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  - Select “Edit” from the tool bar at the top of your screen
  - From the drop down menu select “Preferences”
  - Scroll down to “General”
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    - Select “Visual Notifications” Uncheck anything you don’t want to receive and “apply”
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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, NIDILRR - Disability and Rehabilitation Research Program (DRRP)
Acknowledgements

- Lex Frieden (PI)
- Joy Hammel (Co-PI)
- Katie McDonald
- Michael Morris
- Peter Blanck
- Janet Smith
- Danbi Lee
- Lauren Nolan
- Lindsay Broughel
- Vinh Nguyen
- Roxy Funchess
- Bob Gattis
- Jill Bezyak
- Rachael Stafford
- Scott Sabella
- Lewis Kraus
- Terence Ng
- Marian Vessels
- Karen Goss
- Oce Harrison
- Ann Deschamps
- Christy Stuart
- Maynor Guillen
- Pam Williamson
- Barry Whaley
- Sally Weiss
- Robin Jones
- Peter Berg
- Candice Alder
- Erica Jones
- Michael Richardson
- Kathe 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 (Region 7)</td>
<td>Arkansas, Louisiana, New Mexico, Oklahoma, Texas</td>
<td>Houston, TX</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Tulsa, OK</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Austin, TX</td>
</tr>
<tr>
<td>Great Lakes (Region 5)</td>
<td>Illinois, Indiana, Michigan, Minnesota, Ohio, Wisconsin</td>
<td>Chicago, IL</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Detroit, MI</td>
</tr>
<tr>
<td>Southeast (Region 4)</td>
<td>Alabama, Florida, Georgia, Kentucky, Mississippi, North Carolina, South Carolina, Tennessee</td>
<td>Raleigh, NC</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Greensboro, NC</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Asheville, NC</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Gastonia, NC</td>
</tr>
<tr>
<td>Pacific (Region 9)</td>
<td>Arizona, California, Hawaii, Nevada, the Pacific Basin</td>
<td>Oakland, CA</td>
</tr>
<tr>
<td></td>
<td></td>
<td>San Francisco, CA</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Riverside, CA</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Sacramento, CA</td>
</tr>
<tr>
<td>Rocky Mountain (Region 8)</td>
<td>Colorado, Montana, North Dakota, South Dakota, Utah, Wyoming</td>
<td>Denver, CO</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Salt Lake City, UT</td>
</tr>
<tr>
<td>Mid-Atlantic (Region 3)</td>
<td>DC, Delaware, Maryland, Pennsylvania, Virginia, West Virginia</td>
<td>Baltimore, MD</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Washington, DC</td>
</tr>
<tr>
<td>Northwest (Region 10)</td>
<td>Alaska, Idaho, Oregon, Washington</td>
<td>Seattle, WA</td>
</tr>
</tbody>
</table>

### Tracking 3 Major Participation Areas

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- **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
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 for 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

Percentage of People with Disabilities Living in an Institution

Data source: 2017 to 14. Characteristics of the group quarters population in the United States, 2010 to 2014 American Community Survey 3-Year Estimates Table S2021A

Calculations: Number of people with disabilities living in an institution divided by the total number of people with any disability.

Note: Institutions include: nursing homes, hospital facilities, and correctional and juvenile institutions.
Benchmarking: Summarizing Community Living Participation at State Level (2013-15)

<table>
<thead>
<tr>
<th>Score</th>
<th>State</th>
<th>Summary Score across Community Living Indicators</th>
</tr>
</thead>
<tbody>
<tr>
<td>90</td>
<td>Alaska</td>
<td>Best States</td>
</tr>
<tr>
<td>89</td>
<td>Oregon</td>
<td></td>
</tr>
<tr>
<td>87</td>
<td>Arizona</td>
<td></td>
</tr>
<tr>
<td>85</td>
<td>Hawaii</td>
<td></td>
</tr>
<tr>
<td>83</td>
<td>Nevada</td>
<td></td>
</tr>
<tr>
<td>20</td>
<td>Kansas</td>
<td>Worst states</td>
</tr>
<tr>
<td>19</td>
<td>Connecticut</td>
<td></td>
</tr>
<tr>
<td>8</td>
<td>Iowa</td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>North Dakota</td>
<td></td>
</tr>
<tr>
<td>0</td>
<td>Utah</td>
<td></td>
</tr>
</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

A member of the ADA National Network

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**

- **US average: 82%**
  - < 75% Occupied (11 states)
  - 76-85% Occupied (18 states)
  - 86-90% Occupied (16 states)
  - >90% Occupied (6 states & DC)

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

Figure 28

**Number of Nursing Facility Admissions Per Bed in 2015**

LTC Focus Brown University http://ltcfocus.org/map/1/average-acuity-
index#2015/US/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

<table>
<thead>
<tr>
<th>Year</th>
<th>Private/Other</th>
<th>Medicare</th>
<th>Medicaid</th>
</tr>
</thead>
<tbody>
<tr>
<td>2009</td>
<td>63.7</td>
<td>22.2</td>
<td>14.2</td>
</tr>
<tr>
<td>2010</td>
<td>63.4</td>
<td>22.2</td>
<td>14.2</td>
</tr>
<tr>
<td>2011</td>
<td>64.0</td>
<td>22.2</td>
<td>13.9</td>
</tr>
<tr>
<td>2012</td>
<td>63.6</td>
<td>22.7</td>
<td>14.3</td>
</tr>
<tr>
<td>2013</td>
<td>63.0</td>
<td>23.3</td>
<td>14.2</td>
</tr>
<tr>
<td>2014</td>
<td>62.5</td>
<td>24.2</td>
<td>14.2</td>
</tr>
<tr>
<td>2015</td>
<td>61.6</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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

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

SOURCE: Harrington, Carrillo, and Garfield, based on OSCAR/CASPER data.
Figure 35
Share of Nursing Facilities that are For-Profit 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

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

<table>
<thead>
<tr>
<th>Year</th>
<th>Total Nurse Hours</th>
<th>Licensed Nurse Hours</th>
<th>RN Hours</th>
</tr>
</thead>
<tbody>
<tr>
<td>2009</td>
<td>3.9</td>
<td>1.5</td>
<td>0.7</td>
</tr>
<tr>
<td>2010</td>
<td>3.9</td>
<td>1.5</td>
<td>0.7</td>
</tr>
<tr>
<td>2011</td>
<td>4.0</td>
<td>1.5</td>
<td>0.7</td>
</tr>
<tr>
<td>2012</td>
<td>4.0</td>
<td>1.6</td>
<td>0.8</td>
</tr>
<tr>
<td>2013</td>
<td>4.0</td>
<td>1.6</td>
<td>0.8</td>
</tr>
<tr>
<td>2014</td>
<td>4.0</td>
<td>1.6</td>
<td>0.8</td>
</tr>
<tr>
<td>2015</td>
<td>4.1</td>
<td>1.6</td>
<td>0.8</td>
</tr>
</tbody>
</table>

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
Largest for-profit chains have significantly lower total staffing than all other ownership types. Harrington, et al. 2012. Health Services Research.

Source: Harrington, Carrillo, and Garfield, based on OSCAR/CASPER data.
Most Common Nursing Home Deficiencies, 2015

<table>
<thead>
<tr>
<th>Deficiency</th>
<th>Share of Facilities with Deficiency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Infection Control</td>
<td>47.4</td>
</tr>
<tr>
<td>Accident Environment</td>
<td>42.0</td>
</tr>
<tr>
<td>Food Sanitation</td>
<td>43.7</td>
</tr>
<tr>
<td>Quality of Care</td>
<td>36.1</td>
</tr>
<tr>
<td>Unnecessary Drugs</td>
<td>28.6</td>
</tr>
<tr>
<td>Pharmacy Consultation</td>
<td>28.9</td>
</tr>
<tr>
<td>Comprehensive Care Plan</td>
<td>27.4</td>
</tr>
<tr>
<td>Clinical Records</td>
<td>22.8</td>
</tr>
<tr>
<td>Dignity</td>
<td>21.9</td>
</tr>
<tr>
<td>Qualified Personnel</td>
<td>19.7</td>
</tr>
</tbody>
</table>

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

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

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

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


* Data for FY 1987 are excluded. Reported ICF/IID data were nearly double expenditures for adjacent years, which skewed totals.


HCBS Expenditures have Increased at a Faster Rate than Institutional Expenditures


<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Institutional LTSS</td>
<td>3.4%</td>
<td>5.7%</td>
<td>8.5%</td>
<td>1.8%</td>
<td>1.7%</td>
<td>(0.5%)</td>
<td>(2.2%)</td>
</tr>
<tr>
<td>HCBS</td>
<td>67.6%</td>
<td>19.7%</td>
<td>18.5%</td>
<td>13.1%</td>
<td>11.0%</td>
<td>9.0%</td>
<td>3.1%</td>
</tr>
<tr>
<td>Total LTSS</td>
<td>5.1%</td>
<td>7.0%</td>
<td>10.0%</td>
<td>4.2%</td>
<td>4.6%</td>
<td>3.4%</td>
<td>0.4%</td>
</tr>
</tbody>
</table>

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

Distribution of HCBS Expenditures by Type of Service, FY 2014

- 1915(c) waivers: 51%
- Personal care: 18%
- HCBS - managed care authorities: 7%
- Home health: 6%
- Community first choice: 5%
- Rehabilitative services: 4%
- Case management: 3%
- PACE: 2%
- Private duty nursing: 1.0%
- Health homes: 0.6%
- MFP demonstration: 0.5%
- HCBS - 1915(i): 0.5%
- HCBS - 1915(j): 0.4%


Nursing Facility Expenditures Account for Most Institutional LTSS

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

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

Two-thirds of Medicaid LTSS Beneficiaries Receive HCBS

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

- Institutional: 1,431,805 (30%)
- HCBS: 3,174,734 (66%)
- Both: 219,473 (4%)


A Majority of Medicaid LTSS Beneficiaries are Under Age 65

Distribution of Medicaid LTSS Beneficiaries by Age Group, 2012

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

Source: Eiken, 2016.
Balance Varies by Subgroup


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

Rehabilitative services reporting begins in 2010


Balance Varies by Age

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

- Under 21: 86% HCBS Only, 12% Institutional Only, 2% Both
- 21 to 64: 78% HCBS Only, 18% Institutional Only, 4% Both
- 65 and older: 48% HCBS Only, 46% Institutional Only

Source: Eiken, 2016.
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


Seven of Ten States with the Greatest Percent Increase in HCBS Expenditures (FY 2012-14) were Balancing Incentive Program States

Questions & Discussions

For More Information

Steve Eiken
Research Manager
Truven Health Analytics, an IBM Company
seiken@us.ibm.com
651-917-4174

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, 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?
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

Source: Mathematica’s analysis of Medicaid and Medicare expenditures for MFP participants who transitioned from institutional to community-based long-term services and supports from 2008 through 2011. Pre-transition is defined as the 12 months before the transition, and post-transition is the 12 months after the transition. Data only represent young adults who transitioned from nursing home care.

Large Improvements in Quality of Life

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 March 2015.


**Large Improvements in Quality of Life**

**Quality of Life of MFP Participants**

**Pre- and Post-Transition**

![Bar chart showing improvements in quality of life](chart.png)

Source: Mathematica's analysis of MFP Quality-of-Life surveys and program participation data submitted to CMS through March 2015.

Note: Lower percentages indicate an improvement. Unmet care needs include bathing, eating, medication management, or toileting. Barriers to participating in the community are measured as an affirmative response to "Is there anything you want to do outside [the facility/your home] that you cannot do now?"

---

**Rebalancing Program**
MFP Rebalancing Fund Expenditures Continue to Grow

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


States Use Rebalancing Funds in Different Ways

Types of Rebalancing Initiatives in 2014

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
  – CIrvin@mathematica-mpr.com
  – CMS MFP website
    • https://www.medicaid.gov/medicaid/ltss/money-follows-the-person/index.html
  – Mathematica MFP website
Questions?

**Telephone:** Follow the instructions given by the Operator

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The next scheduled session is:

_There will be NO Session held during the Month of May._

_Watch the Schedule for future postings_

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