings from the National Evaluation of the Money Follows the Person Rebalancing Demonstration

Webinar on Community Living of People with Disabilities
April 19, 2017

Carol V. Irvin

Money Follows the Person (MFP) Rebalancing Demonstration

Principal Aims
• Reduce reliance on institutional care
• Develop community-based long-term care opportunities
• Enable people with disabilities to participate fully in their communities and improve their quality of life
Most States Participate in the MFP Demonstration

Note: New Mexico and Florida received MFP grant awards in 2011. New Mexico withdrew from the program in 2012, Florida withdrew in 2013, and Oregon withdrew in 2014.

The Transition Program

More than 63,000 Transitions by the End of 2015

MFP Transitions and Current MFP Participants, June 2008 to December 2015

Transitions are not Evenly Distributed Across States

- Cumulative number of transitions varies across states
  - < 50 in South Dakota and Alabama
  - > 10,000 in Texas
- The volume of transitions are concentrated among 7 states that account for more than half (54 percent) of all MFP participants
  - California, Connecticut, Maryland, Michigan, Ohio, Texas, and Washington

Putting the Volume of MFP Transitions in Perspective

- Since 2010, annual MFP transitions represent about 1 percent of the people eligible for the demonstration during the year
  - May be a conservative estimate
- Volume reflects funding level
  - $4 billion
  - Funding allotments started in 2007 and ended in 2016 – 10 years
  - States have until 2020 to spend their allotments – 14 years
  - Funding for 44 states and the District of Columbia

Factors Associated with Leading Programs

- Characteristics of growing transition programs
  - Strong referral networks
  - Strong partnerships with state agencies that serve the targeted populations
  - Ongoing outreach
  - Good working relationship with facilities
  - Strong partnerships with housing agencies
  - Strong partnerships with providers of support services
- Barriers faced by most, if not all, grantees
  - Insufficient supply of affordable and accessible housing
  - Insufficient supply of community-based services
  - Challenges serving people with mental and behavioral health conditions
Key Factors to Transitioning Working-Age Adult Nursing Home Residents

- Grantees have few age-based procedures and processes
- Specific factors
  - Networks of peers and informal supports
  - Highly motivated
- General factors
  - Strong transition coordination services
  - Flexible community-based LTSS
- Improved integration of mental health services with other community-based LTSS providers
  - Specialized behavioral health supports for MFP participants
  - Modified 1915(c) waivers that better integrate mental health care

Key Questions for MFP Transition Programs

- Have grantee states increased the rate of transitions?
  - Assess a specific type of transition – from the institution to community-based LTSS
- How do MFP participants compare to others?
  - The eligible population
  - Other transitioners
- Did post-transition outcomes improve after grantee states implemented their MFP demonstrations?
  - Remain in the community
  - Return to institutional care
  - Died in the community

Other Research Questions

- How do total health care costs change after the transition?
  - Is MFP associated with changes in post-transition costs?
- How does the quality of life change?
How Do Health Care Costs Change after the Transition?

Total Health Care Costs Notably Decline when Working-Age Adults Residing in Nursing Homes Transition to Community Living

How Do Health Care Costs Change after the Transition?

Large Improvements in Quality of Life

Quality of Life of MFP Participants Pre- and Post-Transition

Large Improvements in Quality of Life

Quality of Life of MFP Participants Pre- and Post-Transition

How Do Health Care Costs Change after the Transition?

Total Health Care Costs Notably Decline when Working-Age Adults Residing in Nursing Homes Transition to Community Living

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Quality of Life of MFP Participants Pre- and Post-Transition

Large Improvements in Quality of Life

Quality of Life of MFP Participants Pre- and Post-Transition
Rebalancing Program

MFP Rebalancing Fund Expenditures Continue to Grow
Cumulative Expenditures of State Rebalancing Funds, December 2009 to December 2014

Types of Rebalancing Initiatives in 2014

Source: Mathematica analysis of State MFP Grantee Semiannual Progress Reports, 2010-2015. States may spend rebalancing funds on multiple types of initiatives and can be counted in multiple categories.
Looking to the Future

Sustaining Gains

- Sustaining formal transition programs
  - Outreach and referrals
  - Transition coordinators
  - Interagency partnerships (health-housing in particular)
  - Housing specialists
- Fostering a philosophy of assisting transitions to community-living
  - Payment policies
  - Quality/Performance measures
- Strengthening community-based LTSS
  - Work force
  - Supports for family and informal caregivers

Other Avenues

- Diverting people from institutional care
  - Medicare policy
  - Medicaid policy
  - Health homes
  - PACE
  - Accountable Care Organizations (ACOs)
  - Payment policies
  - No wrong door systems
  - Assessment of care needs
- Bending the cost curve for institutional care
  - Quality measurement and value-based purchasing
For More Information

- Carol Irvin
  - Cirvin@mathematica-mpr.com
  - CMS MFP website
  - Mathematica MFP website

Questions?

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