





ADA Audio Conference Series
April 19, 2017

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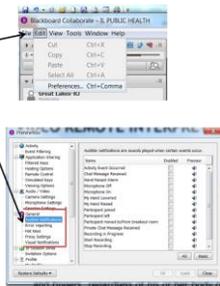
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Looking at Institutional and Community Living Through Data- An ADA Participatory Action Research Consortium (ADA-PARC) Report

Principal Investigators: Lex Frieden, LLD & 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

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Funding

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 - Department of Health and Human Services, Administration For Community Living, NIDILRR - Disability and Rehabilitation Research Program (DRRP)

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The ADA Participation Action Research Consortium



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Acknowledgements

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- Peter Berg
- Candice Alder
- Erica Jones
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- Kathe Matrone
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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

ADA Center	States	Selected Cities		
Southwest (Region 7)	Arkansas, Louisiana, New Mexico, Oklahoma, Texas	Houston, TX Tulsa, OK Austin, TX	Albuquerque, NM Little Rock, AR Baton Rouge, LA	New Orleans, LA
Great Lakes (Region 5)	Illinois, Indiana, Michigan, Minnesota, Ohio, Wisconsin	Chicago, IL Detroit, MI	Lansing, MI Columbus, OH	Minneapolis, MN
Southeast (Region 4)	Alabama, Florida, Georgia, Kentucky, Mississippi, North Carolina, South Carolina, Tennessee	Raleigh, NC Greensboro, NC Asheville, NC Gastonia, NC	Nashville, TN Memphis, TN Birmingham, AL Montgomery, AL	Tampa, FL St. Pete, FL Columbia, SC
Pacific (Region 9)	Arizona, California, Hawaii, Nevada, the Pacific Basin	Oakland, CA San Francisco, CA Riverside, CA Sacramento, CA	Fresno, CA Santa Barbara, CA Las Vegas, NV Phoenix, AZ	Tucson, AZ Honolulu, HI
Rocky Mountain (Region 8)	Colorado, Montana, North Dakota, South Dakota, Utah, Wyoming	Denver, CO	Salt Lake City, UT	Missoula, MT
Mid-Atlantic (Region 3)	DC, Delaware, Maryland, Pennsylvania, Virginia, West Virginia	Baltimore, MD Washington, DC	Richmond, VA Pittsburgh, PA	
Northwest (Region 10)	Alaska, Idaho, Oregon, Washington	Seattle, WA	Portland, OR	Boise, ID

Tracking 3 Major Participation Areas

adaparc.org

- **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 basic goal of people with disabilities and an underlying concept of the Americans with Disabilities Act (ADA) is equality and the freedom to choose to live independently in the community. One demonstration of this was the 1999 Supreme Court ruling in the Olmstead case, which found that institutionalization of individuals who are able and want to receive care at home and in the community constitutes discrimination under the Americans with Disabilities Act.

In this section of the ADA-PARC, we provide indicators that can be useful in determining whether people with disabilities are living in the community. The community living section includes measures on:

Where People with Disabilities Live in the Community

1. [Percentage of People with Disabilities Living in an Institution](#)
2. [Percentage of People with Disabilities Living at Home](#)
3. [Percentage of People with Disabilities Living in Other Group Quarters](#)

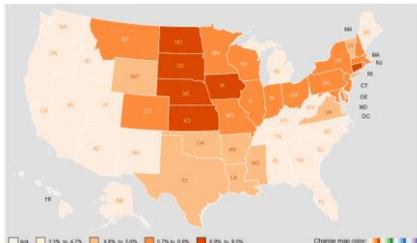
Programs and Spending for Community Living

4. [Ratio of Home and Community-Based Services \(HCBS\) Participants to Total Long-Term Support Services \(LTSS\)](#)
5. [Ratio of HCBS Expenditures to Total LTSS](#)
6. [Number of Persons on Medicaid 1915\(c\) HCBS Waiver Wait Lists](#)
7. [Number of Money Follows the Person Transitions Since Inception](#)

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Percentage of People with Disabilities Living in an Institution

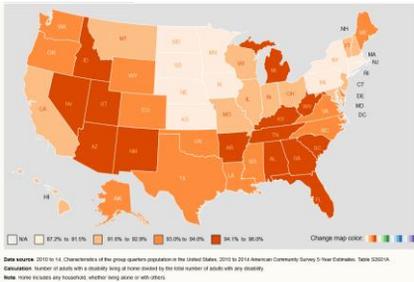


Data source: 2010 to 14. Characteristics of the group quarters population in the United States, 2010 to 2014 American Community Survey 5-Year Estimates. Table S2001A. Calculation: Number of people with a disability living in an institution divided by the total number of people with any disability. Note: Institutions include nursing homes, assisted living, and correctional and juvenile facilities.

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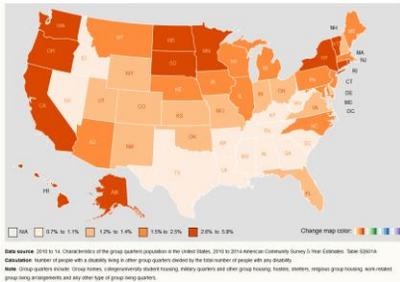
Percentage of People with Disabilities Living at Home



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Percentage of People with Disabilities Living in Other Group Quarters



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

	Best States		Worst states	
Summary Score across Community Living Indicators	90	Alaska	20	Kansas
	89	Oregon	19	Connecticut
	87	Arizona	8	Iowa
	85	Hawaii	2	North Dakota
	83	Nevada	0	Utah

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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

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Speakers

- Charlene Harrington
Professor of Sociology and Nursing
University of California San Francisco

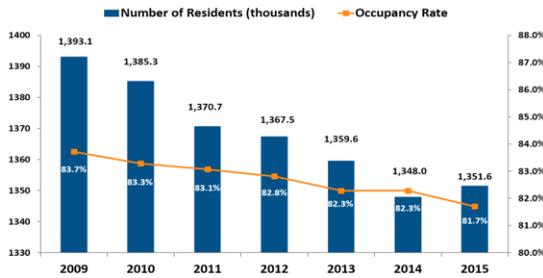


Trends in Nursing Facilities, Staffing, Residents and Deficiencies in the U.S.

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

Figure 26

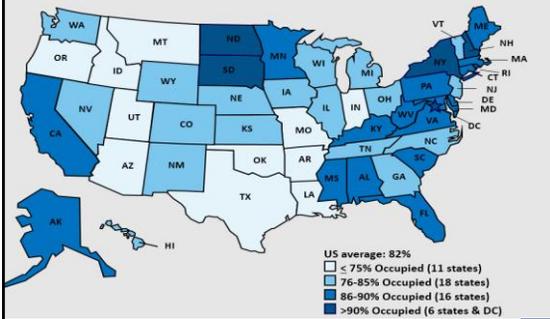
Number of Nursing Facility Residents and Occupancy Rates, 2009-2015



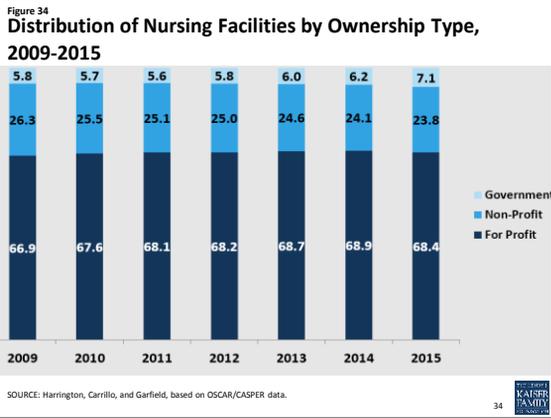
SOURCE: Harrington, Carrillo, and Garfield, based on OSCAR/CASPER data

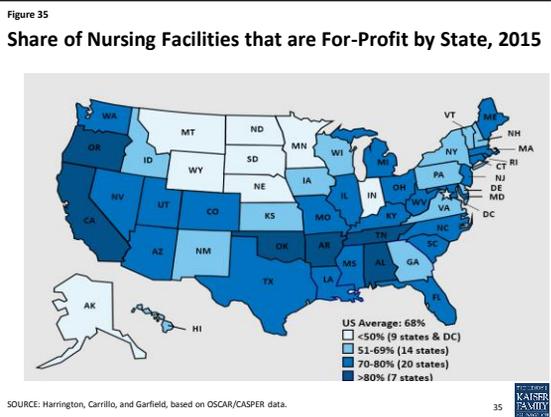
Figure 27

Average Nursing Facility Occupancy Rates By States, 2015



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





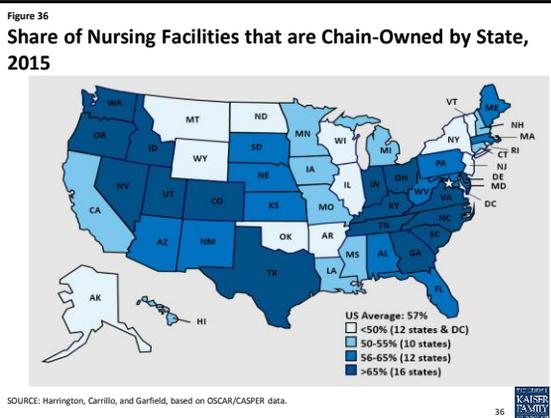


Figure 40
Average Number of Deficiencies Per Nursing Facility by State, 2015

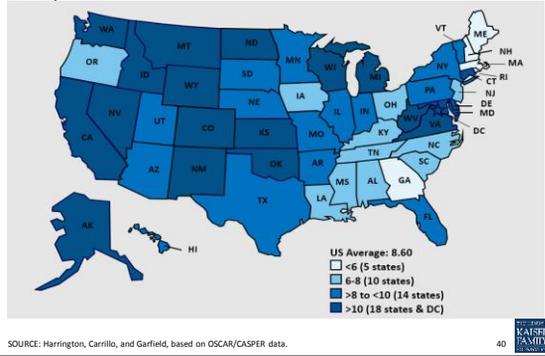


Figure 41
Most Common Nursing Home Deficiencies, 2015

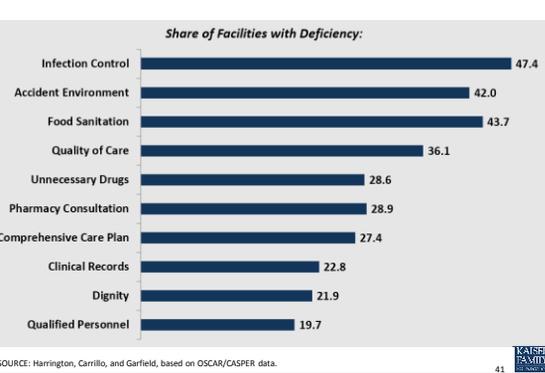


Figure 42

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



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

Steve Eiken

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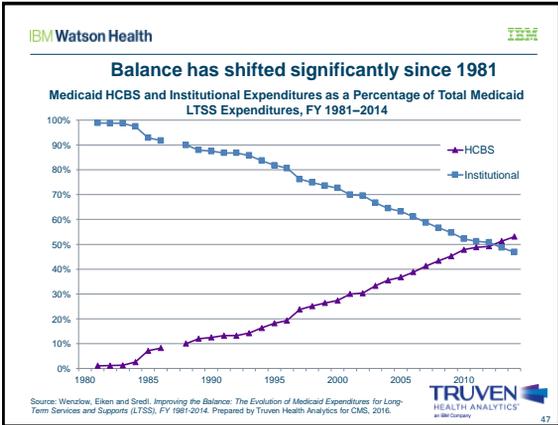
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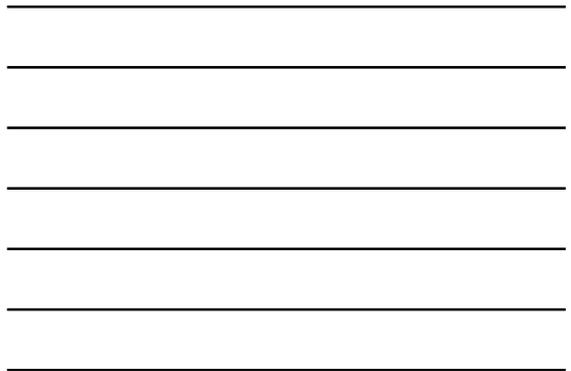
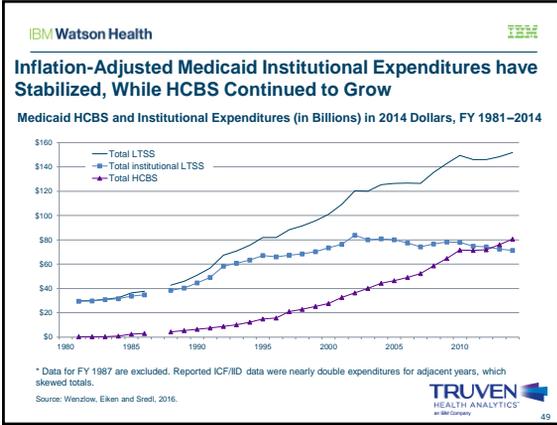
Three Decades of Policy and Legislative Changes have Supported the Expansion of HCBS

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

Source: Wenzlow, Eiken and Sredl, 2016.

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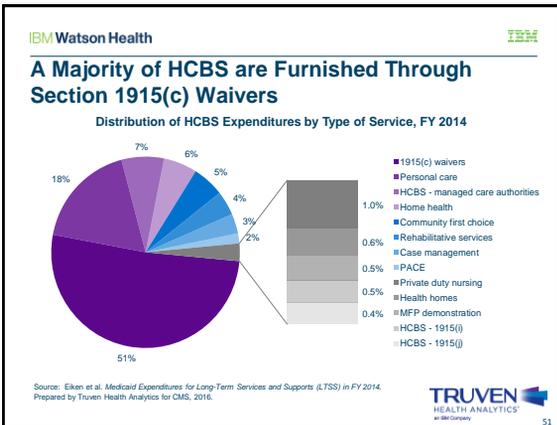
HCBS Expenditures have Increased at a Faster Rate than Institutional Expenditures

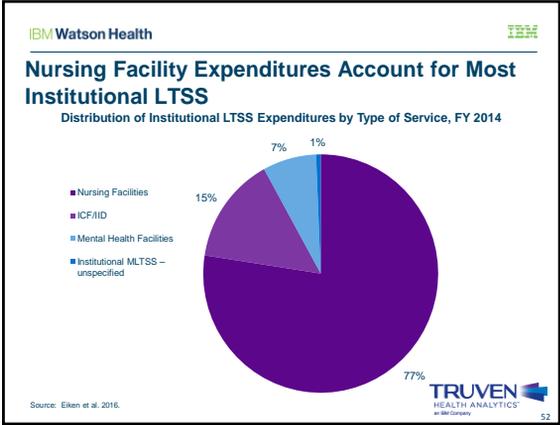
Average Annual Rate of Growth in HCBS and Institutional LTSS Expenditures in 2014 Dollars, FY 1981–2014

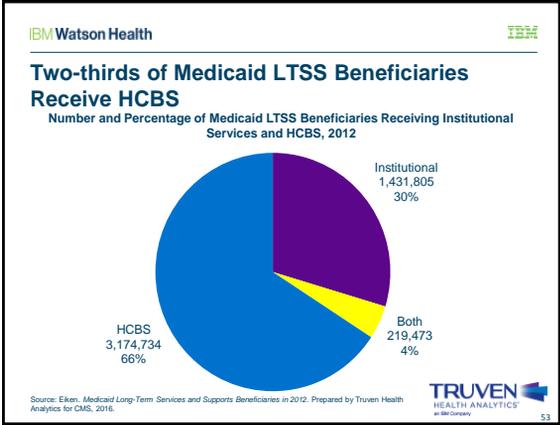
Service Type	1981 – 1985	1986 – 1990	1991 – 1995	1996 – 2000	2001 – 2005	2006 – 2010	2011 – 2014
Institutional LTSS	3.4%	5.7%	8.5%	1.8%	1.7%	(0.5%)	(2.2%)
HCBS	67.6%	19.7%	18.5%	13.1%	11.0%	9.0%	3.1%
Total LTSS	5.1%	7.0%	10.0%	4.2%	4.6%	3.4%	0.4%

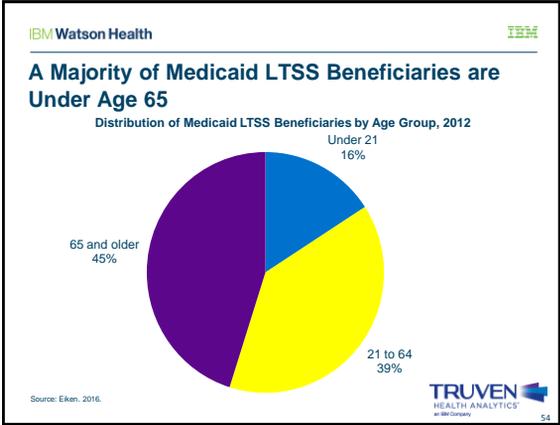
Source: Wendlow, Eiken and Sredt, 2016.

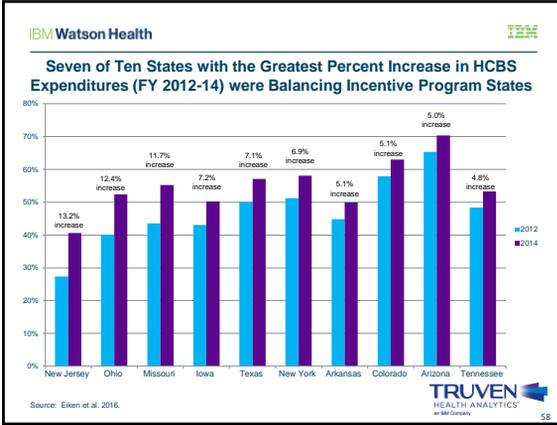
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Questions & Discussions

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For More Information

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Annual and historical reports on LTSS Medicaid expenditures and beneficiaries: <https://www.medicaid.gov/medicaid/ltss/reports-and-evaluations/index.html>.

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Speakers

- Carol Irvin
Mathematica Policy Research



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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

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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



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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, it 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?

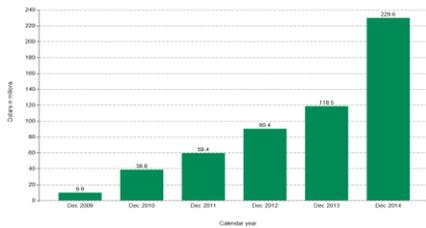


Rebalancing Program



MFP Rebalancing Fund Expenditures Continue to Grow

Cumulative Expenditures of State Rebalancing Funds, December 2009 to December 2014

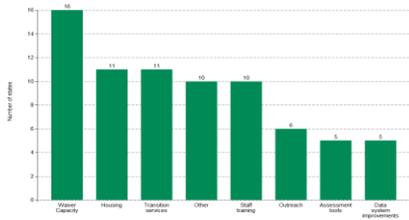


Source: Mathematica analysis of State MFP Grantee Semiannual Progress Reports, 2015.
Note: N = 16 states in 2009, 19 states in 2010, 20 states in 2011, 25 states in 2012, 22 states in 2013, and 27 states in 2014.



States Use Rebalancing Funds in Different Ways

Types of Rebalancing Initiatives in 2014



Source: Mathematica analysis of State MFP Grantee Semiannual Progress Reports, 2015.
Notes: States may spend rebalancing funds on multiple types of initiatives and can be counted in multiple categories.
N = 41 states.



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
 - Clrvin@mathematica-mpr.com
 - CMS MFP website
 - <https://www.medicaid.gov/medicaid/tss/money-follows-the-person/index.html>
 - Mathematica MFP website
 - <http://www.disabilitypolicyresearch.org/our-publications-and-findings/projects/research-and-evaluation-of-the-money-follows-the-person-mfp-demonstration-grants>





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