

**The CMS Final Rule on HCBS &
The DOJ's Enforcement of Title II
of the ADA and "Olmstead"
Assuring Community Integration**

**A Webinar for
Irwin Siegel Agency, Inc.**

November 9, 2016

Allan I. Bergman





What's Driving HCBS and all of these Changes?

Administration for Community Living

- Established by HHS Secretary Sebelius
 - A single agency charged with developing policies and improving **supports for seniors and people with disabilities.....**
 - Committed to the 4 goals of the ADA
 - Committed to a shared common vision:...
- “All Americans... the right to live in a home of their choosing, with people with whom they care about, that is integrated into a community that values their participation & contributions.”**

April 18, 2012

The Administration for Community Living

ACL is based on a commitment to one fundamental principle—that **people with disabilities and older adults should be able to live where they choose, with the people they choose, and fully participate in their communities.**

Inherent in this principle is the core belief that **everyone can contribute throughout their lives.**

FUNDING:

Money Matters...and Drives Practice



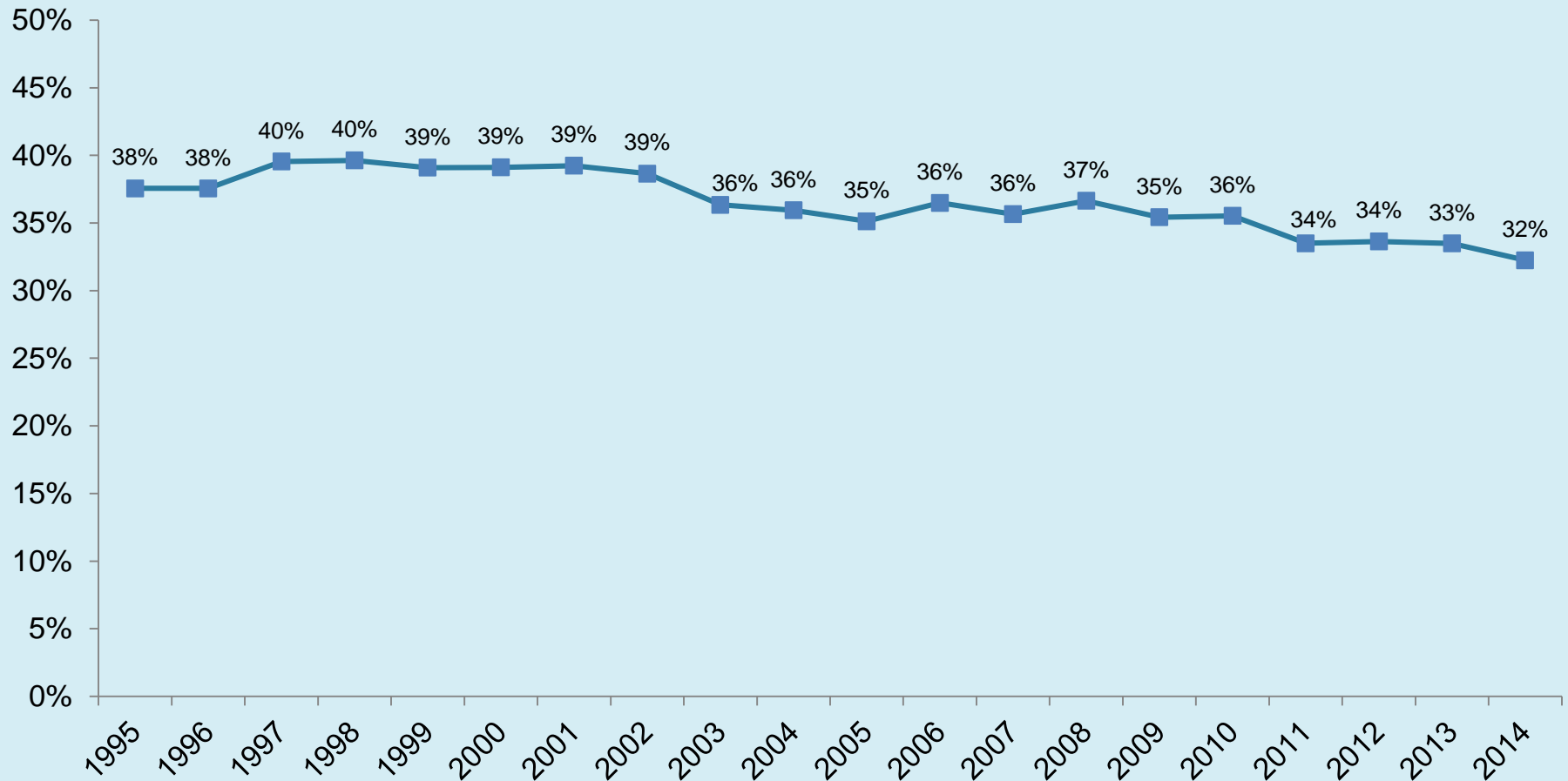
Be Bold. Embrace Difference. Change Lives.

Medicaid Overview: 2012 data from Congressional Budget Office; 5-2013

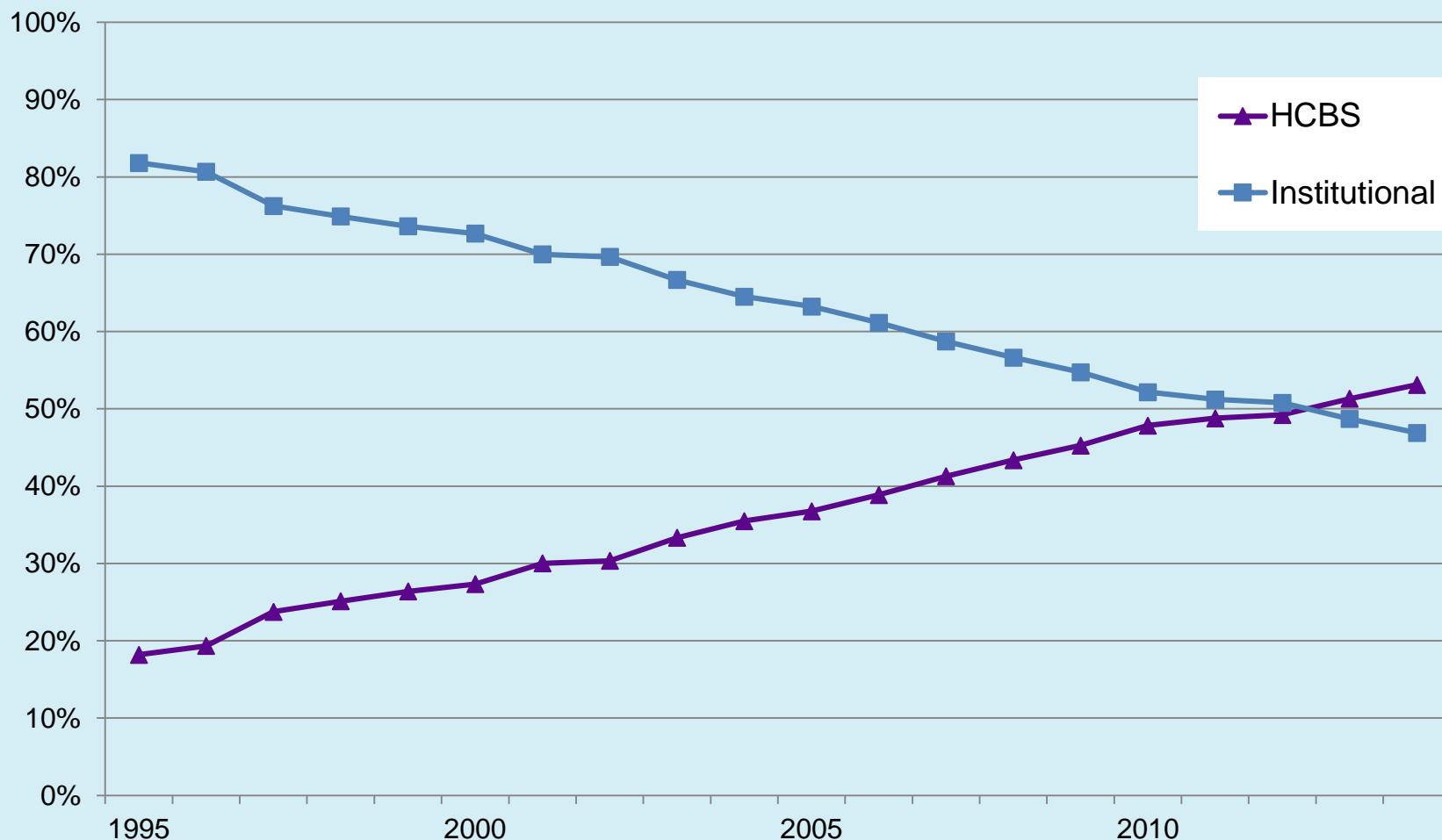
- 67 million beneficiaries:
 - 47 % children ; 21% of expenditures
 - 28% adults; 15% of expenditures
 - **9% seniors; 15% of expenditures**
 - **16% PWD; 44% of expenditures**

Total expenditures for state and federal governments, FY'11: **\$432 Billion...**

LTSS as a Percentage of Total Medicaid Expenditures, FY 1995–2014



Medicaid HCBS and Institutional Expenditures as a Percentage of Total Medicaid LTSS Expenditures, FY 1995–2014

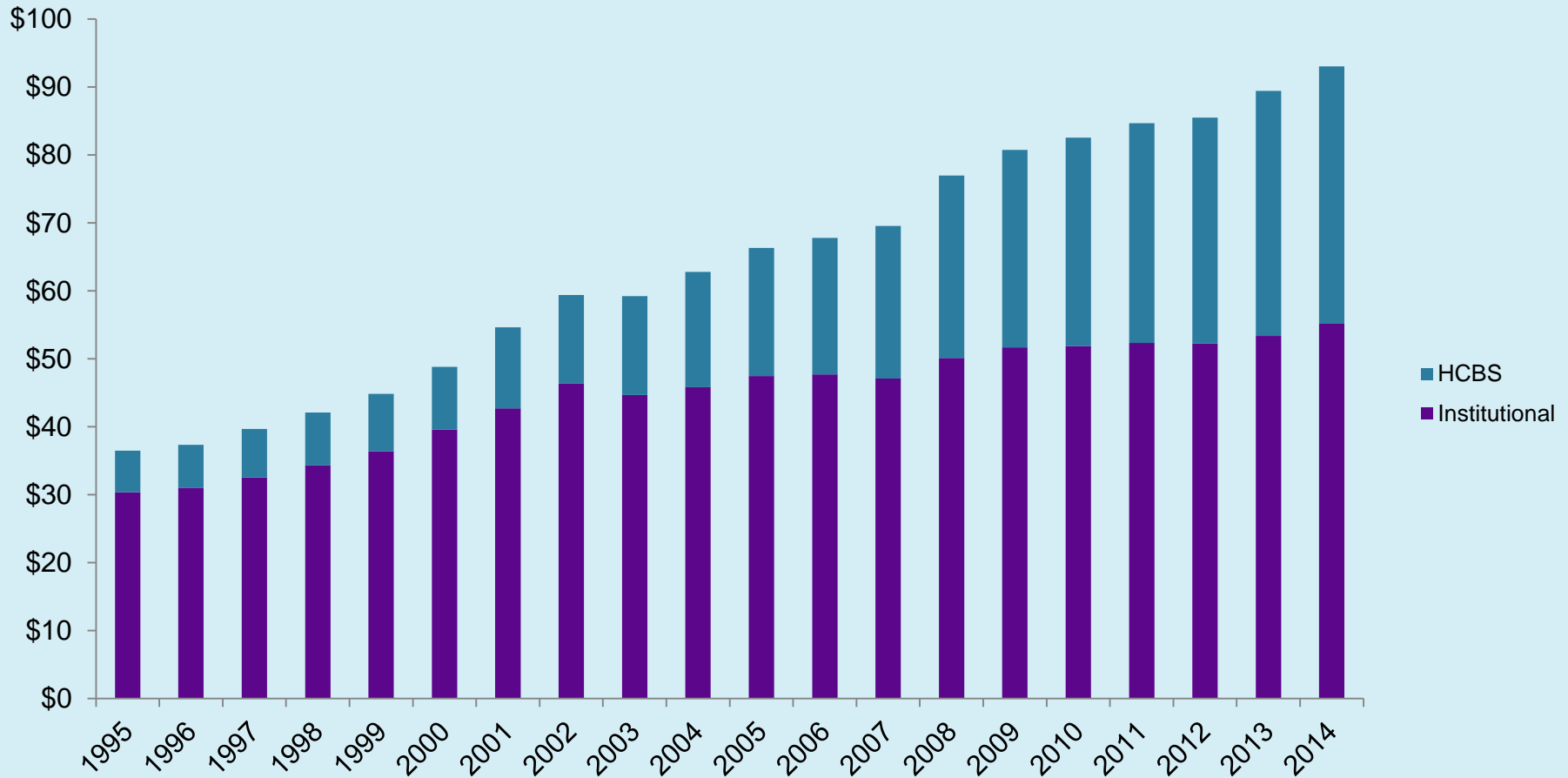


Medicaid HCBS Expenditures as a Percent of Total Medicaid LTSS Expenditures, by State, FY 2014

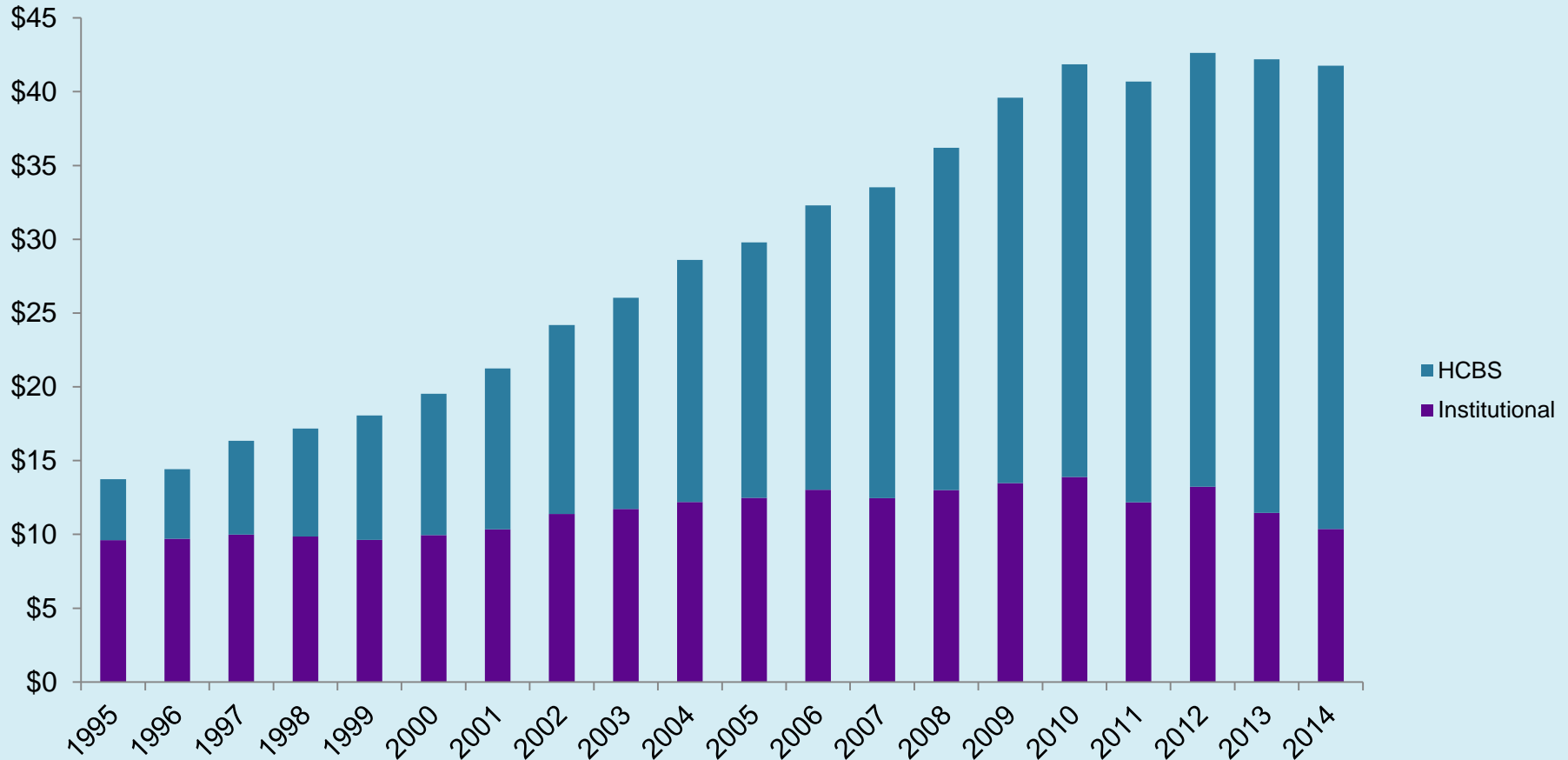


* North Carolina was not included because a high proportion of data were not reported.

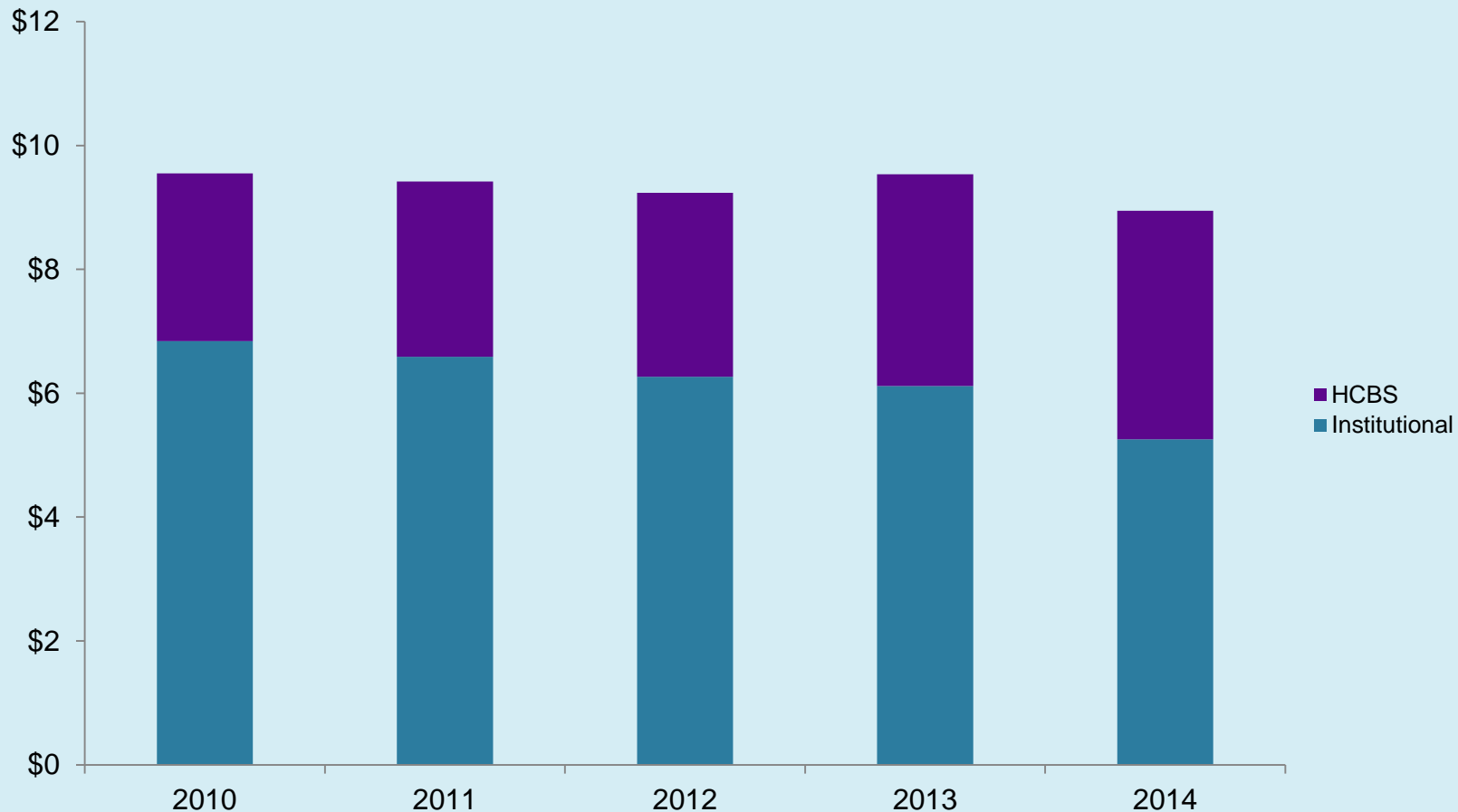
LTSS Spending Targeted to Older People and People with Physical Disabilities, in billions, FFY 1995-2014



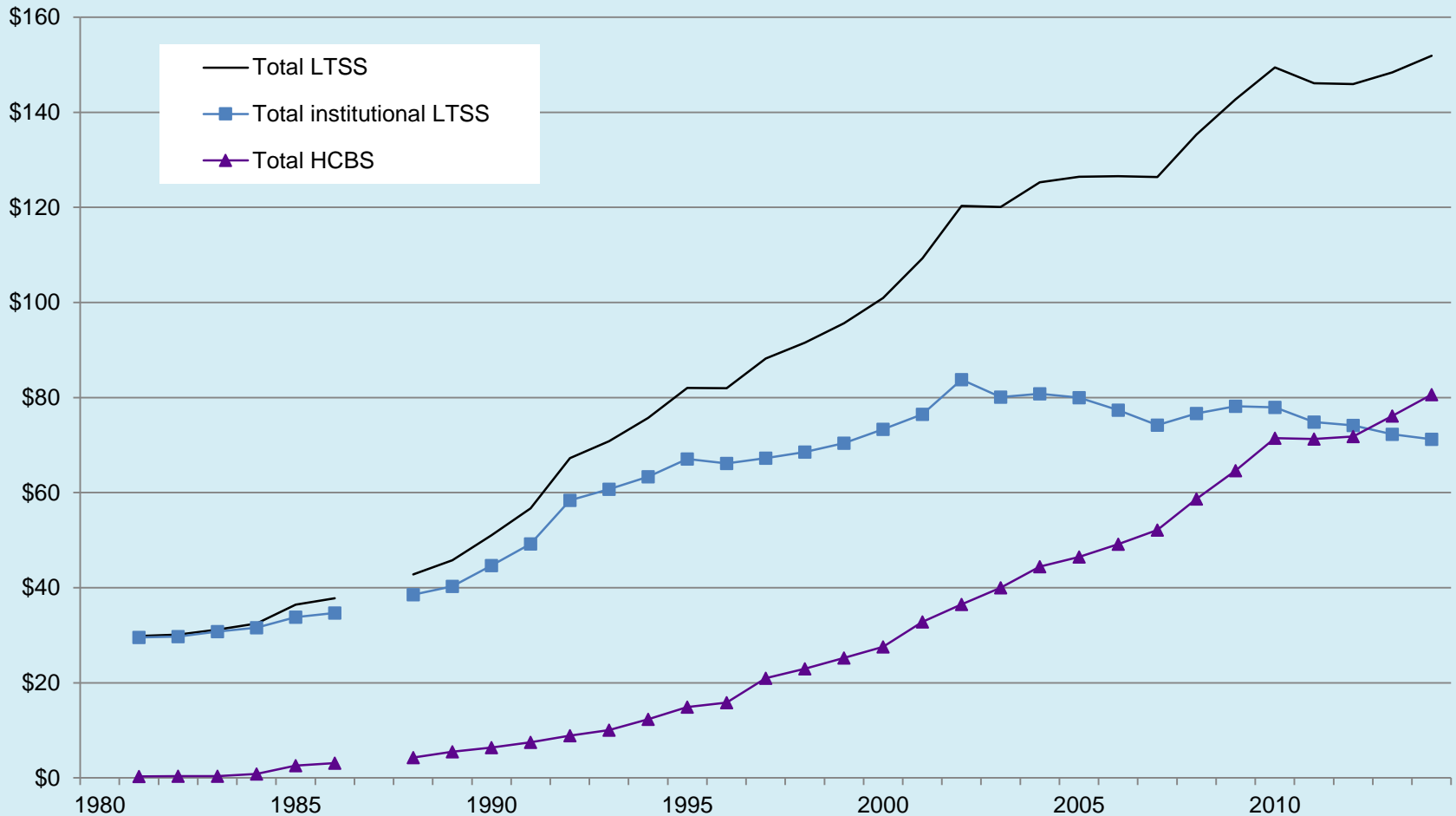
LTSS Spending Targeted to People with Developmental Disabilities, in billions, FY 1995-2014



LTSS Expenditures Targeted to People with Serious Mental Illness or Serious Emotional Disturbance, in billions, FY 2010-2014

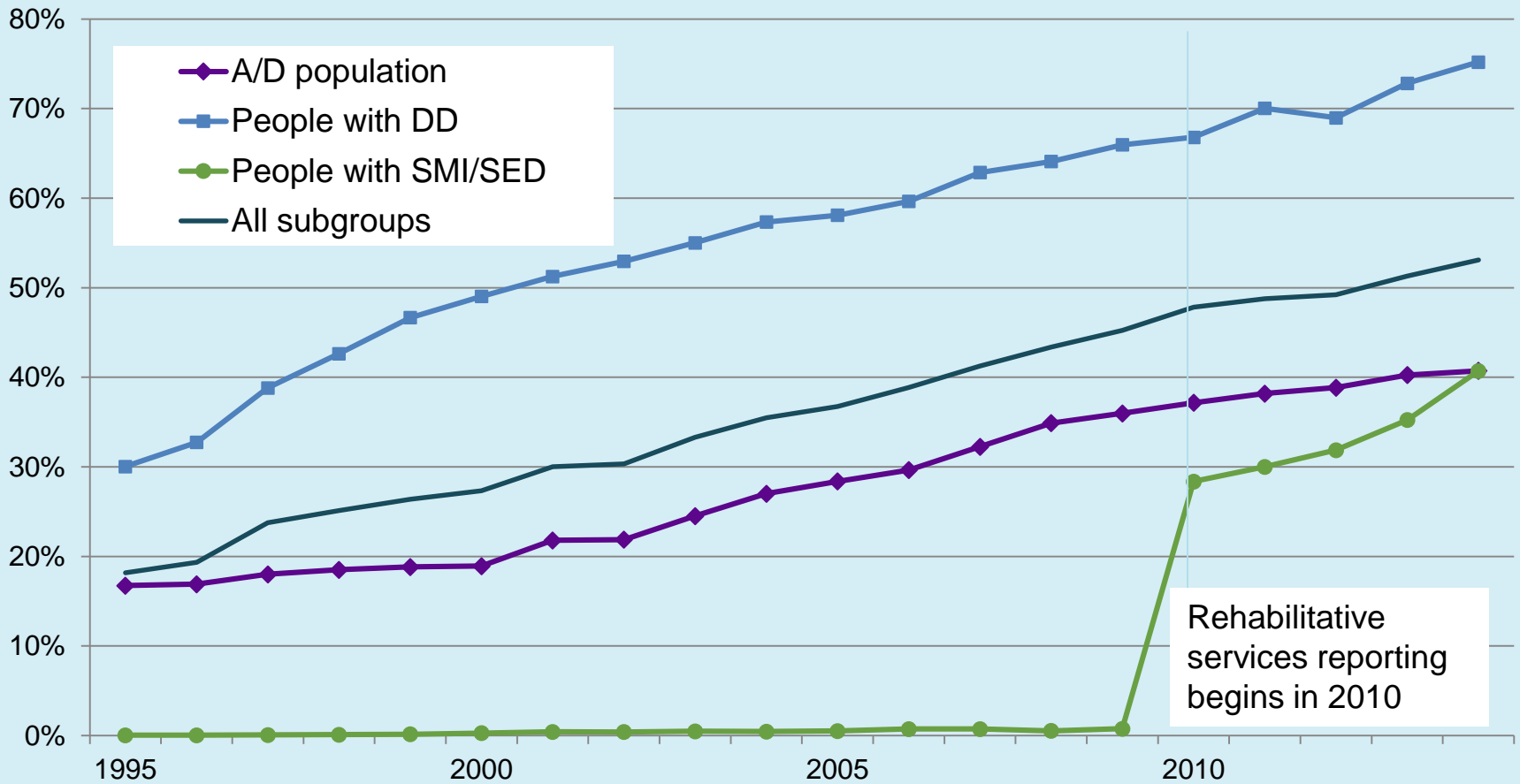


Medicaid HCBS and Institutional Expenditures (in Billions) in 2014 Dollars, FY 1981–2014

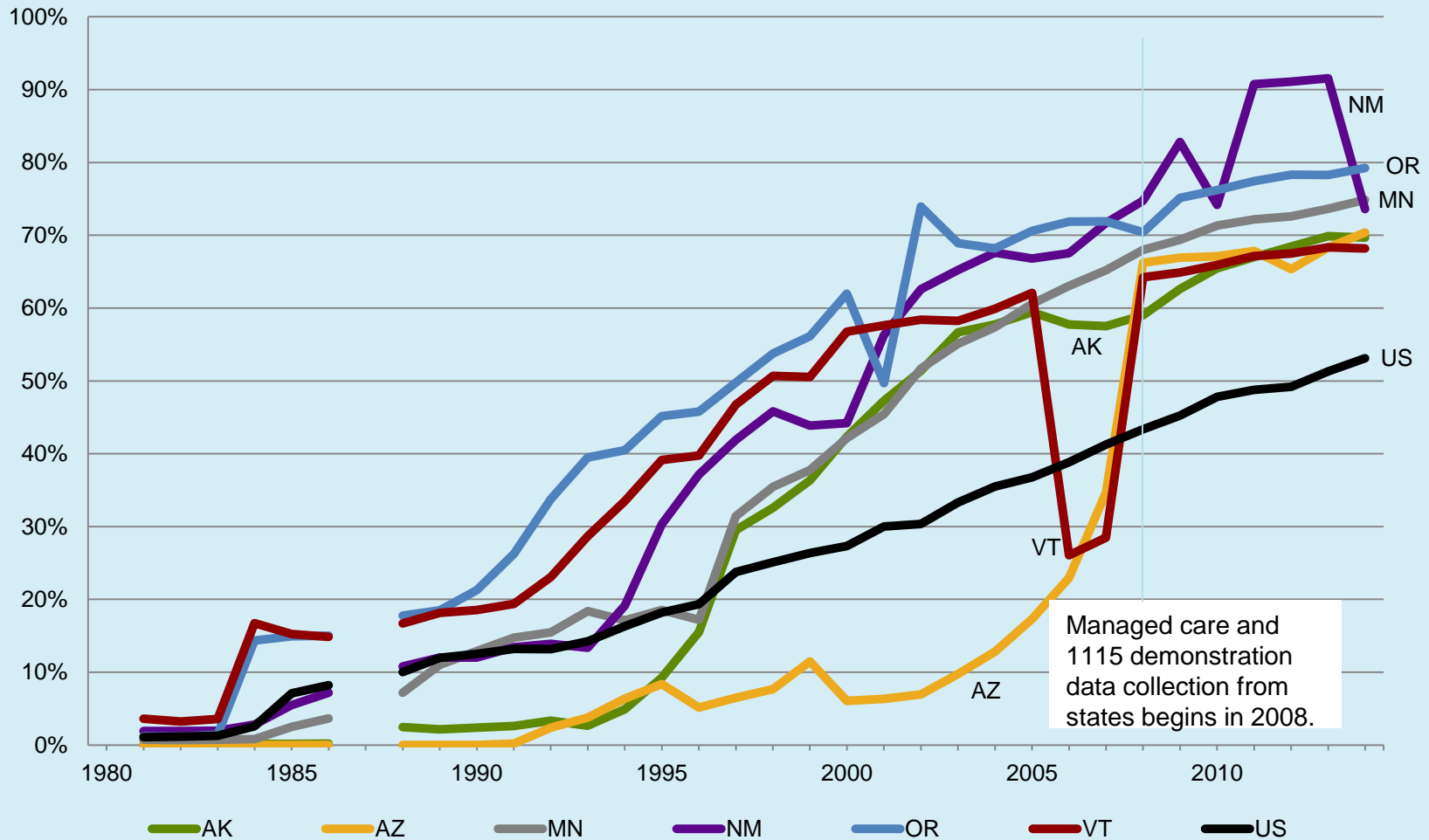


* Data for FY 1987 are excluded. Reported ICF/IID data were nearly double expenditures for adjacent years, which skewed totals.

Medicaid HCBS Expenditures as a Percentage of Total Medicaid LTSS Expenditures, by Population Subgroup, FY 1995–2014



Medicaid HCBS Expenditures as a Percentage of Total Medicaid LTSS Expenditures, FY 1981–2014, Top Six States in 2014



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



Coleman Institute for Cognitive Disabilities

UNIVERSITY OF COLORADO

Boulder | Colorado Springs | Denver | Anschutz Medical Campus

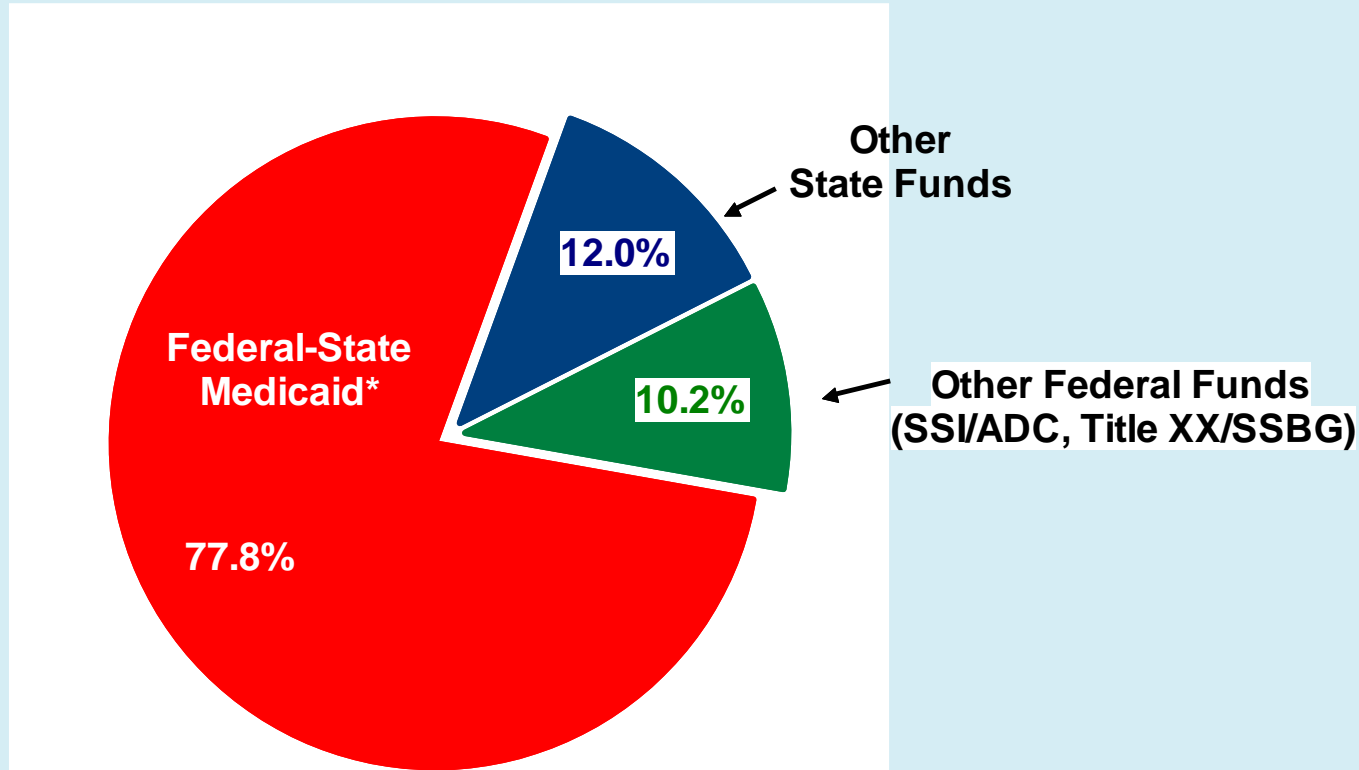
THE STATE OF THE STATES IN DEVELOPMENTAL DISABILITIES

Richard Hemp, Mary Kay Rizzolo, Shea Tanis,
& David Braddock

Universities of Colorado and Illinois-Chicago

AUGUST 5, 2014

MEDICAID WAS 78% OF TOTAL I/DD SPENDING IN 2013 --66% OF MEDICAID WAS HCBS WAIVER SPENDING



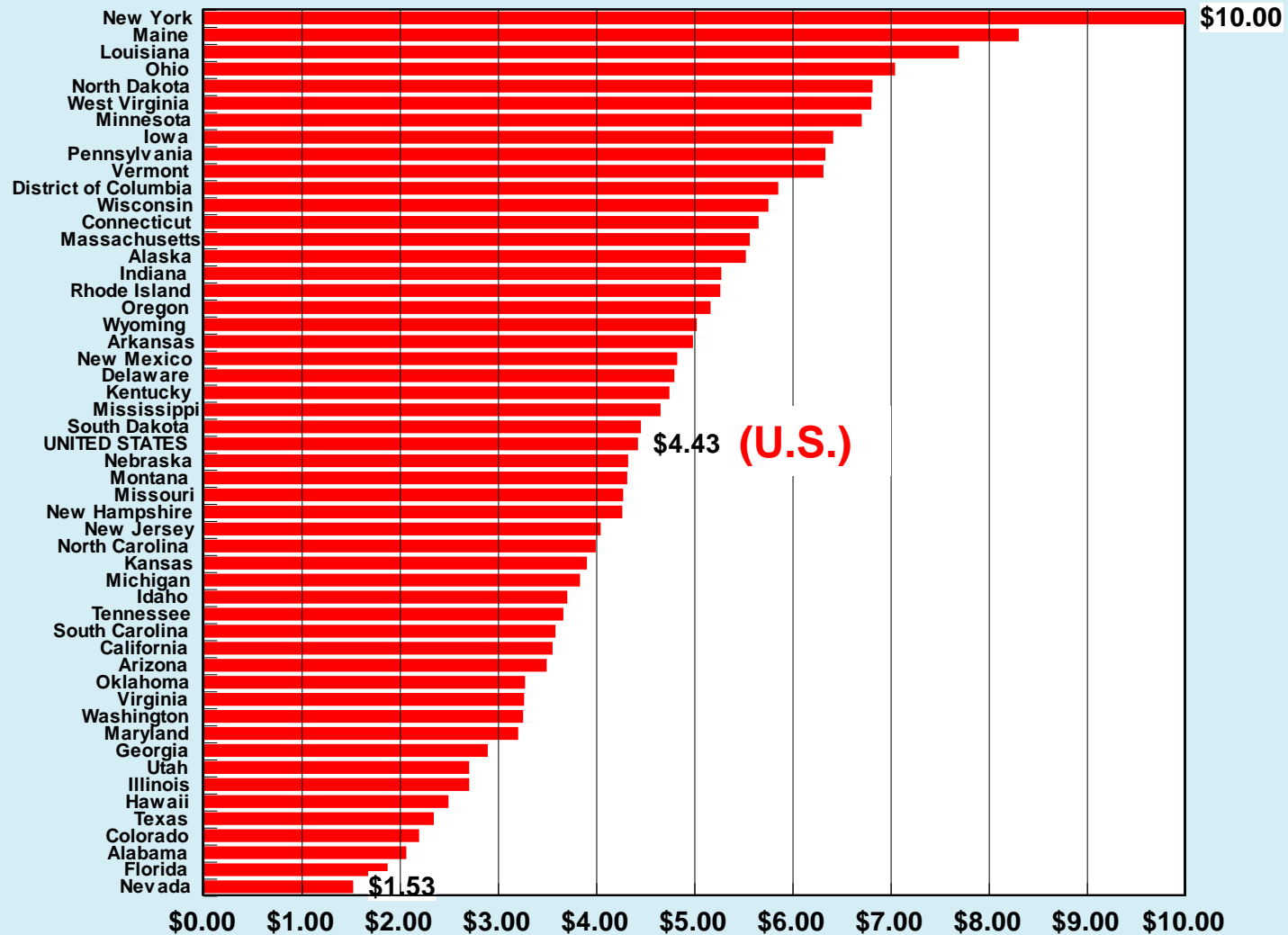
Total I/DD Spending: \$61.65 Billion

*Total federal-state Medicaid: \$48.0 billion
a) HCBS Waiver (66%);
b) Public & Private ICFs/ID (27%); and
c) Related Medicaid (7%)

1. DISTRICT OF COLUMBIA (1991)
2. NEW HAMPSHIRE (1991)
3. VERMONT (1993)
4. RHODE ISLAND (1994)
5. ALASKA (1997)
6. NEW MEXICO (1997)
7. WEST VIRGINIA (1998)
8. HAWAII (1999)
9. MAINE (1999)
10. INDIANA (2013)*
11. MICHIGAN (2009)
12. OREGON (2009)
13. MINNESOTA (2011)
14. ALABAMA (2012)
15. OKLAHOMA (2015)

***Indiana closed I/DD units at Madison, Evansville and Richmond MH Centers in 2012 and at Logansport in 2013**

TOTAL I/DD SERVICES FISCAL EFFORT: 2013*



* Dollars per \$1,000 of Statewide Aggregate Personal Income

Source: Bureau of Economic Analysis (2014)

Private ICF/DD Numbers: Smallest, 2013

▪ <u>MD</u> , MASS, <u>MI</u> , <u>MT</u> ,		▪ <u>NV.</u>	54
<u>OR</u> , S.C., <u>WY</u>	0	▪ <u>DE.</u>	66
▪ <u>VT.</u>	6	▪ <u>HI.</u>	87
▪ <u>R.I.</u>	18	▪ MO.	92
▪ <u>CO.</u>	20	▪ GA.	108
▪ <u>N.H.</u>	25	▪ KS.	154
▪ <u>AL.</u>	35	▪ KY.	154
▪ <u>AZ</u>	39	▪ <u>ME.</u>	170
▪ N.J.	44		
▪ <u>S.D.</u>	44		

Red = no state
institutions

Private ICF/DD Numbers: Largest

■ CA	7,339	+ 1,744 St. = 9,083
■ IL	6,426	+ 2,034 St. = 8,460
■ OH	6,137	+ 1,228 St. = 7,365
■ NY	6,063	+ 1,313 St. = 7,376
■ TX	5,583	+ 4,331 St. = 9,914
■ IN	3,870	
■ LA	3,799	
■ NC	2,633	
■ PA	2,578	+ 1,572 St. = 4,150
■ FL	1,976	+ 1,174 St. = 3,150

Data on SSI Beneficiaries, 2014

- **4.9 million between ages 18 and 64**
(30% of these beneficiaries also received some type of Social Security payment)
- **Only 4.7% of the SSI beneficiaries of working age reported earned income**
- The average earned income is \$300/year
(for individuals who are blind, \$460/year)
- Less than 1% leave the rolls per year and only 1/2 of those for employment

Source: SSA

SOCIAL SECURITY DATA AND TRENDS

- **SSDI and Medicare beneficiaries:**
 - 7.3 million in 2008
 - 8.8 million in 2013 (+ 1 million DAC)
 - 11.7 million projected in 2020

- **SSI and Medicaid beneficiaries**
 - 6.1 million in 2008; 8 million in 2013
 - 10.0 million projected in 2020

- Total cost in 2008: \$428 billion
- **Projected in 2018: \$1.0 trillion**

Poverty *By The Numbers*

SUBPOPULATION	2009 Poverty Rate	2014 Poverty Rate
Children	20.7%	21.1%
African-American	25.8%	26.2%
Hispanic	25.3%	23.6%
Disability	25.0%	28.5%
Total U.S. Population	14.3%	14.8%

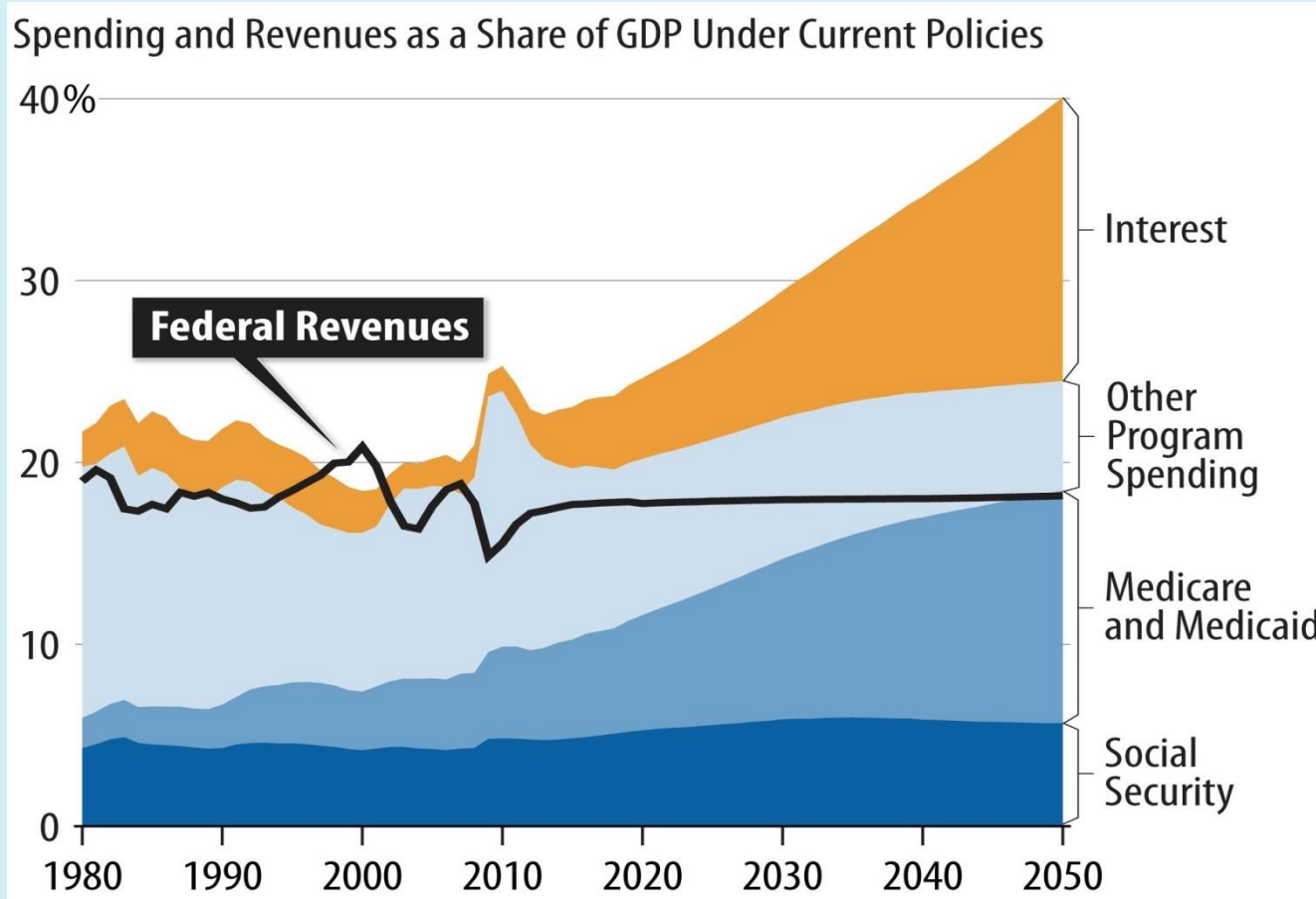
U.S. Census Bureau (September 2015)

46.657 million Americans were living in poverty in 2014.

Persons with Disabilities experienced the highest rates of poverty of any other subcategory of Americans for the 13th year in a row.

It is expected that SSDI/SSI annual payments will reach over \$1 trillion by 2023.

Current Policies Are Not Fiscally Sustainable



Source: CBPP projections based on CBO data.

Vision.....

“The only thing
that is constant
is change.”

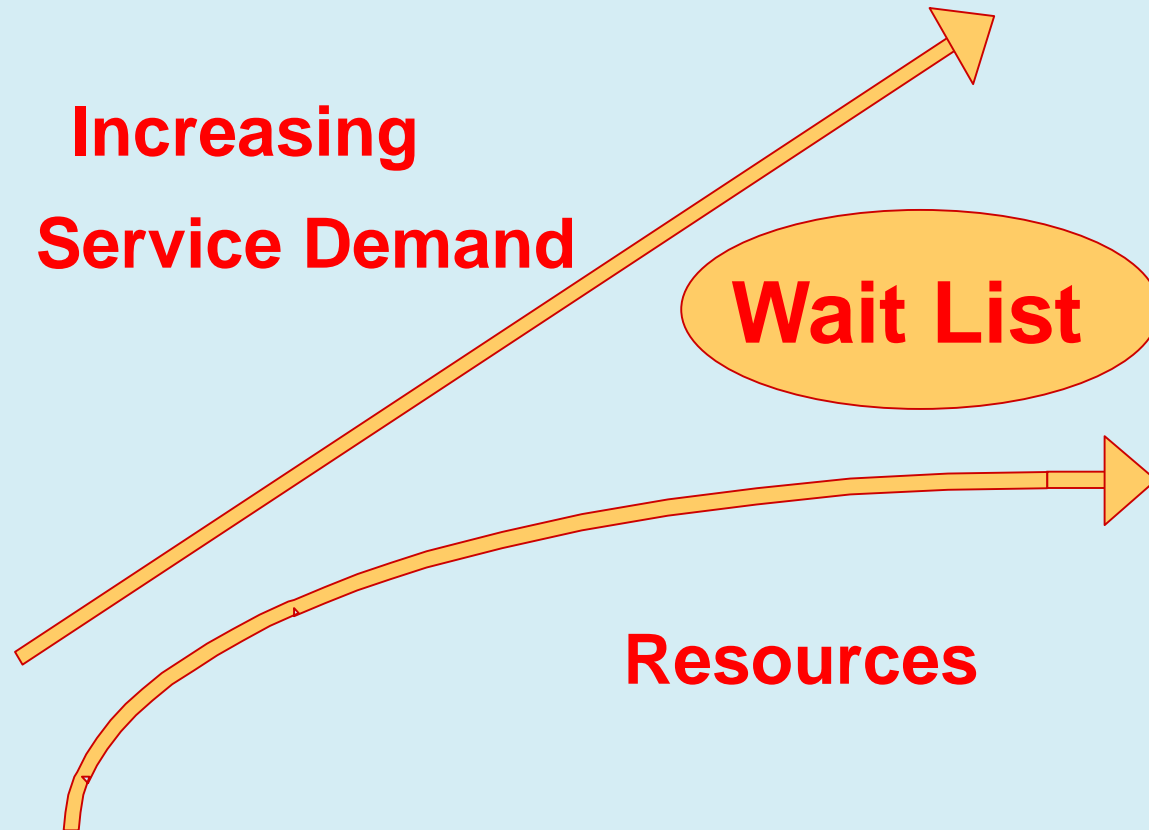
Heraclitis

New Leadership at Microsoft

“ Our industry does not respect tradition. It only respects innovation.”

Satya Nadella
February 2014

We Face a Big Problem...



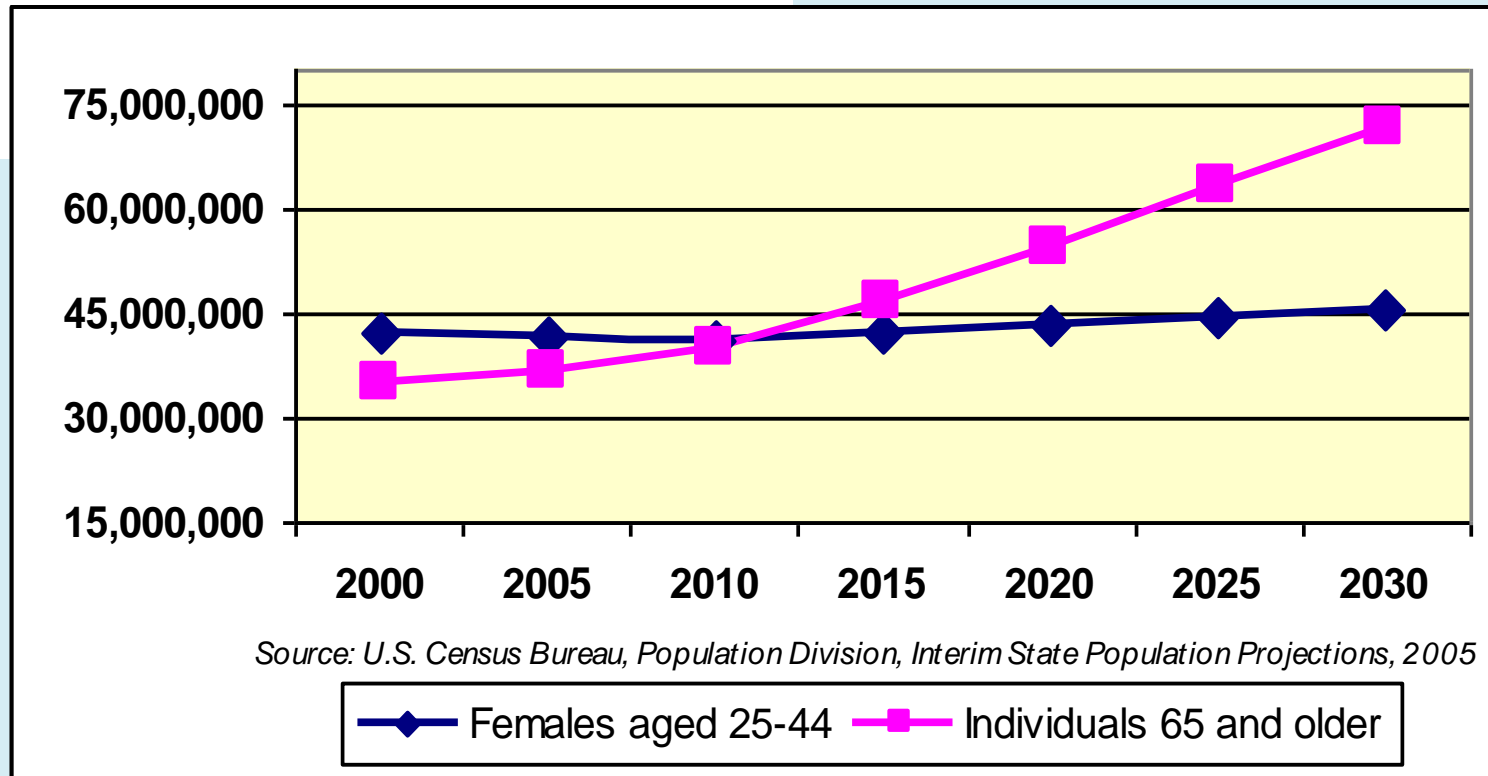
People Waiting for In-Home or Residential LTSS 1999 to 2012



New York OPWDD Age Distribution of Individuals Getting Direct Medicaid Services, 09-10

▪ Age 00-10	▪ 10,400
▪ Age 11-20	▪ 18,093
▪ Age 21-30	▪ 20,562
▪ Age 31-40	▪ 14,320
▪ Age 41-50	▪ 15,768
▪ Age 51-60	▪ 12,111
▪ Age 61-70	▪ 6,024
▪ Age 71-80	▪ 2,267
▪ Age 81 +	▪ <u>887</u>
	▪ 100,433

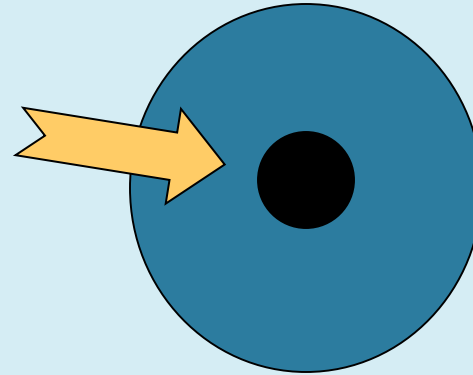
Demographic Shift - Not Enough Workers to Take Care of the Baby Boomers



Larson, Edelstein, 2006

What To Do???

We can't stay on
this spot



We need to rethink
what we do – **affirm
our values** and
resolutely search for
“valued outcomes”

“Suit the Actions to the Words”

"Life is not a "Program"

**Transforming from Paper &
Process Compliance to
Accountability and Payment for
Valued Outcomes**

What is our Vision for People?

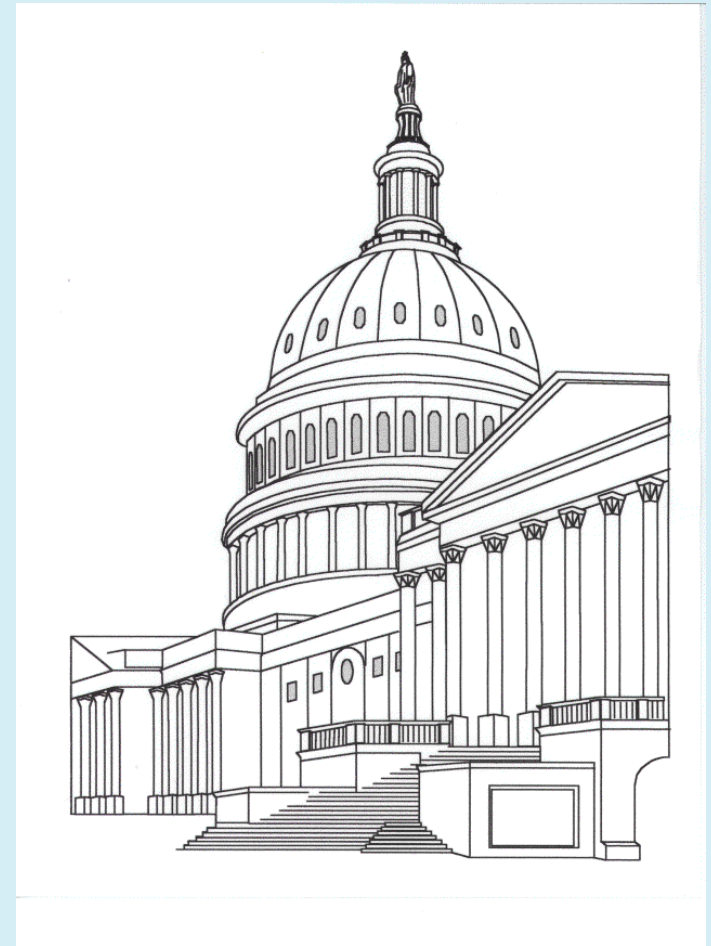
- Support people with disabilities to have **lives like people without disabilities**
- Provide opportunities for true integration, independence, **experientially-based informed choice**, and self-determination in all aspects of life
- Ensure **quality services** that meet people's needs and help them achieve goals they have identified through **real person-centered planning and measurable outcomes (CQL POMs, NCI, others)**

Vision 2016.....

“Each citizen should plan his part in the community according to his individual gifts.”

Plato

Values, Outcomes and Guiding Principles within Federal Legislation and the Court



DISABILITY CONSTRUCT IN LAWS

- “Disability is a natural part of the human experience and in **no way diminishes the right of individuals to:**
 - Live independently
 - Enjoy self determination
 - Make choices
 - Contribute to society
 - Pursue meaningful careers
 - Enjoy full inclusion and integration in the economic, political, social, cultural, and educational mainstream of American society.

Assistive Technology Defined:

“...any item, piece of equipment, or product system, whether acquired commercially, modified, or customized that is **used to increase, maintain, or improve functional capabilities** of individuals with disabilities.”

- Includes accessibility adaptations to the workplace and special equipment to help people work;
- Definition in 4 federal laws: IDEA; Rehab. Act; Assistive Technology Act; DD Act;

Purpose of Medicaid, Title XIX of the Social Security Act

- “...(2) rehabilitation and other services to help such families and individuals **attain or retain capability for independence or self care.**”

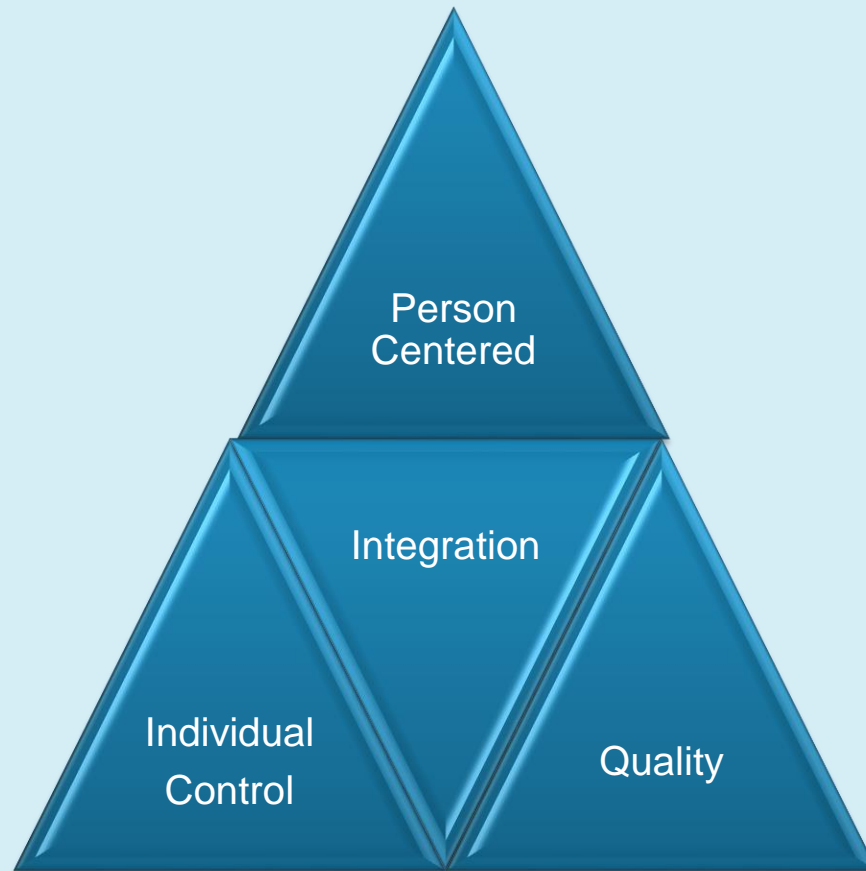
42 U.S.C. Sec. 1396

Values from the former CMS Administrator

“ There is more evidence than ever that people who need long-term care prefer to live in their own homes and communities whenever possible. To restrict those individuals to institutions where even the simplest decisions of the day such as when to get up, what to eat and when to sleep are made by someone else must no longer be the norm.”

Donald Berwick, M.D., 2-23-2011

The Foundation for a Redesigned Service System for Individuals with Chronic Conditions, by CMS



Money Follows the Person

- Provides enhanced match for each person for 365 days after leaving institution, including transition and admin. costs
- **“To increase the use of HCBS and to decrease the use of institutional services**
- To eliminate barriers and mechanisms in State law, State Medicaid plans or State budgets that prevent or restrict the flexible use of Medicaid funds to enable Medicaid eligible individuals to receive long term care in the settings of their choice

Money Follows the Person, cont.

- To strengthen the ability of Medicaid plans to assure continued provision of HCBS to those individuals who choose to transition from institutions: and,
- To ensure that procedures are in place to provide quality insurance and continuous quality improvement of HCBS”
- IL. Goal: 3,423 over 5 years; mostly people who are elderly or with physical D.

“Qualified Residence” under MFP

- “A home owned or leased by the individual or individual’s family member;
- An apartment with an individual lease with lockable access and egress, and which includes living, sleeping, bathing and cooking areas over which the individual or the individual’s family has domain or control; or, a residence, in a community-based setting in which no more than 4 unrelated individuals reside”

Findings of Congress in the Americans with Disabilities Act

- “physical or mental disabilities in no way diminish a person’s right to fully participate in all aspects of society, yet many people with physical or mental disabilities have been **precluded from doing so because of discrimination** others who have a record of a disability or are regarded as having a disability also have been subjected to discrimination.”
- Signed into law July 26, 1990 (24 yrs. ago)

ADA Findings, cont.

- **“Historically, society has tended to isolate and segregate individuals with disabilities,** and, despite some improvements, **such forms of discrimination** against individuals with disabilities continue to be a serious and pervasive social problem.

ADA Findings, cont.

- “Individuals with disabilities continually encounter various forms of discrimination, including outright intentional exclusion... overprotective rules and policies, failure to make modifications to existing facilities and practices, exclusionary qualification standards and criteria, segregation, and relegation to lesser services, programs, activities, jobs.....

Goals of the Americans with Disabilities Act of 1990

- The nation's proper goals regarding individuals with disabilities are to assure:
 - Equality of Opportunity
 - **Full Participation**
 - Independent Living
 - **Economic Self Sufficiency**

ADA INTEGRATION MANDATE

- “A public entity shall administer services, programs and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities.”

28CFR section 35.130(D)

Olmstead v. L.C. & E.W.

11th Circuit (1999)

- "...the state (Georgia) **discriminated** against L.C. and E.W. by **confining** them in a **segregated institution** rather than providing them services in **integrated community settings**
- ...the state's actions in this case constituted **discrimination...**
- ...the state has **violated the core principle underlying the ADA's integration mandate...**"

OLMSTEAD vs. L.C. & E.W.:

Supreme Court Decision (June, 1999)

1. What Did the Supreme Court Say?

A. **The ADA is a fundamental civil rights statute!**

B. The Court acknowledged that Congress found that **discrimination against people with disabilities includes segregation, isolation & institutionalization**

OLMSTEAD vs. L.C. & E.W.:

C. Under ADA, **a legal right to be served in the most integrated setting. Not open to state's discretion.**

D. Unnecessary isolation and institutionalization is **discrimination**

OLMSTEAD vs. L.C. & E.W.:

E. “Unjustified institutional isolation...is a form of discrimination”

“Institutional placement of persons who can handle and benefit from community settings **perpetuates unwarranted assumptions that persons so isolated are incapable or unworthy of participating in community life.**”

OLMSTEAD vs. L.C. & E.W.:

“Confinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, education advancement, and cultural enrichment.”

Conclusions from Olmstead:

- The ADA is a **Civil Rights Law** that applies to all people with disabilities across the age span
- The Integration Mandate is not only for Medicaid beneficiaries and Medicaid services
- **The Integration Mandate is really about how states and counties organize services and supports**
- Olmstead is about planning & systems change

The Role of the ADA and Olmstead..

- Cannot be ignored with current DOJ
- **June 22nd 2011** was 12th anniversary of the Olmstead Supreme Court Decision
- DOJ issued:

Statement of the Department of Justice
on Enforcement of the Integration
Mandate of Title II of the Americans
with Disabilities Act and the Olmstead
v. Lois Curtis & Elaine Wilson

DOJ on the ADA, June 22, 2011

- **Integrated settings are located in mainstream society**; offer access to community activities and opportunities at times, frequencies, and with person's of an individual's choosing; afford individuals choice in their daily life and activities; and, provide individuals the opportunities.....

DOJ on the ADA, June 22, 2011

- The “most integrated setting” is defined as “a setting that enables individuals with disabilities to interact with non-disabled persons to the fullest extent possible.”

DOJ, June 22, 2011, cont.

- Segregated settings include, but are not limited to:
 - (1) **congregate settings populated exclusively or primarily with individuals with disabilities;**

DOJ, June 22, 2011, cont.

- Segregated settings include, but are not limited to:
 - (2) congregate settings characterized by **regimentation in daily activities, lack of privacy or autonomy**, policies limiting visitors, or **limits on individuals ability to engage freely in community activities** and to manage their own activities of daily living

DOJ, June 22, 2011, cont.

Segregated settings include, but are not limited to:

(3) settings that provide for daytime activities primarily with other individuals with disabilities

DOJ, June 22, 2011, cont.

- When is the ADA's integration mandate implicated?

...when **a public entity administers its programs in a manner that results in unjustified segregation of persons with disabilities.**

DOJ, June 22, 2011, cont.

- A public entity may violate the ADA if it **promotes or relies upon the segregation of individuals with disabilities** through its:
 - Planning
 - Service system design
 - Funding choices, or
 - Service implementation practices

DOJ, June 22, 2011, cont.

- **Public entities are required to have:**
 - **“a comprehensive, effectively working Olmstead plan...that must contain concrete and reliable commitments to expand integrated opportunities.**

DOJ, June 22, 2011, cont.

- The plan **must have specific and reasonable timeframes and measurable goals**... the public entity may be **held accountable**, and there must be funding to support the plan, which may come from reallocating existing service dollars

DOJ, June 22, 2011, cont.

- The plan **should include commitments** for each group unnecessarily segregated such as individuals with developmental disabilities **spending their days in sheltered workshops and segregated day programs.**
- The plan must demonstrate **success by moving individuals to integrated settings in accordance with the plan.”**

U.S. v. State of Rhode Island

Proposed Consent Decree

- April 2014 to resolve complaint filed January 2013
- Does not impact interim settlement of June 2013 re: Providence
- **Ten year plan to transform entire system**
- **Annual targets and benchmarks**
- Many service definitions including customized employment and discovery

U.S. v. Rhode Island, cont.

- Transition finding: **about 5%** of youth with ID/DD leaving school between 2010-2012 transitioned into integrated employment
- R.I. Dept. of Ed. will adopt an Employment First policy, making integrated employment a priority service for youth
- State agencies will promote the implementation of school to work transition planning process with specific timelines and benchmarks **for all youth 14 - 21**

U.S. v. Rhode Island, cont.

- Youth in transition will receive
 - **Integrated vocational and situational assessments, including Discovery**
 - **Trial work experiences**
 - An array of other services to ensure that they have meaningful opportunities to work in the community after exit school
 - **Work will average 20 hours/week for the group**
 - **Integrated work & non-work hours will total 40 hours/week.**

Statement of Eve Hill, Sr. Counselor, to Asst. Attorney General for Civil Rights

“ The Supreme Court made clear over a decade ago that **unnecessary segregation of PWD is discriminatory**. Such segregation is **impermissible in any state or local government program** whether it be residential services, employment services or other programs. Unfortunately the type of segregation and exploitation we found at TPP & Birch is all too **common when states allow low expectations to shape their disability programs.**”

DOJ Files Complaint to Intervene in Lane, et.al. v. Kitzhaber; 3/27/2013 Court granted motion, 5/22/2013 (original suit filed 1/25/2012)

- “1. The United States alleges that Defendant, the State of Oregon (“State”), **discriminates** against individuals with intellectual or developmental disabilities (“I/DD”) by **unnecessarily segregating them in sheltered workshops** and by placing them at risk of such segregation in violation of Title II of the ADA and Section 504 of the Rehabilitation Act.”

DOJ-Oregon Settlement

- Announced September 8, 2015
- After 13 days of mediation; trial had been set for December 1, 2015
- Key provisions of **the 7 year agreement**:
 - Converts the goals, commitments, and structural reforms of the Governor's Executive Order of Into enforceable obligations.
 - Requires Oregon to provide 1,115 working age individuals who are or were in sheltered workshops with Competitive Integrated Employment.

Key Provisions, DOJ-Oregon, cont.

- Expects the number of persons in sheltered workshops to be reduced from 2,700 to no more than 1,530 or lower;
- **Creates a right to integrated supported employment services** that allow individuals with I/DD to work in integrated employment settings for all persons in sheltered workshops who want them.
- Ensures that **4,900 youth will receive Employment Services and that half of those who do receive Employment**

Key Provisions: DOJ-Oregon, cont.

Services **will get an Individual**

Employment Plan from VR that should lead to competitive employment;

- Requires that the State issue policies and promote the expectation that all individuals with I/DD **work an average of 20 hours/week, consistent with their choices and abilities;**
- Mandates that Oregon continue to fund a **training and technical assistance entity** and its provider transformation grants at current levels for **the next four years**

DOJ Actions on Living Arrangements:

- Virginia
- North Carolina
- Georgia
- Ohio

Nursing Home Residents, U.S. 2011

CMS Nursing Home Compendium, 2012

■ Total number	1,431,730
■ Male	32.8%
■ Female	67.2%
■ Age: 0 – 21	0.2%
■ Age: 22-30	0.3%
■ Age: 31-64	14.4%
■ Age: 65-74	14.6%
■ Age: 75-84	27.5%
■ Age: 85-94	35.3%
■ Age: 95 +	7.6%

DOJ on the Application of the Integration Mandate on Publicly Funded Employment Services: Issued October, 31, 2016

“Nationally, millions of individuals with disabilities **spend the majority of their daytime hours receiving employment and day services in segregated sheltered workshops and segregated day settings** where they are segregated from non-disabled persons....

DOJ on Employment Services, 2

“...yet despite these advances, many individuals with disabilities who receive employment and day services that are planned, funded, and administered by state and local governments **continue unnecessarily to receive services, and spend the majority of their daytime hours, in segregated settings.**”

DOJ on Employment Services, 3

“The **civil rights** of persons with disabilities, including individuals with mental illness, intellectual or developmental disabilities, or physical disabilities, **are violated by unnecessary segregation** in a wide variety of settings, including in segregated employment vocational and day programs.”

DOJ on Employment Services, 4

- **Segregated settings are defined** as:
“...managed, operated, or licensed by a service provider to serve primarily people with disabilities...who are supervised by paid support staff...or to **groups of employees with disabilities who routinely work in isolation from non-disabled peers or coworkers or who do not interact with customers or the general public..** are examples of services provided in a segregated employment setting.”

DOJ on Employment Services, 5

- **Access to Integration During Non-Work Hours:**
- **Chosen activities in the community** at times and frequencies and with persons of their own choosing, and interacting to the fullest extent possible with non-disabled peers **instead of being relegated to services in segregated settings.**

DOJ on Employment Services, 6

- “...integrated day services allow persons ...to **participate in and gain membership in mainstream community-based** social, recreational, educational, cultural, and athletic activities, including community volunteer activities and training activities.
- Such integrated non-work activities can allow individuals with disabilities to **develop autonomy & self-determination, networks of contacts, models, & mentors...improving employment opportunities & outcomes.”**

DOJ on Employment, 7

- Employment Criteria:

“...the ADA and its regulations **do not** require a person with a disability to have a medical or vocational rehabilitation professional determine that he or she is capable of competitive, integrated employment.

“...**Limiting the evidence** on which people with disabilities may rely **would enable public entities to circumvent their Olmstead obligations...**”

DOJ on Employment, 8

“**Affirmative steps** may include:”

1. Vocational & Situational Assessments
2. Career Development Planning
3. Discovery in Integrated Employment Settings
4. Arranging Peer to Peer Mentoring
5. Conducting Job Exploration
6. Work Experience in Integrated Job Settings
7. Providing Benefits Education and Counseling

DOJ on Employment, 8

Persons at **Serious Risk of Segregation:**

“...public entities may be contributing to a **pipeline to segregation** if VR counselors, caseworkers...are not available to assist youth... to prepare for and transition to competitive integrated employment...

Need to ensure students with disabilities can make **informed choices** prior to being referred to sheltered **work...offering timely & adequate transition services designed ...to understand & experience the benefits of work in an integrated setting.”**

Where is the Future?



Contact Information

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NASDDDS: Mary Sower, Nancy Thaler, Mary Lee Fay

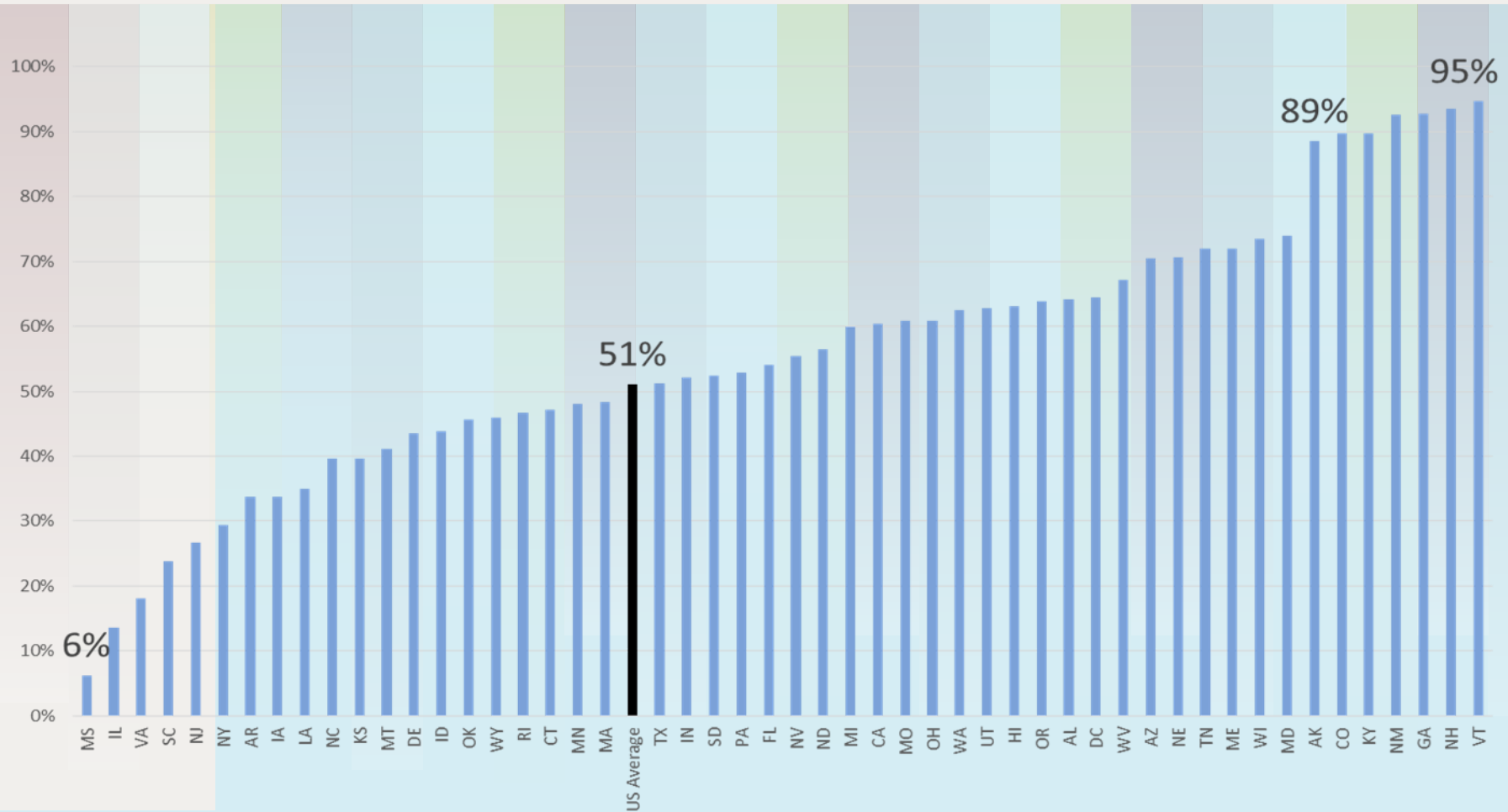
Characteristics of High-Quality Community Living: 50 years research

- Where and with whom a person lives;
- Where a person works and how he or she earns money;
- What a person does during the day;
- The quality of relationships developed with others during daily activities;

Characteristics/Key Components (2)

- What and with whom a person does activities of personal interest;
 - An individual's health, both physical and emotional;
 - If, where and with whom they worship;
 - Their interest and opportunities to engage in learning and personal growth; and,
 - Their ability to make informed decisions about their lives.
- Hewitt, 2014

% Living in a home with 3 or fewer people with IDD (Other than with a family member)



% of People Residing in Settings of 3 or Fewer

■ 95-89%

- Vermont*
- New Hampshire*
- Georgia
- New Mexico*
- Kentucky
- Colorado
- Alaska*

■ 75-70%

- Maryland
- Wisconsin
- Maine*
- Tennessee
- Nebraska
- Arizona

* No Institutions

% of People Residing in Settings of 3 or Fewer

■ 69-60%

- West Virginia*
- District of Columbia*
- Alabama*
- Oregon*
- Hawaii*
- Utah
- Washington
- Ohio
- Missouri
- California

* No Institutions

■ 6-35%

- Mississippi***
- Illinois***
- Virginia***
- South Carolina
- New Jersey***
- New York***
- Arkansas
- Iowa
- Louisiana

*** Among 10 states with largest state institutional populations

Community Supported Living:WI.

- Separates place from supports
- Presumes that everyone can live in their own “home” with support
- Presumes that everyone can make a valued contribution to community life with support
- Presumes person does not need to be “fixed”
- Built on presumption of “integration”/inclusion
- Community Care of Central Wisconsin's data:
 - 98 people in supportive living; \$61.45/day
 - In 1-8 person facility with sleep staff at night average \$77.03/day (20% more)
 - In 1-8 person facility with awake staff at night average of \$107.03/day (42% more)

System Centered

- **Deficit Based**
- **Segregation/Isolation**
- Professional/Provider Control
- Rejecting Community/Loneliness
- **Paper Compliance; health & life safety**
- No Accountability for Outcomes
- Person/Family Devalued

From System Centered

- Focus on Labels
- Emphasize Deficits and Needs
- Standardized Testing and Assessments
\$\$\$
- Professional Judgments
- Written Reports
- See People in the Context of Human Service Systems
- Distance People by Emphasizing Difference

Toward Person Centered

- See **People First**
- Search for **Capacities and Gifts**
- **Spend Time Getting to Know People**
- Depend on People, Families and Direct Service Workers to Build Good Descriptions
- Gather Folklore from People Who Know People Well

Toward Person Centered-2

- **See People in the Context of Their Local Community**
- Bring People Together By Discovering Common Experience

Beth Mount, Ph.D.

Background on New HCBS Rule

Issued 1-16-2014; effective 3-17-2014

- Regulations are the result of nearly 5 years of dialogue and over 2,000 comments received during multiple public comment periods
- Intend to distinguish “home and community-based settings” (HCBS) from institutional settings
- States have 120 days - after submitting an existing waiver for renewal – to submit a transition plan to bring the state into compliance

CMS Issues Final Rules on HCBS and the Definition of Community: Jan. 16, 2014

- Applies to 1915(c) HCBS waivers; 1915(i) state plan amendments for HCBS; and, 1915(k) Community First Choice state plan amendments; effective March 17, 2014;
- Extensive criteria for the development of a “person centered plan”
- “Informed choice”

Person-Centered Service Plans

Final rule includes changes to the requirements regarding person-centered service plans for HCBS waivers under 1915(c) and HCBS state plan benefits under 1915(i) -

- Identical for 1915(c) and 1915(i)
- The person-centered service plan must be developed through a person-centered planning process

1915(c) and 1915(i) Home and Community- Based Services

- The person-centered planning process is driven by the individual
- Includes people chosen by the individual
- Provides necessary information and support to the individual to ensure that the individual directs the process to the maximum extent possible
- Is timely and occurs at times/locations of convenience to the individual
- Reflects cultural considerations/uses plain language
- Includes strategies for solving disagreement

1915(c) and 1915(i) Home and Community- Person-Centered Service Plans

- Offers choices to the individual regarding services and supports the individual receives and from whom
- Provides method to request updates
- Conducted to reflect what is important to the individual to ensure delivery of services in a manner reflecting personal preferences and ensuring health and welfare
- Identifies the strengths, preferences, needs (clinical and support), and desired outcomes of the individual
- May include whether and what services are self-directed
- Includes individually identified goals and preferences related to relationships, community participation, employment, income and savings, healthcare and wellness, education and others

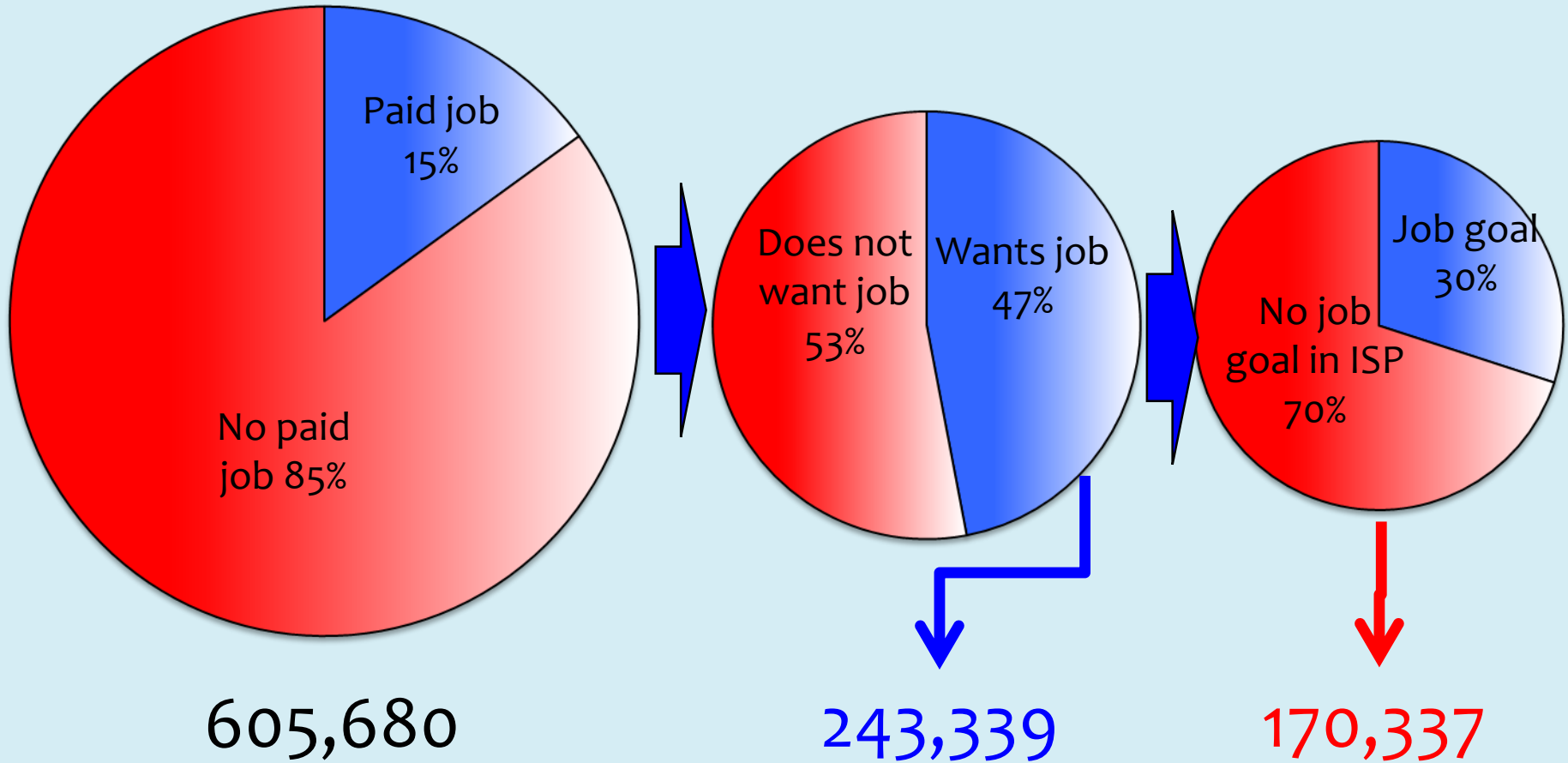
1915(i) State Plan HCBS Benefit – Self-Directed Services

- Services that are planned and purchased under the direction and control of the individual (or representative)
- Services include the amount, duration, scope, provider, and location
- Person-centered service plan must meet additional requirements when individual chooses to direct some/all HCBS
- Person-centered service plan specifies employer authority, limits to authority, and parties responsible for functions outside individual authority

CMS Issues Final Rules on HCBS and the Definition of Community: Jan. 16, 2014

- “Providers of HCBS for the individual, or those who have an interest in or are employed by a provider of HCBS for the individual **must not provide case management or develop the Person Centered Service Plan.....**
- ...except when the State demonstrates that the only willing and qualified entity to provide case management and/or develop person-centered service plans in a geographic area also provides HCBS.”

Choice



Intent of HCBS Regulation

- Align HCBS funding with civil rights protections under the **Americans with Disabilities Act (ADA)**
- Address **concerns** that HCBS funding is used for “institutional style” settings that “isolate” and lack opportunities for people to engage meaningfully in the community

Intent of HCBS Regulation

- Maximize opportunities **to receive services in integrated settings, realize the benefits of community living** and seek **opportunities for employment in competitive integrated settings.**
- Regulation is outcome oriented—focuses on **nature and quality of individual experience** in the setting and whether individuals have the “**same degree of access**” as others in the community.
- Final regulation applies to **all settings**, residential and non-residential.

Settings PRESUMED not to Be Home And Community-based

- ❑ Settings in a publicly or privately-owned facility providing inpatient treatment
- ❑ Settings on grounds of, or adjacent to, a public institution
- ❑ Settings with the effect of isolating individuals from the broader community of individuals not receiving Medicaid HCBS

Settings that Isolate and are Presumed to have Institutional Qualities

- The setting is designed specifically for people with disabilities.
- The individuals in the setting are primarily or exclusively people with disabilities and on-site staff provides many services to them.
- Individuals in the setting have limited, if any interaction with the broader community.
- Settings that use/authorize interventions/restrictions that are used in institutional settings that are used in institutional settings or are deemed unacceptable in Medicaid institutional settings (e.g. seclusion).
- Source: CMS guidance: <http://www.medicaid.gov/Medicaid-CHIP-Program-Information/By-Topics/Long-Term-Services-and-Supports/Home-and-Community-Based-Services/Downloads/Settings-that-isolate.pdf>

Settings that **Isolate**

- CMS has provided specific examples of residential settings that isolate, including:
 - **Disability-specific farms**
 - **Gated disability communities**
 - **Residential schools**
 - **Congregate, disability-specific settings that are co-located, operationally related**
- CMS has not provided specific examples of non-residential settings that isolate
 - But it has made clear the “**settings that isolate**” guidance applies to non-residential settings too



But....

- The rules give the Secretary of HHS the discretion to ascertain if certain settings meet the HCB settings character
- That means that with regard to the settings described on the previous slide, states may make the case that the setting(s) *does* meet HCB settings character
 - This is an uphill battle that will likely fail

Which brings us to Hcbs characteristics:



- The home and community-based setting requirements establish an **outcome oriented** definition that focuses on the **nature & quality of individuals' experiences**
- The requirements maximize opportunities for individuals to have access to the benefits of community living and the opportunity to receive services in the most integrated setting
- **The new standards are "experiential" and about "qualities" of the setting**

CMS Final Rules on HCBS

continued

- Home & Community-Based Settings –
“**must have** all of the following qualities,
and such other qualities that the Secretary
determines to be appropriate, **based on
the needs of the individual as indicated in
their person-centered service plan:.....**”

CMS Final Rule, 1-16-2014, cont.

“ (i) The **setting is integrated** in and supports **full access** of individuals receiving Medicaid HCBS **to the greater community**, including opportunities **to seek employment and work in competitive integrated settings**, **engage in community life**, control personal resources, and receive services in the community, **to the same degree of access as individuals not receiving Medicaid HCBS.**

CMS Final Rules on HCBS

continued

#2. "The setting is selected by the individual from among setting options including....

non-disability specific settings & an option for a private unit in a residential setting.

- The setting options are identified & documented in the person-centered service plan & are based on the individual's needs, preferences and, for residential settings, resources available for room and board."
- Ensures an **individual's rights of privacy, dignity, respect & freedom from coercion and restraint.**

CMS Final Rules on HCBS

continued



#3. “Optimizes, but **does not regiment individual initiative, autonomy, and independence in making life choices,** including, but not limited to, daily activities, physical environment, & with whom to interact.”

Choice of Non-Disability Specific Setting

- Rule requires states to offer individuals a choice of a “non-disability specific setting”
 - This requirement applies to both residential and non-residential settings
 - Examples include choice to live in one’s own home (residential) or to work in competitive, integrated employment (non-residential)
- States should assess their current capacity of non-disability specific settings & develop a plan to increase capacity so all individuals have real, meaningful choice

States Must Assess and Categorize **All Settings**

- 1) Meets all requirements of the rules (or can with modifications)
- 2) Can never meet requirements of the rules because it is an institution (nursing home, ICF, hospital or IMD)
- 3) Is presumed institutional
 - Setting is unallowable unless a state can prove through a **“heightened scrutiny”** process that the setting overcomes the institutional presumption and meets the rules’ requirements

CMS Guidance: Heightened Scrutiny

- CMS reviews the request to determine:
 - Every one of HCBS characteristics is met for every resident;
 - People in the setting are not isolated from the greater community
 - Proximity, resources, activities, transp
 - Varied schedules based on interests; not all activities provider organized
 - Activities that foster relationships with community members
 - Choice of setting (including non-D)
 - Strong evidence of different practices,

Heightened Scrutiny Guidance (cont'd)

- Settings on grounds/adjacent to institution:
 - Must prove a meaningful distinction between the facility & HCBS & that are integrated, with full community access.
- For settings that isolate, evidence proving
 - P without disabilities in same community consider it part of their community
 - People in the setting regularly engage in community activities other than those organized by a provider & in a way that fosters relationships with community members unaffiliated with the setting

Qualities of an HCBS Setting

1. The setting reflects the individual's needs and preferences.
2. Individuals must have opportunities to make informed choices.
3. **Informed choice must include opportunities to discover, explore and experience a variety of options.**
4. Choices must include opportunities to combine more than one service in any given day or week. (rate \$\$\$ implications)

Qualities of HCBS Settings, 2

- 5. There must be opportunities to review, update and change preferences and choices at least annually.
- 6. There must be sufficient supports to assist an individual in **making informed choices and exercising autonomy to the greatest extent possible.**
- 7. There must be opportunities for the individual to **negotiate work schedules, break times, benefits, etc.** same as people without disabilities.
- 8. **Tasks and activities are comparable to tasks and activities for people who do not have disabilities.**

1
2
3

Qualities of an HCBS Setting, 3

- 9. **Freedom of movement inside/outside** setting-people are not restricted to one room or area.
- 10. **Information about individuals kept private-** i.e., no posting of schedules for medications, restricted diet, etc.
- 11. **Access to meals/snacks at any time** consistent with individuals in similar and/or same setting who do not receive HCBS.

Qualities of a HCBS Setting,4

12. The setting must be in a location that is accessible to other businesses, residences, restaurants, etc. **to facilitate interaction with the public.**

13. To the extent possible, the setting should be accessible by public transportation, para transit and other forms of transportation. Individuals with disabilities must **have training and access to information about transportation options.**

14. The setting **cannot be co-located** with a public or private institution, or located on the grounds of a public institution (hospital, SNF, ICF or IMD)

Planned Activities in the home community in all life's domains:

- **Work**
- Volunteering - at soup kitchen, community clean up, or other neighborhood service
- **Learning experiences and activities; books on tape; book clubs and art classes; self-help classes**
- **Joining community organizations**
- **Recreation – swimming, bowling, dancing, movies**
- **Social Life – getting together with family and friends**
- **Peer support groups**

125

Planned Activities in the Home Community Within All of Life's Domains

- **Shopping**
- **Maintain health and wellness – walking; gym membership; diet groups; going to medical appt.**
- **Personal care – hairstyling, having nails done,**
- Maintaining home; maintenance and improvement; cleaning; laundry
- Caring for others; relatives or friends
- **Spirituality: worship; meditation; yoga classes;**
- **Hobbies: Pet care – walking the dog; gardening, painting; photography**
- Going on vacation

1
2
7

CMS FAQ HCB Settings Requirements (6/26/15)

- <http://www.medicaid.gov/medicaid-chip-program-information/by-topics/long-term-services-and-supports/home-and-community-based-services/downloads/home-and-community-based-setting-requirements.pdf>
- **Page 11: State Flexibility**
- **Q16. May states establish requirements for that are more stringent than requirements in the federal regulation?**
- **A16. Yes.**

Factors to consider in establishing Service Standards and Requirements

- **What type activity in the community meets the standard?**
 - *Access to the greater community*, including opportunities to seek employment and work in competitive integrated settings, engage in community life, control personal resources, and receive services in the community, *to the same degree of access as individuals not receiving Medicaid HCBS*
 - Optimizes, but **does not regiment, individual initiative, autonomy, and independence in making life choices, including but not limited to, daily activities, physical environment, and with whom to interact**

“Supports full access to the greater community – opportunities to engage in community life – choice of daily activities and with whom to interact”

How do people engage in community life? What are daily activities? What is an everyday life?

Unplanned interaction with the community

- Quick stop at the convenience store; borrowing items from a neighbor, waiting at the bus stop, shoveling snow a neighbor, walking the dog, hanging out at the pizza parlor, greeting the delivery man, answering the door when the boy scouts collect for the food drive, etc.

HCBS Final Rule:

**CMS TOOLKIT & ADDITIONAL GUIDANCE
ON APPLICATIONS OF RULE TO NON-
RESIDENTIAL SETTINGS**

HCBS Settings Requirement Compliance Toolkit: PURPOSE

- To assist states develop Home and Community-Based 1915(c) waiver and 1915(i) SPA amendment or renewal application(s) to comply with new requirements in the recently published Home and Community Based Services' (HCBS) regulations.

HCBS Settings Requirement Compliance Toolkit: CONTENTS

- A summary of the regulatory requirements of fully compliant HCB settings and those settings that are excluded.
 - Schematic drawings of the heightened scrutiny process ~~part~~ of the regular waiver life cycle and the HCBS 1915(c) compliance flowchart.
- Additional technical guidance on regulatory language regarding settings that isolate.

What characteristics of community design encourage the social integration of persons with disabilities into community activities?*

- Safe neighborhoods
- Walkable neighborhoods
- User friendly transportation systems
- Natural environments and green spaces
- Public gathering spaces
- Nearby businesses, organizations, and institutions
- Proximity to family, friends, and associations

*(The Impact of Community Design and Land-Use Choices on Public Health: A Scientific Research Agenda, Am J Public Health. 2003 September; 93(9): 1500–1508.)

Coming into compliance: State Transition Plans



- CMS has termed coming into compliance with the HCB settings requirements, “Transition”
- States will have to provide a transition plan, *“detailing any actions necessary to achieve or document compliance with setting requirements”*
- What states have to do—and how quickly—depends on the timing of new waivers, amendments and renewals

The State's "Settings" Transition Plan

- **Assess infrastructure and need for modifications:**
 1. Service definitions
 2. Service standards and requirements
 - Regulations
 - Provider qualifications
 - Training requirements
 3. Service contracts, rate methodology, billing and adequacy of rates
 4. Person-centered planning requirements and documentation
 5. Conflict Free Case management
 5. **Quality Management Practices**
 - Individual plan monitoring requirements – support coordination
 - UR practices
 - Provider monitoring – licensing, certification
 - Performance outcome measurement – using National Core Indicators
 - Provider Reporting requirements
 6. **Information Systems**
- **Assess waiver and state plan applications**
- **Assess current services** against states requirements **and develop a plan to come into compliance** – incorporate assessment and change into the annual review cycle
- **Develop guidance and training for providers for implementation**
- **Public input is required**

Transition Plan Status

- Statewide transition plans
 - CMS [website](#)
 - All have turned in a plan
- Iterative process
- Individual program transition plans

State Transition Plan Status; 11/7/2016

- **Final Approval:** Tennessee
- **Preliminary Approval:** Connecticut; Delaware; Idaho; Iowa; Kentucky; North Dakota; Ohio; Oregon; and Pennsylvania
- **In Discussion and Negotiation:** 39 states and the District of Columbia

HCBS Settings Requirement Compliance Toolkit: CONTENTS

- Statewide Transition Plan Toolkit for Alignment with HCB Settings Regulation Requirements Suggestions for alternative approaches and considerations for states as they prepare and submit Statewide Transition Plans for the new federal requirements for residential and non-residential home and community-based settings. The regulatory requirements can be found at 42 CFR 441.301(c)(4)(5) and 441.710(a)(1)(2).
- HCBS Basic Element Review Tool for Statewide Transition Plans and HCBS Content Review Tool for Statewide Transition Plans

Resources

- HCBS Settings Rule resources:
 - www.hcbsadvocacy.org (sponsored by national advocates)
 - www.medicaid.gov/hcbs (CMS)

Sources-Resources

- ❑ Home and Community-Based Services: Creating Systems for Success at Home, at Work and in the Community. U. S. National Council on Disability, 2015
<http://www.ncd.gov/publications/2015/02242015/>
- ❑ Outcomes by Size of Community Residence, Summary of the Literature, Eunice Kennedy Shriver Center, May 1, 2014
- ❑ University of Minnesota Rehabilitation Research and Training Center on Community Living,
<http://rtc.umn.edu/rtc/>
- ❑ The Council on Quality and Leadership, <http://www.c-q-l.org/>
- ❑ Costs and Outcomes of Community Services for People with Intellectual Disabilities, Stancliffe and Lakin, 2005 Paul Brookes Publishers

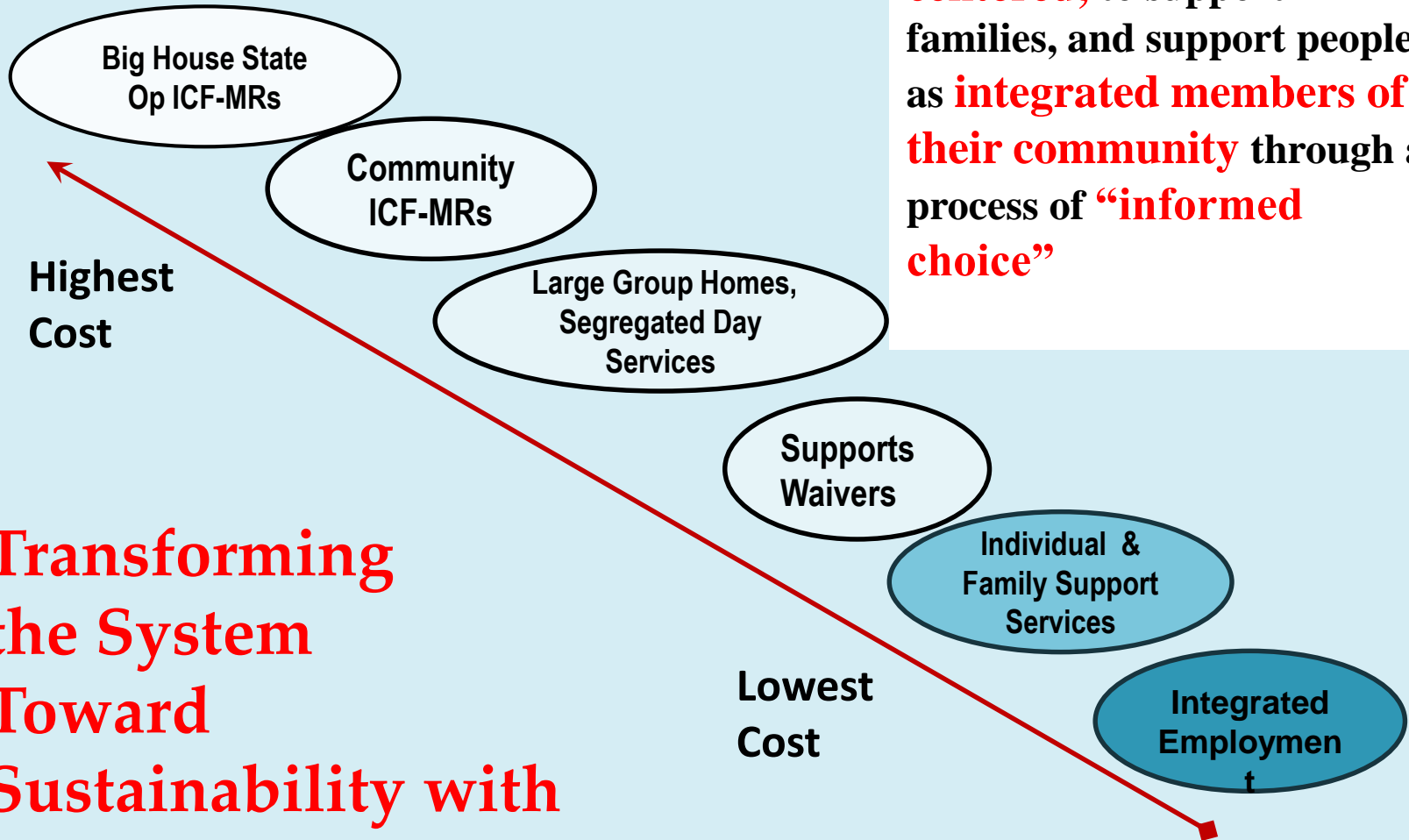
Resources

- hcbsadvocacy.org
 - Updated information on state processes
 - Factsheets & Q&As
 - Alerts on comment periods
- CMS
 - [Guidance & Toolkit](#)
 - State Transition Plan status [site](#)



ALLAN I. BERGMAN

The idea is to transform a system to be **person-centered**, to support families, and support people as **integrated members of their community** through a process of **“informed choice”**



**Transforming
the System
Toward
Sustainability with
“Best practice”,
CMS setting rules
& DOJ “integration”**

Wisdom from Jim Collins

**“Great performance
is about 1% vision
and 99% alignment”**

**(It all starts with a vision and then a
specific plan and process to execute
that vision.)**

Built to Last

Your Role as a Leader

“Act as if what you
do makes a
difference.
It does.”

William James

Change is about people
and behavior...

not about bylaws, structure,
regulations, policies...it is
about vision and overcoming
obstacles



Moving Forward Today and Tomorrow

“The biggest risk is not taking any risk. In a world that’s changing really quickly, the only strategy that is guaranteed to fail is not taking risks.”

Mark Zuckerberg, Facebook founder

Freedom—

(1) the condition of being free of restraints; (2) liberty of the person from slavery; oppression or incarceration; (3) **possession of civil rights**; (4) immunity from the arbitrary exercise of authority; (5) the capacity to exercise choice or free will; (6) *the right of enjoying all of the privileges of membership or citizenship.*

The American Heritage Dictionary

“Equal Justice Under the Law”



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