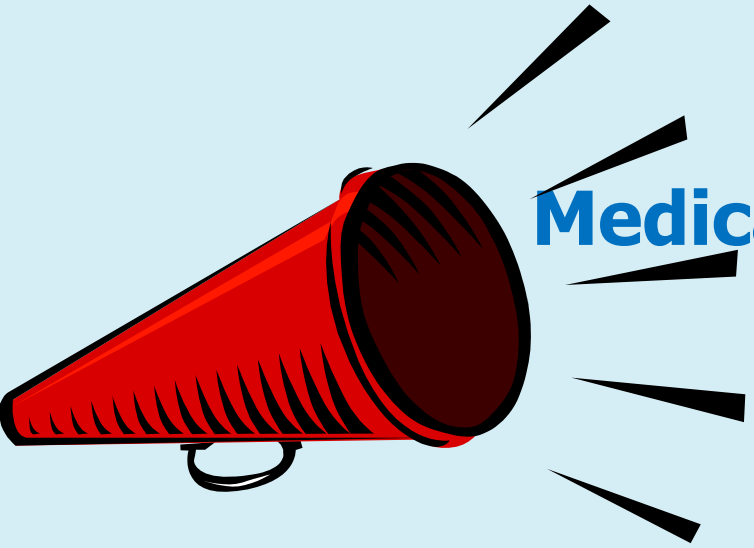
Innovative Ways to Use Medicaid Funding & Reimbursement to Create Incentives for Promoting Integrated Community Services and Supports for Individuals of All Ages



South Dakota Legislature

Payment Methodologies for Medicaid Providers Interim Study

Pierre, SD

August 18, 2016

Today's Agenda:

I. The current socio-economic context
2. The role and permutations of Medicaid
3. The national perspective on disability and aging issues and values in voluntary associations and federal laws
4. Data from other states and research on emerging best practices and creative use of Medicaid funding
5. National outcome measures for policy
6. Potential future scenarios for Medicaid at the federal level?

Heading for a crash!

Weighty Legacy Services & Structures

Rising Unmet Demand

Workforce Shortages

Fragmentation

Quality Problems

Antiquated Technologies

Budget Shortfalls

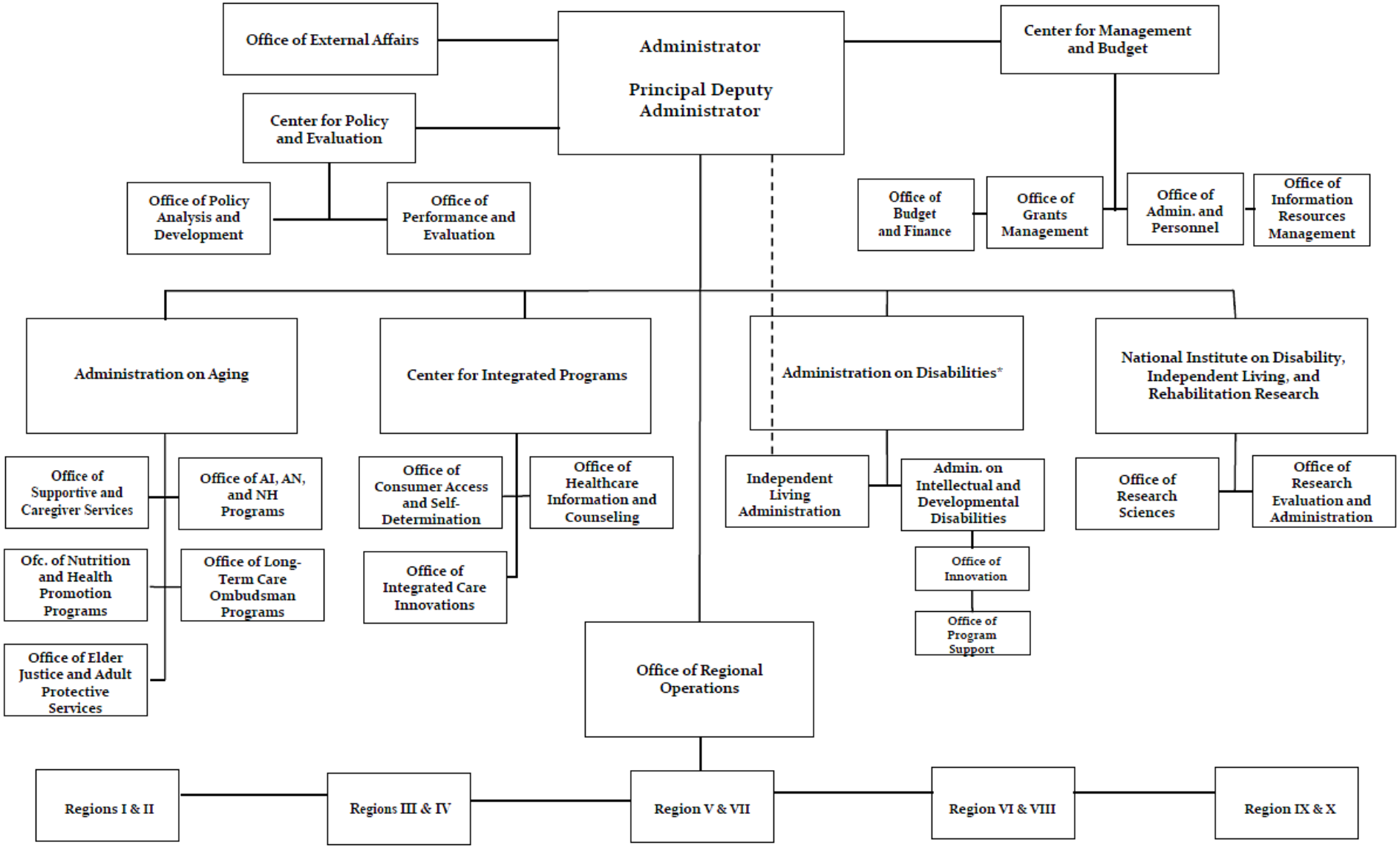
Administration for Community Living

- 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:…

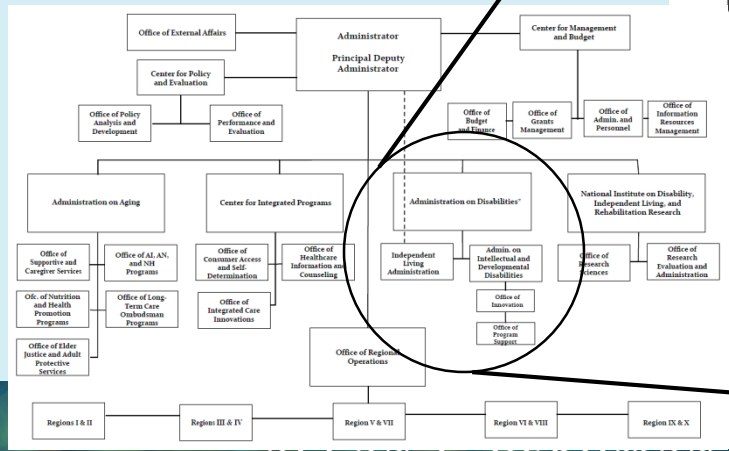
"All Americans… the **right to live in a home of their choosing, with people with whom they care about, that is integrated into a community that values their participation & contributions."**

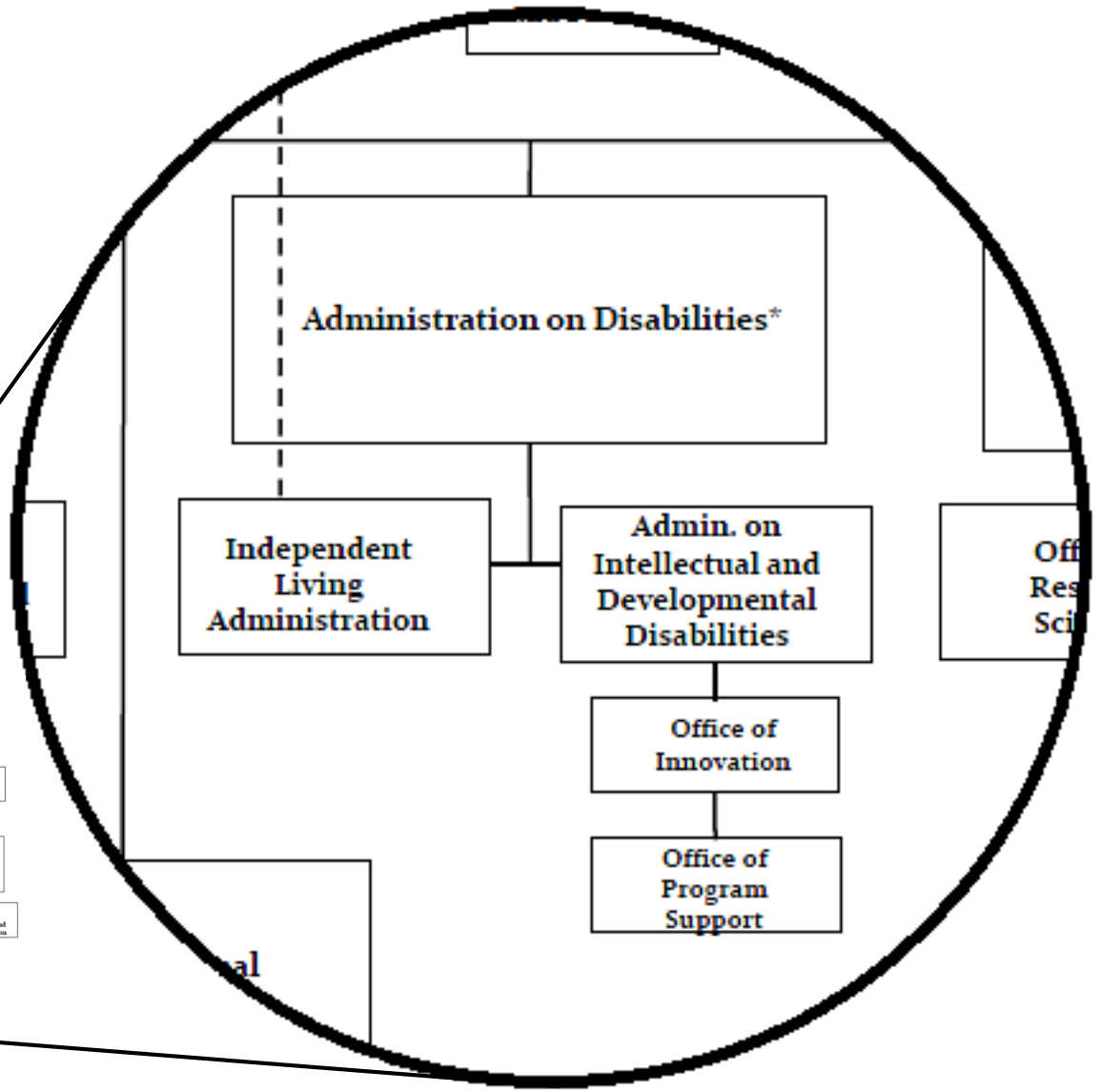
April 18, 2012

The Administration for Community Living



The Administration for Community Living





The Administration for Community Living

Mission

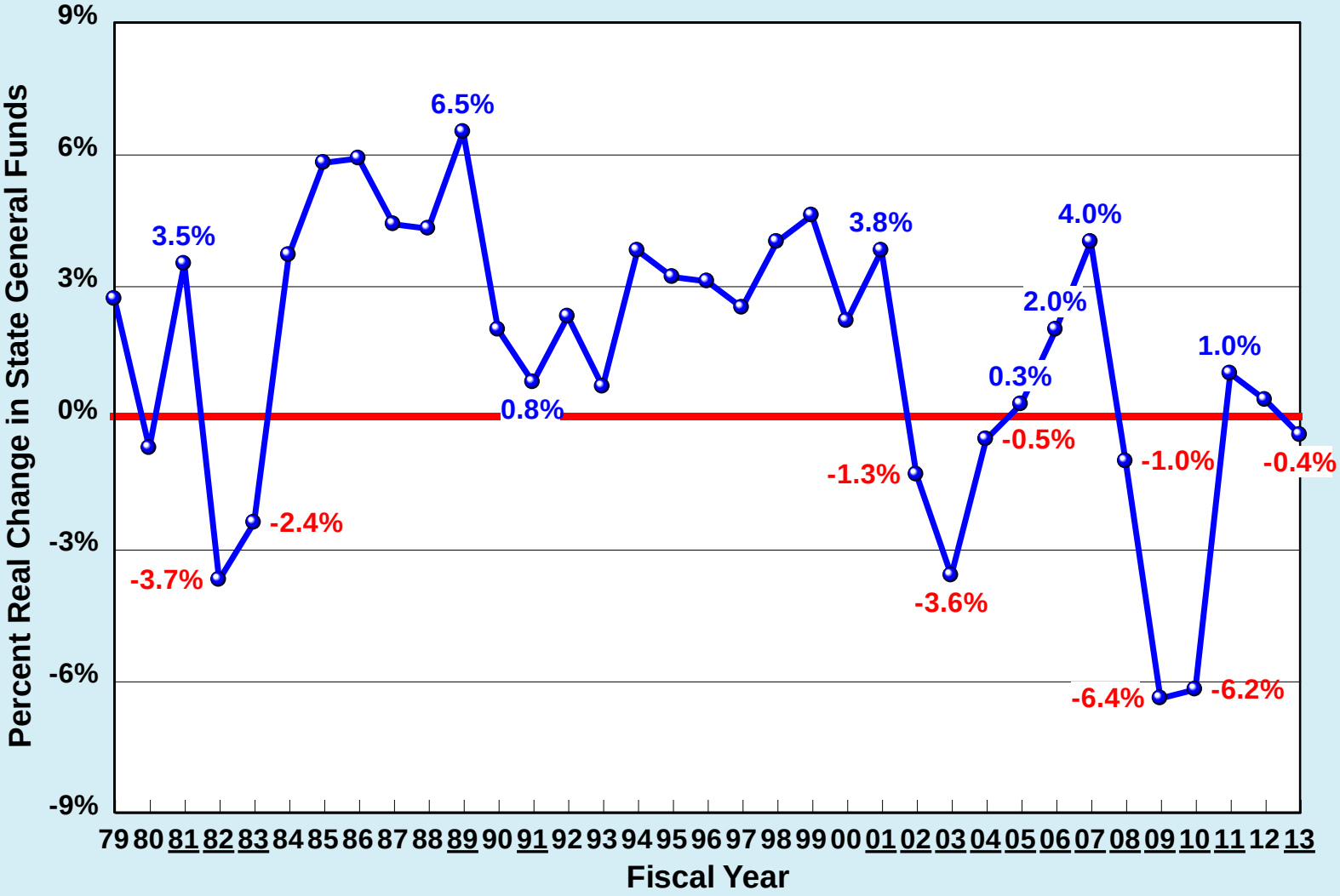
Maximize the **independence, well-being, and health** of older adults, people with disabilities across the lifespan, **and their families and caregivers.**

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.**

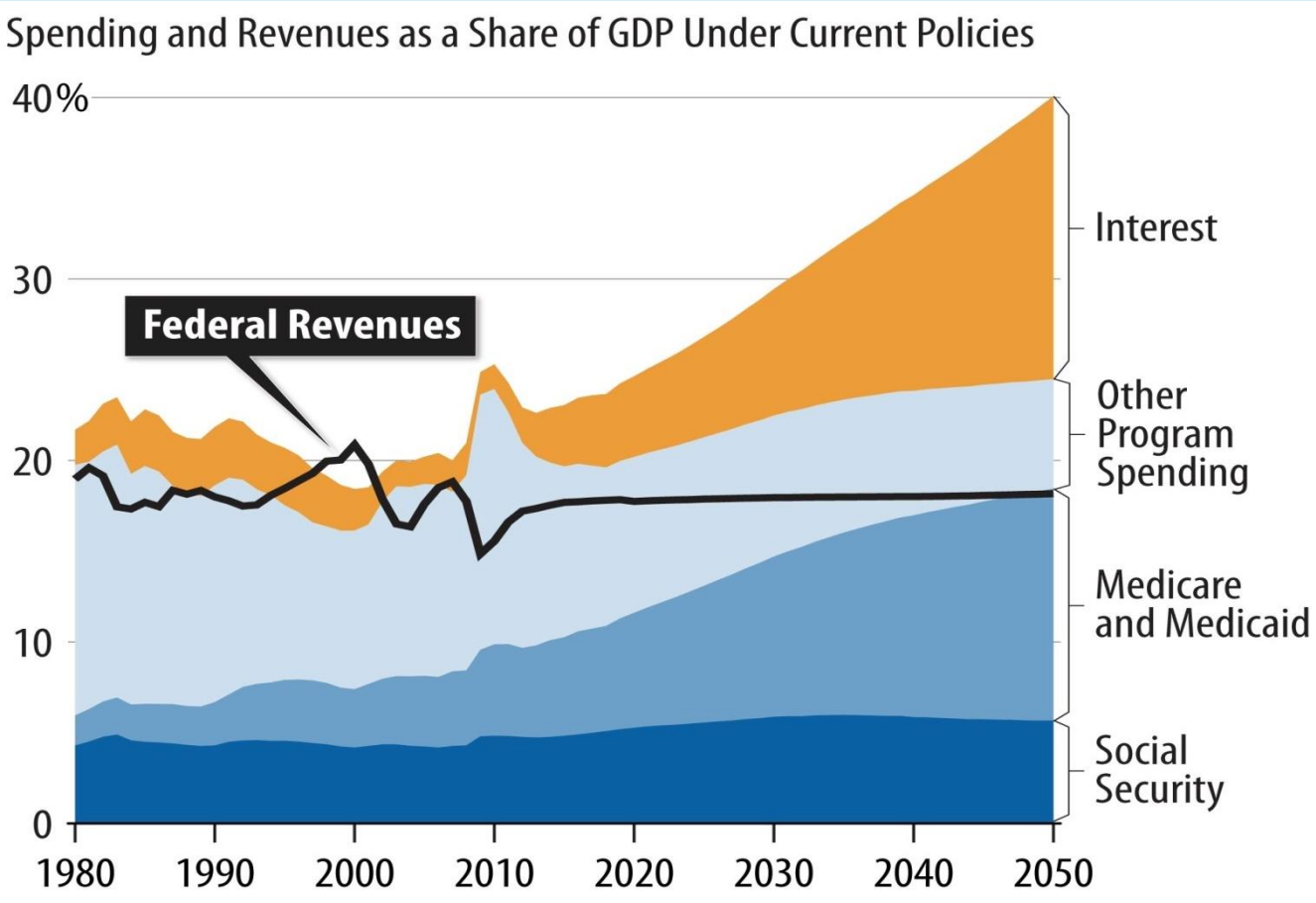
FUNDING:
Money Matters….and Drives Practice

THE "GREAT RECESSION" IMPACTS STATES' GENERAL FUND SPENDING 2008-13



Source: National Governors Association and National Association of State Budget Officers (Spring 2012)
79-11 are "actual" state expenditures; 2012 is "estimated"; and 2013 is "recommended."

Current Policies Are Not Fiscally Sustainable



Source: CBPP projections based on CBO data.

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…

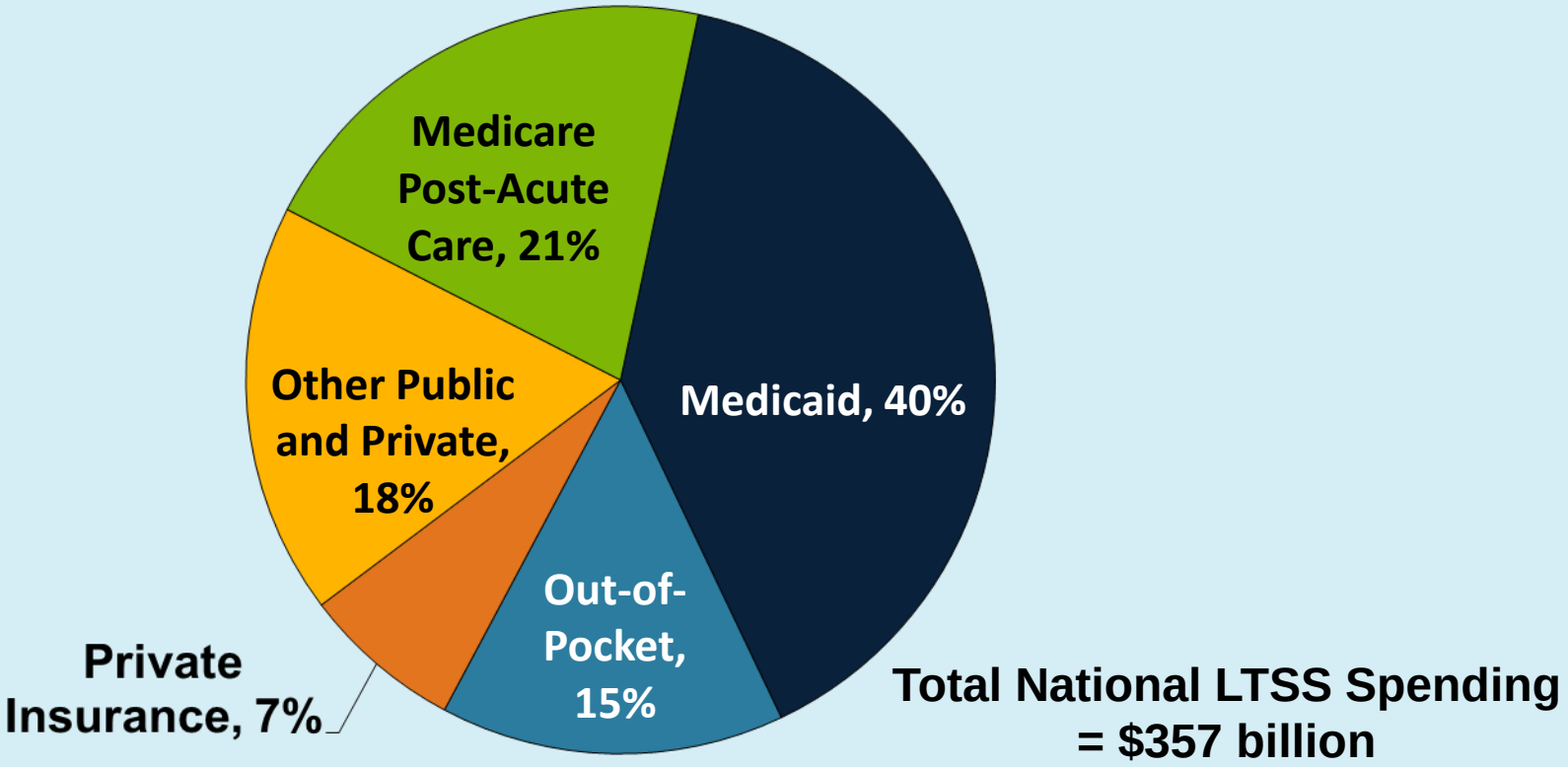
Demographics of Disability in U.S.

- 56 million Americans live with one or more disabling conditions (20%; 1 of 5)
- 29% (3 out of 10) of families have a family member with a disability (51% have a family member or close friend)
- 19% of the population had a mental health issue in 2014
- 13.1% of all students (1 out of 8) between the ages of 3 and 21 have a disability that qualifies for special education

Demographics of Adults with Disabilities: (CDC, August 2015)

- Mobility; 13.0% (over age 65, 20.0%)
- Cognition; 10.6% (concentration, remembering or making decisions)
- Independent Living; 6.5% (errands)
- Vision; 4.6% (over age 65, 17%)
- Self-care; 3.6% (bathing, dressing, etc.)
- Hearing; 3.8% (over age 70, hearing loss of >25dB in better ear, 63.1%)

Medicaid is the Primary Payer for Long-Term Services and Supports (LTSS), FY 2011



NOTE: Total long-term care expenditures include spending on residential care facilities, nursing homes, home health services, personal care services (government-owned and private home health agencies), and § 1915(c) home and community-based waiver services (including home health). Long-term care expenditures also include spending on ambulance providers. All home and community-based waiver services are attributed to Medicaid.
SOURCE: KCMU estimates based on FY 2011 Centers for Medicare & Medicaid Services (CMS) National Health Expenditure Accounts data.

Medicare – Medicaid Dual Eligibles: ACA created Federal Coordinated Health Care Office; Melanie Bella, Director

- 8.8 million dual eligibles
- 66% have 3 or more chronic conditions
- 61% have a cognitive or mental impairment
- More than 50% have incomes below the federal poverty level; 93% have incomes below 200% FPL
- Account for 36% of Medicare spending (21% of beneficiaries) and 40% of Medicaid spending (15% of beneficiaries)
- Total federal and state spending about $250 billion
- Make up less than 20% of total beneficiaries and 40% $$

% of State Population in Nursing Homes, 2012

AK 0.1
AZ 0.2
OR (7,947/4.0M) 0.2
UT. 0.2
NV. 0.2
CO, CA, GA, HI, ID,
NM. & WA. 0.3
FL, MD, MI, NC, SC
TX, VT, VA, **WY 0.4**
(2,387/584,000)

Al, DE, KY, ME, MN,
MS, MT, NH, NJ, OK,
TN, WV, WI, 0.5
AR, IL, IN, KS, LA, MA,
MO, NY, PA, 0.6
CT, NE, OH, 0.7
IA, ND, RI, **SD 0.8**
(6,347/853,000 people)

U.S. Average: 0.4

Percentage of State Population in Nursing Homes, 2012

Ages 65 & over

- **U.S. 2.8%**
- IA. 4.8%
- MN. 3.4%
- MT. 2.6%
- NE 4.2%
- ND 5.2%
- **SD 4.8%**
- WY 2.9%
- AZ, 1.0%; ID, 1.7%;
- NV, 1.1%; NM, 1.7%;
- OR, 1.1%; UT, WA, 1.6%

Ages 85 & over

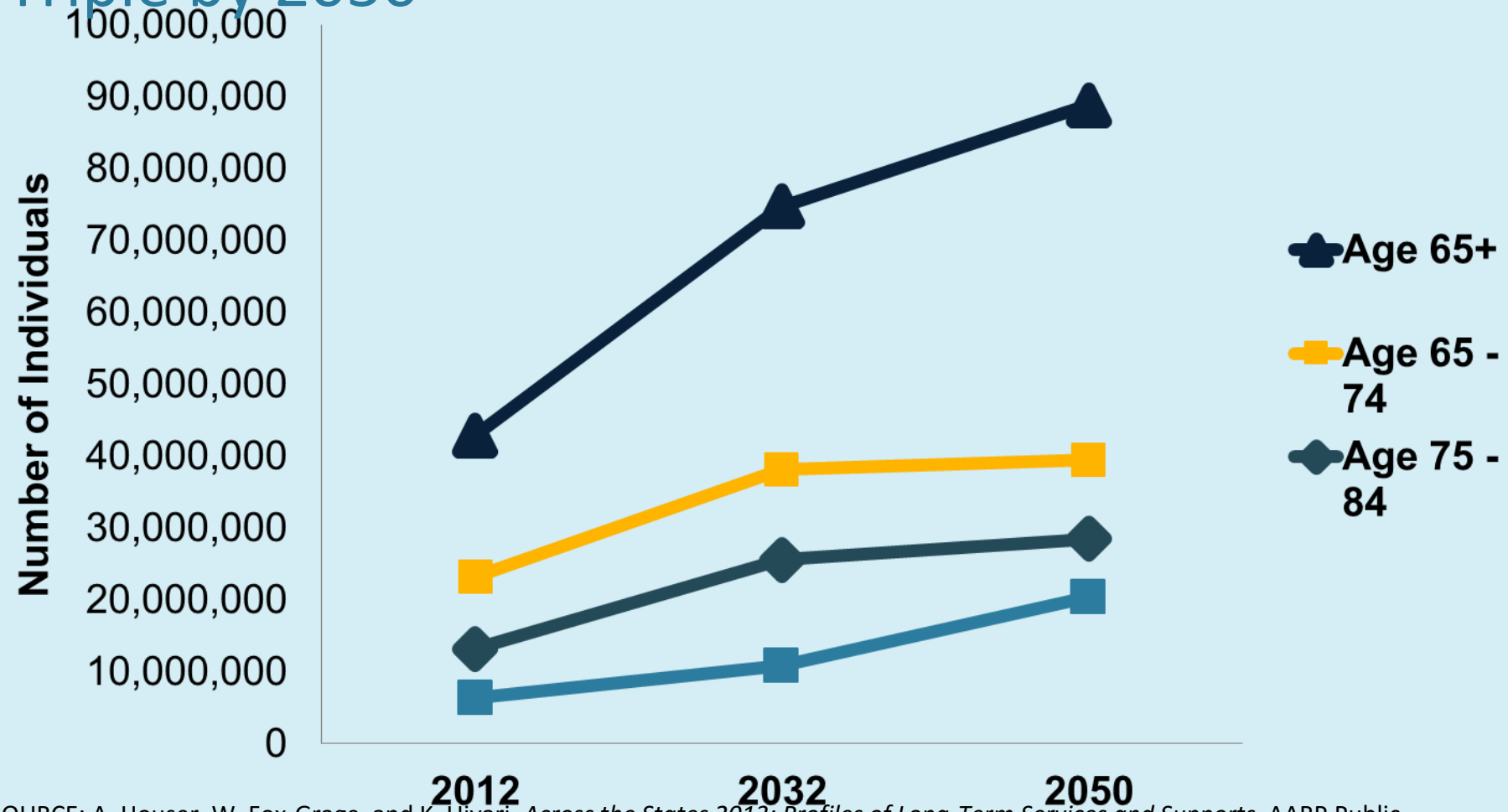
- **U.S. 10.2%**
- IA. 17.9%
- MN. 13.1%
- MT. 10.1%
- NE 15.1%
- ND 19.1%
- **SD 17.3%**
- WY 12.7%
- AZ, 3.6%; ID, 6.1%;
- NV, 4.3%; NM, 6.6%;
- OR, 3.6%; UT, 5.1%;

% of Nursing Home Population, between ages 31 and 64, 2012

UT.	23.0%	N.H.	7.6%
IL.	21.2%	N.D.	7.9%
NV., AK.	20.3%	VT.	8.1%
D.C.	19.8%	**S.D. (527)**	**8.3%**
AZ.	19.6%	IA.	8.5%
LA,	19.4%	R.I.	8.6%
		WY.	9.0%
		ME.	9.1%
		MN.	9.6%

U.S. Average: 14.5%

The 65 and Over Population Will More Than Double and the 85 and Over Population Will More Than Triple by 2050



SOURCE: A. Houser, W. Fox-Grage, and K. Ujvari. *Across the States 2013: Profiles of Long-Term Services and Supports*, AARP Public Policy Institute, September 2012, available at: http://www.aarp.org/content/dam/aarp/research/public_policy_institute/ltc/2012/across-the-states-2012-full-report-AARP-ppi-ltc.pdf.

Life Expectancy

In 2050 life expectancy at birth is predicted to be 86 years for males and 92 years for females. At age 65, the life expectancy is projected to be 25 years (90 years) and 30 years (95 years), respectively.

Projecting the Numbers in Wisconsin

- 2011 spent $1.5 billion on community LTS&S for 43, 500 people
- An additional 16,000 people could be enrolled in these programs within 2 years
- This 36.8 % increase in enrollment could drive program costs to $2.1 billion
- By 2035, Wisconsin's over 65 population will double and the over 85 group will triple
- What are the numbers in other states???

Beth Wroblewski @ ANCOR October, 2011

Coleman Institute for Cognitive Disabilities
UNIVERSITY OF COLORADO
Boulder | Colorado Springs | Denver | Anschutz Medical Campus

THE STATE OF THE STATES IN DEVELOPMENTAL DISABILITIES

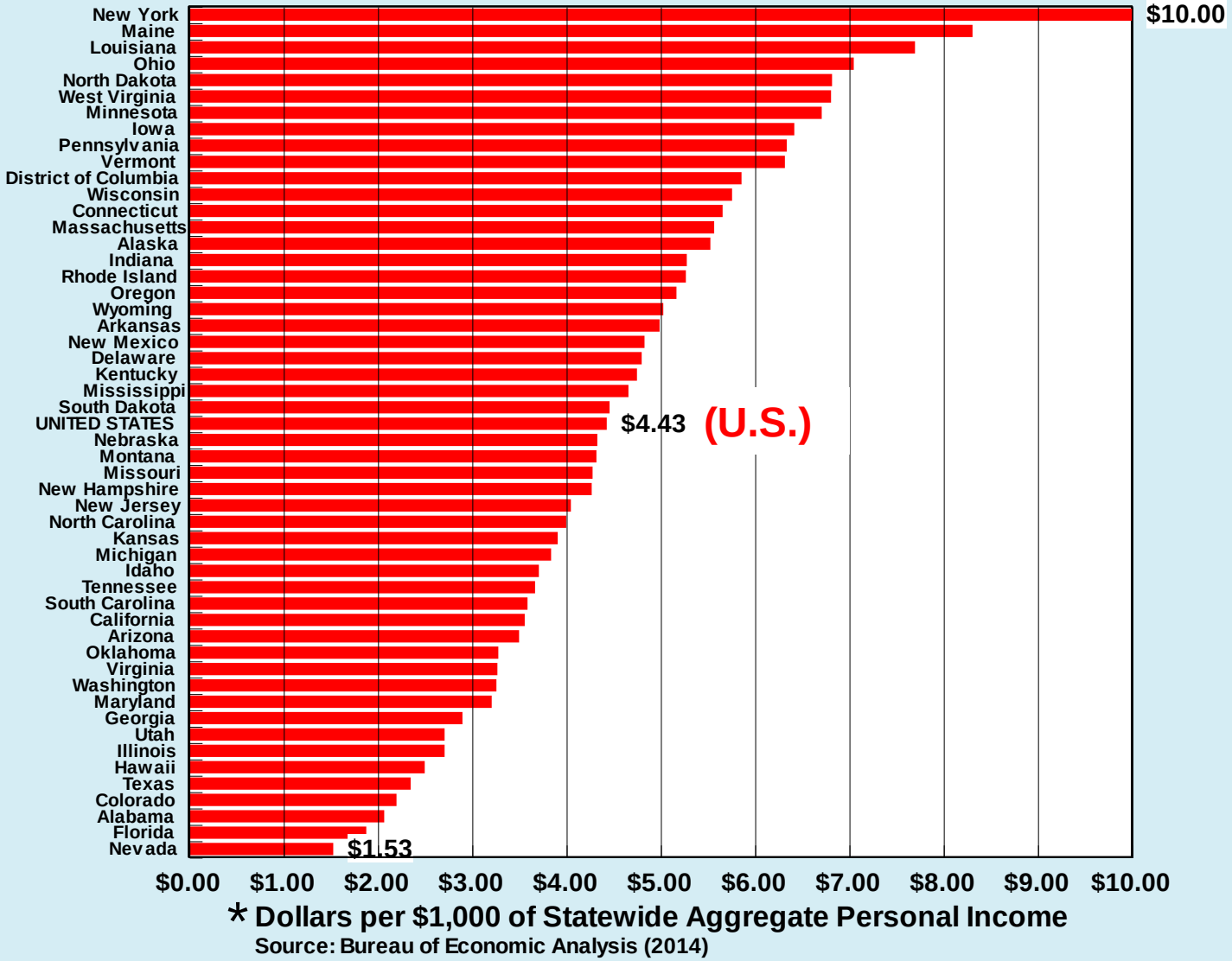
Richard Hemp, Mary Kay Rizzolo, Shea Tanis, & David Braddock
Universities of Colorado and Illinois-Chicago

AUGUST 5, 2014

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*



Source: Braddock, D. et al., *State of the States in Developmental Disabilities*, 2014, preliminary.

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 +	**887**
	100,433

SMALLEST I/DD INSTITUTION CENSUS, 2013		
1	Idaho	36
2	Nevada	47
3	Montana	55
4	Delaware	61
5	Wyoming	78
6	North Dakota	92
7	Arizona	106
8	Maryland	129
9	South Dakota	140
10	Colorado	149

Private ICF/DD Numbers: Smallest, 2013

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

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 ½ 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.

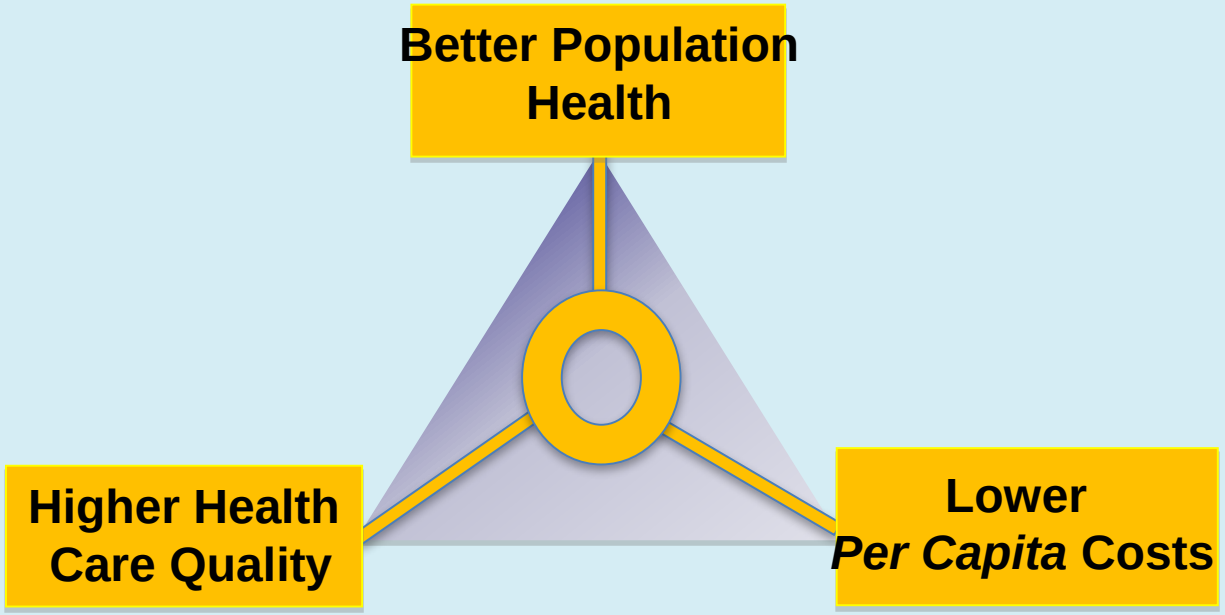
It is expected that SSDI/SSI annual payments will reach over $1 trillion by 2023.

Vision……..

"The only thing that is constant is change."

Heraclitis

Better Care, Better Health, Lower Costs as defined by CMS, Don Berwick, M.D.



New Leadership at Microsoft

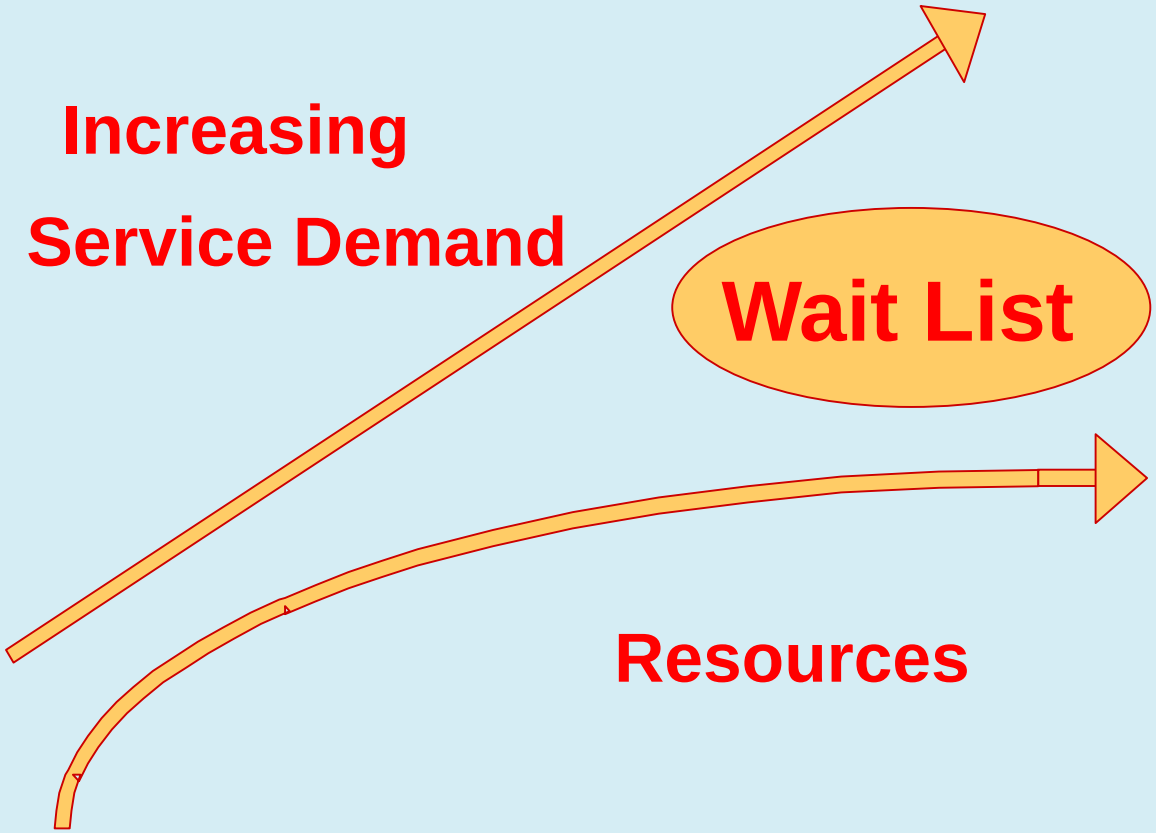
" Our industry does not respect tradition. It only respects innovation."

Satya Nadella
February 2014

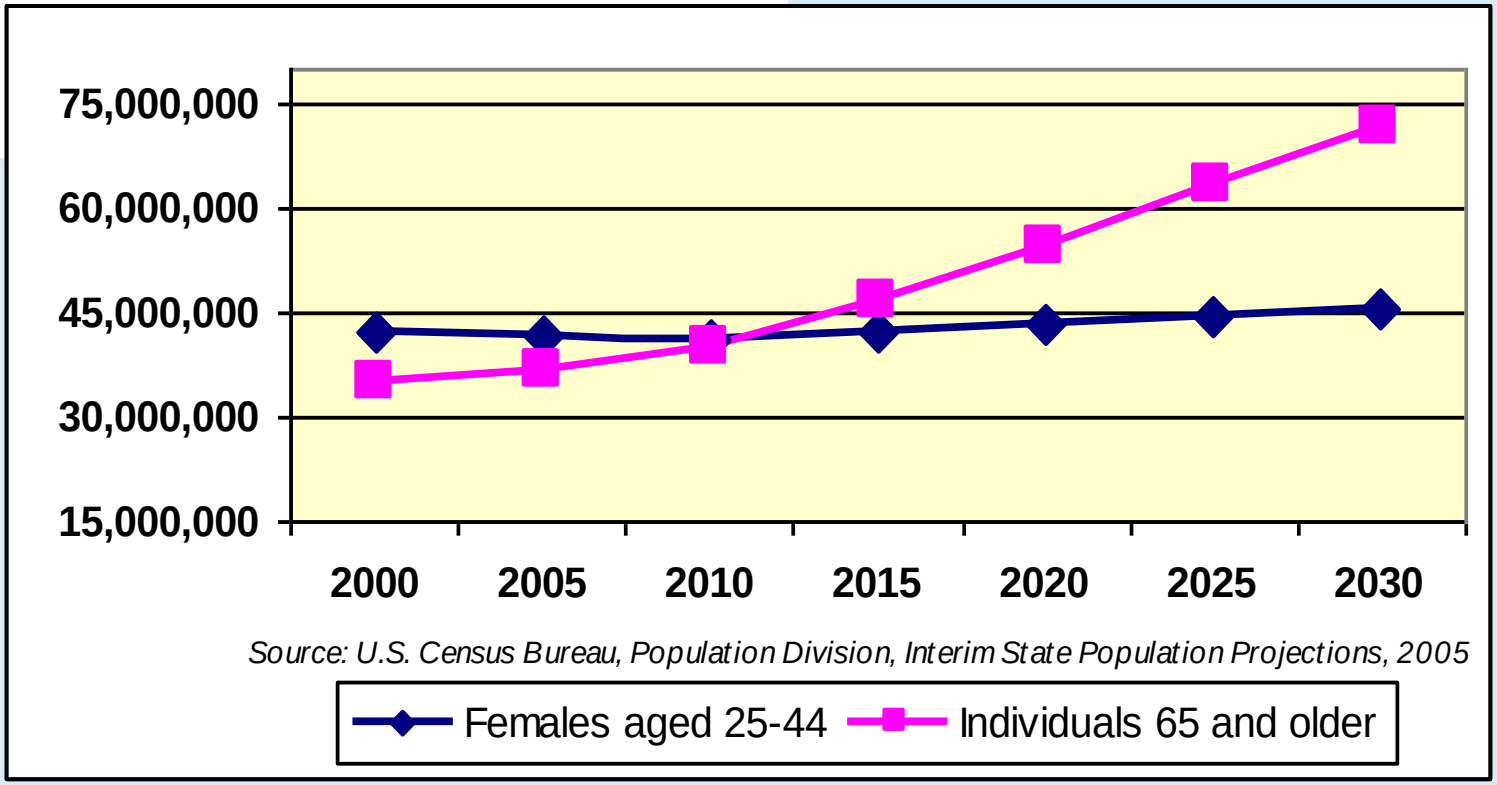
Innovation and Risk Taking

- We struggle with the idea of failure
- Limits desire to take risks and to innovate
- **Perspective is everything**
- Edison tried almost a thousand times to build the light bulb before getting it
- “I have not failed 1,000 times. I have successfully discovered 1,000 ways to NOT make a light bulb.”
- **Innovation is about trying new things and promoting positive change.**
- We learn from our mistakes

We Face a Big Problem…



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



Larson, Edelstein, 2006

Health Maintenance Tasks Able to be Delegated to LTSS Workers

1. Administer Oral Medications
2. Administer Medication, as needed basis
3. Administer Medication via Pre-Filled Insulin or Insulin Pen
4. Draw up Insulin for Dosage Measurement
5. Administer Intramuscular Injection Medications
6. Administer Glucometer Test
7. Administer Medication through Tubes
8. Insert Suppository

Health Maintenance Tasks Able to be Delegated to LTSS Workers

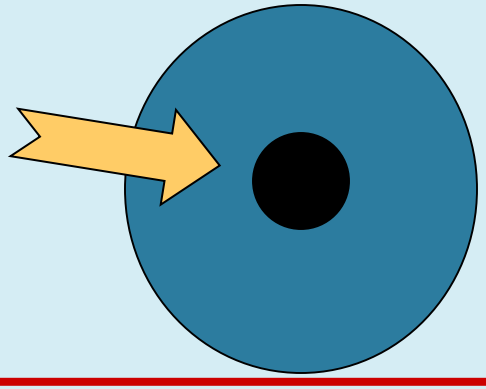
9. Administer eye/ear drops
10. Gastrostomy Tube Feeding
11. Administer Enema
12. Perform Intermittent Catheterization
13. Perform Ostomy Care including Skin Care and Changing Appliance
14. Perform Nebulizer Treatment
15. Administer Oxygen Therapy
16. Perform Ventilator Respiratory Care

States and Nurse Delegation of Tasks

- :Delegate all 16 Tasks by 9 States: Alaska, Colorado, Iowa, Minnesota, Missouri, Nebraska, Oregon, Vermont, Washington. $$$$$$$$$$$$$$$$$$
- South Dakota delegates 11 tasks; does not allow: 1. Administer Medication via Pre-Filled Insulin or Insulin Pen; 2. Draw up Insulin for Dosage Measurement; 3. Administer Intramuscular Injection Medications; 4. Administer Medication through Tubes; and, 5. Perform Ventilator Respiratory Care.

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"**

Arc of the United States mission statement

"The Arc of the United States promotes and protects the human rights of persons with intellectual and developmental disabilities and actively supports their **full inclusion and participation in the community throughout their lifetime.**"

United Cerebral Palsy

The mission of UCP is to advance the independence, **productivity and full citizenship** of people with a spectrum of disabilities.

Life without limits for people with disabilities

Autism Society of America

- Vision: …**meaningful participation and self-determination** in all aspects of life for individuals on the autism spectrum and their families;
- Advocating for **inclusion, participation & self-determination in all aspects of life** for individuals on the autism spectrum and their families.

ALLIANCE FOR FULL PARTICIPATION, 2005

- We want **dignity and respect for all.**
- We want **full participation for all.**

Principles of Independent Living

- Civil rights
- Consumerism
- De-institutionalization
- De-medicalization
- Self-help
- Advocacy
- Barrier removal
- Consumer control
- Peer role models
- Cross-disability

AARP Vision and Mission

" A society in which all people live with dignity and purpose, and fulfill their goals and dreams."

"AARP enhances the quality of life for all as we age. We champion positive social change and deliver value through advocacy, information and service."

"The design & delivery of all **LTSS should promote consumer independence, choice, dignity, autonomy and privacy."**

National Council on Aging

"A just and caring society in which each of us, as we age, lives with dignity, purpose, and security."

"To improve the lives of millions of older adults, especially those who are vulnerable and disadvantaged."

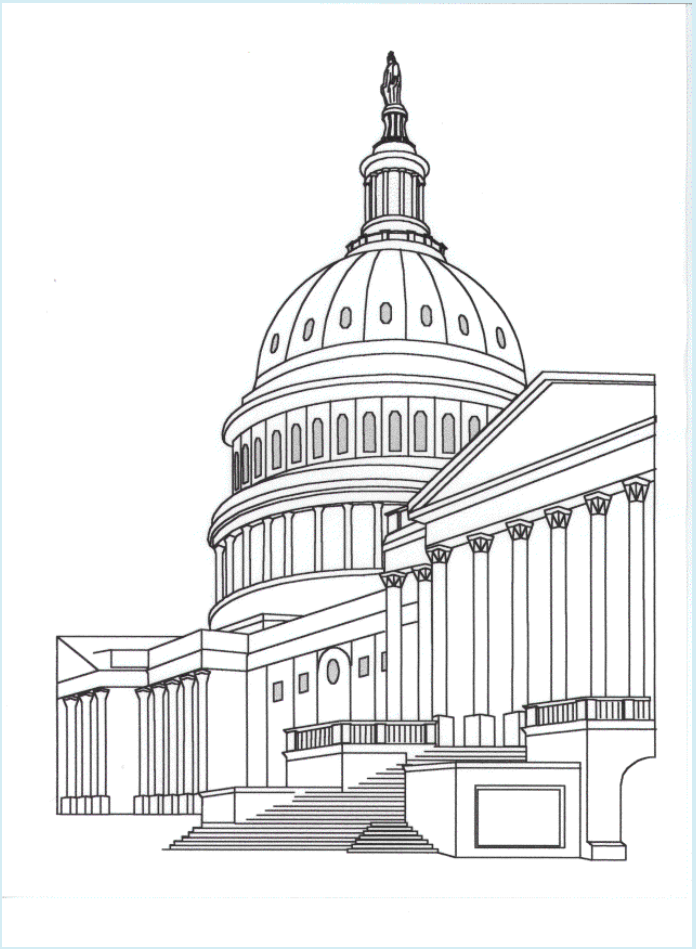
LTSS: "We're leading a national collaborative effort between aging and disability organizations **to make it easier for individuals to get help with daily living – right in their own homes & community.**"

"Suit the Actions to the Words"

"Life is not a "Program"

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

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.

Purpose of DD Act (mission)

"to assure that individuals with DD and their families participate in the design and have access to needed community services, individualized supports, and other forms of assistance that **promote self-determination, independence, productivity, and integration and inclusion in all facets of community life**, through **culturally competent** programs authorized…"

Section 101 (b)

Policy of DD Act

"(2) individuals with DD and their families have **competencies, capabilities, and personal goals** that **should** be recognized, supported, and encouraged, and any assistance to such individuals **should** be provided in an individualized manner, consistent with the **unique strengths, resources, priorities, concerns, abilities and capabilities of such individuals…**"

D. D. ACT: INCLUSION…….

- …means the **acceptance and encouragement of the presence and participation of individuals with DD, by individuals without disabilities,** in social, educational, work and community activities, that enables individuals with DD to
- A. have friendships and relationships with individuals and families of their own choice;
- B. **live in homes close to community resources, with regular contact with individuals without disabilities in their own communities;**

DD ACT: INCLUSION, cont

- C. Enjoy full access to and active participation in the same community activities and types of employment as individuals without disabilities; and,
- D. Take full advantage of their integration into the same community resources as individuals without disabilities, living, learning, working , and enjoying life in regular contact with individuals without disabilities.

Older Americans Act Objectives:

- Obtaining and maintaining suitable **housing, independently selected**, designed and located with reference to special needs & at affordable costs;
- Opportunity for **employment** with no discriminatory personnel practices
- Participating in and **contributing to meaningful activity** within the widest range of **civic, cultural, educational and training and recreational** opportunities

Older Americans Act Objectives

- Retirement in health, honor, dignity – after years of contribution to the economy
- **Freedom, independence, and the free exercise of individual initiative in planning and managing their own lives,** full participation in the planning and operation of community based services and programs provided for their benefit, and protection against abuse, neglect and exploitation

Older Americans Act, Amendments, 2006

- Added Assistive Devices/Technology
- Added Self-Directed Care as an approach to providing services intended to assist an individual with ADL's, in which –
  - Such services are planned, budgeted and purchased under the direction and control of such individual
  - Such individual is provided with such information and assistance as are necessary and appropriate to make informed decisions about his/her options

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;

Older Americans Act, cont.

- The **needs, capabilities and preferences of such individual** with respect to such services, and such individual's ability to direct and control the individual's receipt of such services, are assessed by the area aging on agency involved;
- …a plan of services for such individual that specifies which services such individual will be responsible for directing;
- A determination of the role of family members and others sought by individual
- A **budget** for such services

SAMHSA's Vision:

" A vision for a good and modern mental health and addiction system is grounded in a **public health model** that addresses the determinants of health, system and service coordination, health promotion, prevention, screening and early intervention, treatment, resilience and recovery support **to promote social integration and optimal health and productivity."**

SAMHSA Consensus Statement on Mental Health and Recovery, 2011

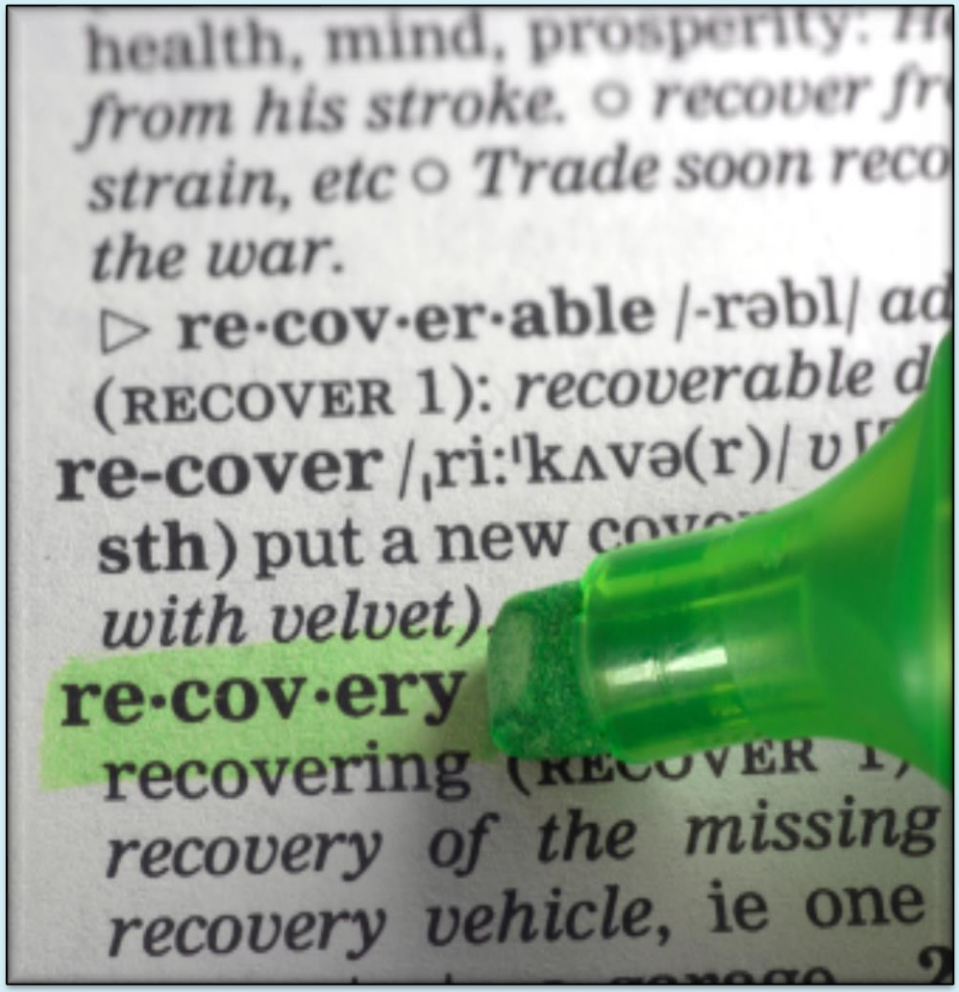
- Person driven
- Occurs via many pathways
- Is holistic
- Is supported by peers
- Is supported through relationships
- Is culturally-based and influenced
- Is supported by addressing trauma
- Involves individual, family and community strengths and responsibility
- Is based on respect
- Emerges from hope
- 4 major domains support recovery:

1) Health
2) Home
3) **Purpose: Employment/Education**
4) Community

RECOVERY, cont.

- **Health**: overcoming or managing one's disease(s) or symptoms and making informed health choices that support physical and emotional well being
- **Home**: a stable and safe place to live
- **Purpose**: meaningful daily activities such as a job, school, volunteerism, family caretaking, or creative endeavors, and the independence, income, and resources to participate in society
- **Community**: relationships & social net-works for support, friendship, love & hope

Defining Recovery



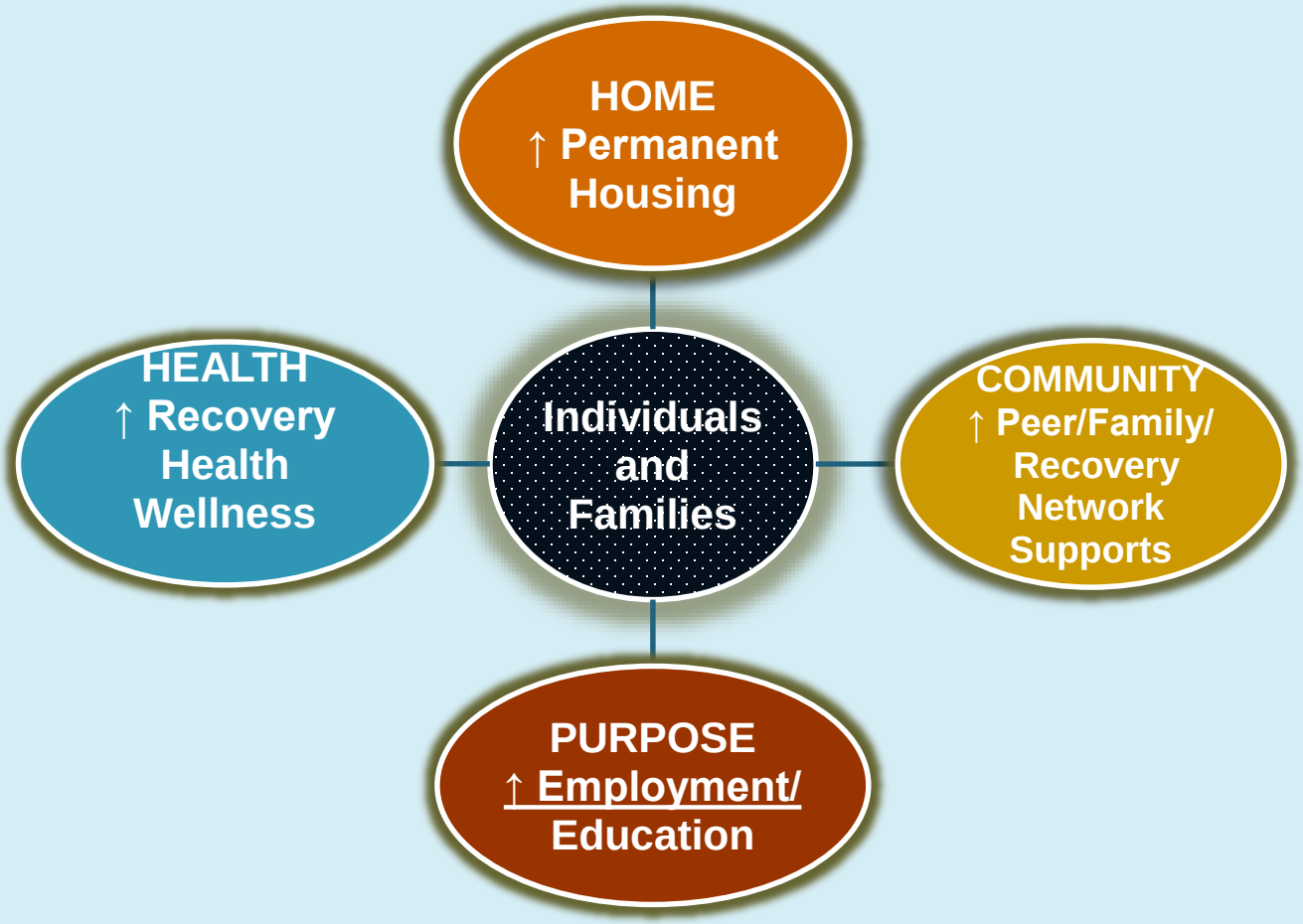
A process of change through which individuals improve their health and wellness, live a self-directed life, and strive to reach their full potential.

– SAMHSA, 2011

Guiding Principles of Recovery

- Holistic
- Person-driven
- Many pathways
- Peer support
- Relational/social
- Strengths/responsibility
- Respect
- Culturally based
- Addresses trauma
- Hope

Recovery Support Strategic Initiative



IPS SUPPORTED EMPLOYMENT

EVIDENCE-BASED PRACTICE

Presenters:

Tish Thomas, IPS State Trainer, DMH/VR/MU

Mickie McDowell, Peer Services Program Specialist DMH - DBH

Why Focus on Employment?

- Viewed as an essential part of recovery & stable housing
- Most people want to work
- A typical role for adults in our society
- Cost-effective alternative to day treatment

Positive Outcomes from Competitive Work

- Higher self-esteem
- Better control of psychiatric symptoms
- More satisfaction with finances and with leisure
- Maintenance of stable housing

Is Work Too Stressful?

- As compared to what?
- Joe Marrone, an employment trainer:

"If you think work is stressful, try unemployment."

- Stresses of work do not translate into higher rates of hospitalization

Negative Effects of Unemployment in General Population

- Increased substance abuse
- Increased physical problems
- Increased psychiatric disorders
- Reduced self-esteem
- Loss of social contacts
- Alienation and apathy

- (Warr, 1987)

Title XIX-Grants To States For Medical Assistance Programs [42 U.S.C. Sec. 1396]

Sec. 1901. For the purpose of enabling each state as far as practicable under the conditions in such State, to furnish (1) medical assistance on behalf of families with dependent children and **of aged, blind or disabled individuals,** whose income and resources are insufficient to meet the costs of necessary medical services, and

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

Medical Necessity Criteria; Critical Michigan Medicaid Provider Manual

"Mental health, developmental disabilities, and substance abuse services are supports, services and treatment:

- Required to identify and evaluate a mental illness, developmental disability, or substance abuse disorder that is inferred or suspected; and/or
- Intended to treat, ameliorate, diminish or stabilize the symptoms of M.I., D.D. or SAD; and/or

Michigan Medical Necessity, 2

- Expected to arrest or delay the progression of a mental illness, developmental disability, or substance abuse disorder; and/or
- Designed to assist the consumer to attain or maintain a sufficient level of functioning in order to achieve his goals of community inclusion and participation, independence, recovery or productivity."

Mandatory State Plan Services:

- Inpatient Hospital Services (not IMD)
- Outpatient Hospital Services and Rural Health Clinic Services
- Other Laboratory and X-Ray Services
- ***Nursing Facility Services for Individuals 21 or Older*** (not IMD)
- Family Planning Services

42CFRss440…

Mandatory State Plan Services-2

- EPSDT
- Physicians' Services and Medical and Surgical services of a Dentist
- Home Health Services
- Nurse-Midwife Services (where licensed)
- Nurse Practitioner Services (where licensed
- Pregnancy-Related Services

EPSDT

requires that any service which you are permitted to cover under Medicaid that is **deemed medically necessary to treat or ameliorate a defect, physical and mental illness, or a condition identified by a screen, must be provided to E.P.S.D.T.** participants through age 21 regardless of whether the service or item is otherwise included in your Medicaid plan.

Optional State Plan Services 1

- Medical or Other Remedial Care Provided by Licensed Practitioners
- Private Duty Nursing Services
- Clinic Services
- Dental Services
- Physical Therapy, Occupational Therapy, and Services for Individuals with Speech, Hearing and Language Disorders

Optional State Plan Services 2

- Prescribed Drugs, Dentures, Prosthetic Devices and Eyeglasses
- Diagnostic, Screening, Preventive, and rehabilitative Services
- Inpatient Hospital, etc. Services for Individuals age 65 or over in IMD's
- ICF/MR Services

Optional State Plan Services 3

- Nursing Facility Services Other than in an IMD
- Inpatient Psychiatric Services for Individuals under age 21
- Personal Care Services
- Any Other Medical Care or Remedial Care Recognized Under State Law, including Transportation

Optional State Plan Services 4

- Emergency Hospital Services
- Respiratory Care for Ventilator-Dependent Individuals
- Home or Community-Based Services, Waiver or State Plan
- Health Homes
- Community First Choice

MEDICAID STATE PLAN OPTION: Health Homes for Chronic Conditions

- (s2703) Adds section 1945 to S.S.Act
- States may choose to permit beneficiaries with at least two chronic conditions, including asthma, diabetes, heart disease, obesity, mental condition, and substance abuse disorder; one condition and risk of developing another; or one serious and persistent mental health condition, to designate a provider as a health home;

Medicaid Health Homes, cont.

- Targeted to serve most expensive folks
- **States may have multiple projects**
- Populations, diagnostic groups and geographic locations can be targeted
- Enhanced integration and coordination of primary, acute, behavioral and long term HCBS & supports, including employment supports; multidisciplinary = person centered and whole person
- Referrals: Hospital ER's refer Medicaid beneficiaries with chronic conditions

CMS State Directors' Letter, 11/16/2010

"The goal of **health homes** is to expand the traditional medical home models to build linkages to other community and social supports, and to enhance coordination of medical and behavioral health care, in keeping with the needs of the **person with multiple chronic illnesses.**"

CMS State Directors' Letter, 2

"This provision supports CMS's overarching approach to improving health care through the simultaneous pursuit of three goals:

- Improving the experience of care;
- Improving the health of populations; &
- Reducing per capita costs of health care (without any harm whatsoever to individuals, families, or communities."

Medicaid Health Home Services:

1. Comprehensive care management/plan;
2. Care coordination and health promotion;
3. Comprehensive transitional care and follow up from inpatient to home/outpatient and other settings
4. Individual and family support;
5. Referral to community and social supports, when needed;
6. Use of Health Information Technology to link services, if applicable

Services Coordinated by Health Homes

- Access to high quality health care services informed by evidence-based clinical practice guidelines
- Preventive and health promotion services, including prevention of mental illness and substance use disorders
- Mental health and substance use services
- Comprehensive care management and care coordination

Services Coordinated by Health Homes-2

- Transitional care across settings including appropriate follow-up from inpatient to other settings, such as participating in discharge planning and facilitating transfer from a pediatric to an adult system of health care
- Chronic disease management, including self-management support to individuals and their families

Services Coordinated by Health Homes-3

- Providing quality-driven, cost-effective, culturally appropriate and person- and family-centered health home services and supports, including referral to community, social support, and recovery services
- Long-term care supports and services

Health Homes are responsible for securing a full array of behavioral, medical and long-term care services.

COMMUNITY FIRST CHOICE MEDICAID STATE PLAN OPTION

- Section 1915 (k)
- An attempt to reduce the “institutional bias” in Medicaid long term services
- Has been attempted since ADAPT’s (American Disabled for Attendant Programs Today) early attempts at MiCASA in the early 1990’s

COMMUNITY FIRST CHOICE, cont.

- Provides comprehensive home and community based services (HCBS) for individuals with disabilities who are eligible for a Medicaid “institutional level of care”
- States who choose this must make community-based attendant services and supports available to all eligible individuals and is an entitlement to HCBS

COMMUNITY FIRST CHOICE

- Services and supports to assist individuals with disabilities with activities of daily living, instrumental activities of daily living, and health related tasks through hands-on-assistance, supervision, or cueing

- States who choose this new Medicaid state plan option will receive an additional 6% federal match rate for this program

COMMUNITY FIRST CHOICE, cont.

- Eligibility based on functional need
- Allows states to have eligibility up to 300% of SSI
- Services to be provided at home or in a community setting
- Excludes room & board, assistive technology devices and services (except emergency back up systems), medical supplies and equipment, & home modifications

COMMUNITY FIRST CHOICE, cont.

- Covers help to acquire, maintain and enhance skills needed for individual to acquire ADL's, IADL's and health related tasks
- Covers back up systems or mechanisms, such as beepers or other electronic devices
- Covers voluntary training on how to select, manage and dismiss attendants

COMMUNITY FIRST CHOICE, cont.

- Other permissible services include:
- Institutional transition costs (rent and utility deposits, bedding, kitchen supplies)
- Needs identified in the PCP that would increase independence or substitute for paid human assistance
- States must provide consumer controlled services, statewide, and in the most integrated setting appropriate

COMMUNITY FIRST CHOICE, cont.

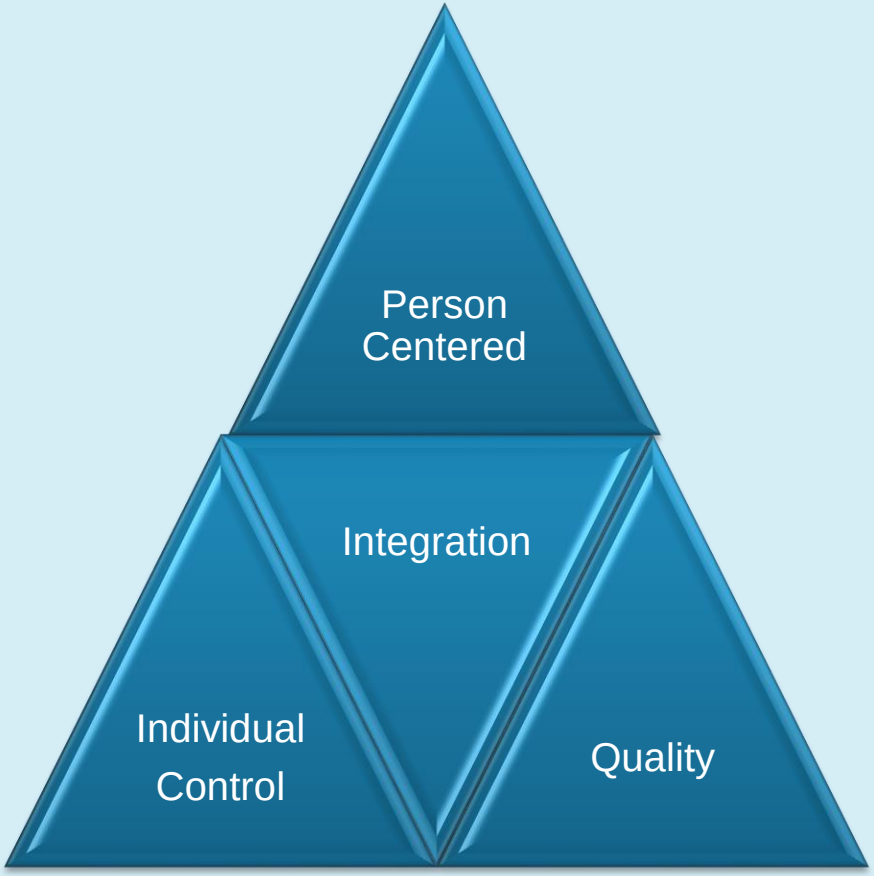
- States must have a development and implementation council; majority of persons with disabilities, elderly individuals and their representatives
- States must establish a comprehensive Q.A. system incorporating feedback from consumers, families, and providers
- During first year, states must maintain same level of expenditures as previous years

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



The Impact of Employment on Medicaid Utilization and Costs

- State of Iowa, calendar year 2011
- Individuals on SSI who became employed and used the Medicaid Buy-In (MEPD)
- SSI beneficiaries who became employed, using MEPD, experienced $161/month lower Medicaid claims.
- Beneficiaries dually covered by Medicaid and Medicare who became employed and used MEPD had a $332/month reduction in Medicaid claims

Iowa Employment-Medicaid Data, 2

- Calendar year 2011, 129,369 MEPD member months produced **$20,828,409 in total Medicaid claims savings.**
- Stated another way, the total claims paid by the individuals who became employed in 2011 were **21.6% less than expected** based on their previous claims experience and the claims experience of SSI related Medicaid beneficiaries.

Individuals with Disabilities are a very heterogeneous and diverse population

No "one size fits all"

- ADHD
- Alcoholism
- Autism
- Bipolar disorder
- Blindness/vision impaired
- Cerebral palsy
- Cystic fibrosis
- Deaf/hearing impaired
- Depression
- Down syndrome
- Epilepsy

Individuals within "labels"

- HIV/AIDS
- Intellectual disabilities
- Multiple sclerosis
- Muscular dystrophy
- Parkinson's disease
- Schizophrenia
- Spina bifida
- Spinal cord injury
- Stroke
- Substance abuse
- Traumatic brain injury

Age Adjusted Prevalence Rates for Chronic Health Conditions, MEPS 2012

No Disability

- Arthritis 9.7%
- Asthma 7.6%
- Cardiovascular 5.1%
- Diabetes 3.7%
- High B.P. 16.1%
- High Cholesterol 16.7%
- Stroke 0.7%

Cognitive Limitation

- Arthritis 26.%
- Asthma 17.0%
- Cardiovascular 13.1%
- Diabetes 18.0%
- High B.P. 27.5%
- High Cholesterol 22.4%
- Stroke 14.2%

Prevalence of Behavioral Health Comorbidities among Medicaid-Only Beneficiaries with Disabilities

Chronic Condition Only

- Hypertension; 31.4%
- Diabetes; 32.1%
- Coronary Heart Disease; 26.3%
- Congestive Heart Failure; 30.1%
- Asthma and/or COPD; 23.8%

Chronic Condition & MI &/or drug/alcohol disorder

- Hypertension; 69.6%
- Diabetes; 67.9%
- Coronary Heart Disease; 73.7%
- Congestive Heart Failure; 69.9%
- Asthma and/or COPD; 76.2%

Kronick, Bella, & Gilmer, 2009

The Role of Medicaid for People with Behavioral Health Conditions Kaiser Family Foundation; 11/16/12

- Medicaid covers more than ¼ of the $135 Billion in total Behavioral Health spending
- **Medicaid has become the largest single payer for behavioral health services**
- 35% of Medicaid beneficiaries live with a chronic mental illness

Medicaid Comorbidity Data: Kronick, Bella & Gilmer; CHCS; 10/2009

- Psychiatric illness and cardiovascular disease; 40.4%
- Psychiatric illness and central nervous system disorders; 39.8%
- Psychiatric illness and pulmonary disorders; 28.6%

Why is Integration of Primary Care and Behavioral Health Important?

NASMHPD, June 2012

- "Over 12 million visits to emergency departments are individuals with behavioral health disorders.
- Over 70 percent of primary care visits stem for psychosocial issues. Most primary care physicians are not equipped or lack the time to fully address the wide range of psychosocial issue that are presented by patients.

Integration of Primary Care & Behavioral Health, cont.

- Nearly half of all cigarette consumption is by individuals with behavioral health disorders.
- Nearly 3 of 4 individuals with significant behavioral health disorders had at least 1 chronic condition, nearly half had 2 chronic diseases and almost one-third had 3 or more conditions. Most of the individuals who have 3 or more physicians do not talk with another or share information.

Integration of Primary Care & Behavioral Health, cont.

- Nearly half of all cigarette consumption is by individuals with behavioral health disorders.
- Nearly 3 of 4 individuals with significant behavioral health disorders had at least 1 chronic condition, nearly half had 2 chronic diseases and almost one-third had 3 or more conditions. Most of the individuals who have 3 or more physicians do not talk with another or share information.

Integration of Primary Care & Behavioral Health, cont.

- Individuals with severe addiction and co-occurring mental illness, a significant percentage of those with substance use or mental health problems, die prematurely – on average 37 years sooner than Americans without severe addiction and mental health problems. People with serious mental illness die 25 years sooner than the general population from common medical conditions such as cancer & heart disease.

Integration of Primary Care & Behavioral Health, cont.

- Health care expenditures of Americans with SMI are 2 to 3 times higher than other patients.”

Fact Sheet on Accelerating Integration of Primary Care, Behavioral Health and Prevention: The SBHA Role; June 2012; NASMHPD

Benefits of Employment

- ✓Get out of poverty; pay taxes
- ✓More independence
- ✓Make Friends
- ✓Make a contribution to the community
- ✓Positive image and valued role within the family and community
- ✓Opportunities for learning and expanding relationships

CMS Issues Updates to Medicaid Waiver Technical Guide on Employment Services; September 16, 2011

"We hope that by emphasizing the importance of employment in the lives of people with disabilities, updating some of our core service definitions, and adding several new core service definitions to better reflect best and promising practices that it will support States' efforts to increase employment opportunities and meaningful community integration for waiver participants."

National Governors Association

A Better Bottom Line: Employing People with Disabilities

- **July 2012**
- Governor Jack Markell (DE.), NGA Chair, 2012- 2013
- Focus on the employment challenges that affect individuals with intellectual and other significant disabilities

Partnerships

- “Government,
- business,
- the general public,
- individuals with disabilities, and their families

…all stand to benefit from increased employment of people with disabilities; all have a role and shared responsibility in reaching this goal.”

A Better Bottom Line: Why?

- **The Right Thing to Do** – Individuals with disabilities have demonstrated ability and are an untapped resource.
- **The Smart Thing for Government to Do - Individuals with disabilities are heavily reliant on government benefits.** When people with disabilities are employed and living more independently, they are **less reliant on government payments and contribute to the economy**

Presumption of Employability

“ Everybody is a genius. But if you judge a fish by its ability to climb a tree, it will live its whole life believing that it is stupid.”

Albert Einstein

CMS Issues Updates to Medicaid Waiver Technical Guide on Employment Services; September 16, 2011

"We hope that by emphasizing the importance of employment in the lives of people with disabilities, updating some of our core service definitions, and adding several new core service definitions to better reflect best and promising practices that it will **support States' efforts to increase employment opportunities and meaningful community integration for waiver participants.**"

Major Changes in Waiver, cont.

- Adds a new core service definition by splitting supported employment into individual and small group
- Adds new service, **career planning**
- Emphasizes critical role of **person centered planning**
- Acknowledges **self-determination, peer support & other best practices**
- Clarifies that Ticket to Work Outcome and Milestone payments are not in conflict with Medicaid services rendered payments

Major Changes in Waiver, cont.

- Modifies both the prevocational and supported employment definitions to clarify that **volunteer work and other activities that are not paid, integrated community employment are appropriately described in pre-voc,** not supported employment services.
- Explains that **pre-voc services are not an end point,** but a time limited (no limit is given) service for the purposes of helping someone obtain competitive employment.

Dept. of Education: PROMISE Grants Promoting Readiness in S.S.I.

- Competitive applications; August 2013
- Funding for 3-6 states for up to 5 years
- State to develop & implement Model Demonstration Projects (MDPs) to promote positive outcomes for children who receive SSI & their families
- To improve provision & coordination of services/supports for this population to achieve improved results with Outcome-based Payment Models (OBP).

Promise Grants Awarded; Sept. 2013

- Arkansas $32,427.44
- California $50,000.00
- Maryland $31,190.76
- New York $32,500.00
- Wisconsin $32,497.81
- **ASPIRE- 6 state $32,500.00**

Collaboration of Utah, S. Dakota, N. Dakota, Montana, Colorado and Arizona

Workforce Innovation & Opportunity Act

- July 22, 2014; P.L. 113-128
- Major changes in Workforce Investment Act and Vocational Rehabilitation Act
- Joint Performance Measures for the State VR agency and the State Workforce Agency with one integrated plan
- **Emphasis on Transition and Youth with most significant disabilities for S.E.**
- **Customized Employment defined in law**

Workforce Innovation & Opportunity Act

- Supported Employment in VR Act:
  - Definition modified to clarify that **S.E. is integrated competitive employment,** or an individual working short-term in an integrated employment setting toward integrated competitive employment
  - **50%** of the State's Supported Employment funds **must be used** to support youth with **the most significant disabilities (up to age 24)** & they may receive supports for up to 4 years.

Workforce Innovation & Opportunity Act

- V.R. may maintain an open case file for up to 24 months while in supported employment

- Section 511 **prohibits PWD under the age of 24 from working for less than minimum wage unless they first try V.R. services among other requirements.**

- Sen. Tom Harkin **& Rep. Pete Sessions** ++

Workforce Innovation & Opportunity Act

- Requires that the State VR Agency have a **Formal Cooperative Agreement** with the State Medicaid Agency
- Requires that the State VR Agency have a **Formal Cooperative Agreement** with the agencies responsible for providing long term services and supports for people with disabilities; ID/DD; mental health; physical; sensory;
- Must define the respective roles in the provision of VR services, including extended services

Wisdom from President John F. Kennedy

" The great enemy of the truth is very often not the lie – deliberate, contrived and dishonest – but **the myth** – persistent, persuasive, and unrealistic."

Customized Employment

According to the 2014 Amendments to the Rehab Act (H.R. 803 Section 7 (7) (29 U.S.C. 705)

Customized Employment means competitive integrated employment, for an individual with a significant disability, that is based on an individualized determination of the strengths, needs, and interests of the individual with a significant disability, is designed to meet the specific abilities of the individual with a significant disability and the business needs of the employer, and is carried out through flexible strategies, such as:

The “flexible strategies” of Customized Employment in WIOA

(A) job exploration by the individual;

(B) working with an employer to facilitate placement, including —

(i) customizing a job description based on current employer needs or on previously unidentified and unmet employer needs;

(ii) developing a set of job duties, a work schedule and job arrangement, and specifics of supervision (including performance evaluation and review), and determining a job location;

(iii) representation by a professional chosen by the individual, or self-representation of the individual, in working with an employer to facilitate placement; and

(iv) providing services and supports at the job location.

Customized Employment Requires Building a "Positive Personal Profile"

- **Believe in your job seeker**
- Focus on skills – not deficits
- Positive; strengths based
- **No prerequisites**
- Everyone is "job ready"
- **What will employer value** about the job seeker?

RESEARCH AND BEST PRACTICES

- **Continuum of services is a myth and does not work; based upon a medical model**
- Competency/Deviancy Hypothesis by the late Dr. Marc Gold; “place and train rather than train and place”
- I.Q. does not correlate with productivity
- Supported Employment; Bellamy/Mank
- Refined by Callahan to Customized Employment; Self-Employment by Hammis and Griffin

Evidence-Based Principles

- Eligibility based on individual choice
- SE integrated with treatment
- Competitive employment
- Personalized benefits planning
- Rapid job search
- Continuous follow-along supports
- Individual preferences with supports
- Systematic job development

Eligibility Is Based on Choice

- People are not excluded because they are not "ready" or because of prior work history, hospitalization history, substance use, symptoms, or other characteristics.
- No one is excluded who wants to participate.

Employment First

"Employment is nature's best physician and is essential to human happiness."

— Galen, Greek physician

ADA Findings, P.L.101-336; 1990

- The continuing existence of unfair and unnecessary discrimination and prejudice denies people with disabilities the opportunity to compete on an equal basis and to pursue those opportunities for which our free society is justifiably famous, and **costs the United States billions of dollars in unnecessary expenses**

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 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**

Conclusions from Olmstead:

- The Integration Mandate is not only for Medicaid funding. It **applies to <u>all</u> publicly funded services**
- **The Integration Mandate is really about how states and counties organize services and supports**
- The Integration Mandate is about informed consumer choice
- **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 20, 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.**"
- **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, June 20, 2011

- **Segregated settings include**, but are not limited to:
  (1) **congregate settings populated exclusively or primarily with individuals with disabilities;**
  (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 20, 2011, cont.

(3) **settings that provide for <u>daytime activities</u> primarily with other individuals with disabilities**

- When is the ADA's integration mandate implicated?

  ...where a public entity administers its programs in a manner that results in **unjustified segregation of persons with disabilities.** More specifically, a public entity may violate the ADA's integration mandate when it:

DOJ, June 20, 2011, cont.

(1) directly or indirectly operates facilities and/or programs that segregate individuals with disabilities;
(2) finances the segregation of individuals with disabilities in private facilities; and/or
(3) through its planning**, service system design, funding choices, or service implementation practices, promotes or relies upon the segregation** of individuals with disabilities in private facilities or programs.

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 2913 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

Where is the Future?

Contact Information

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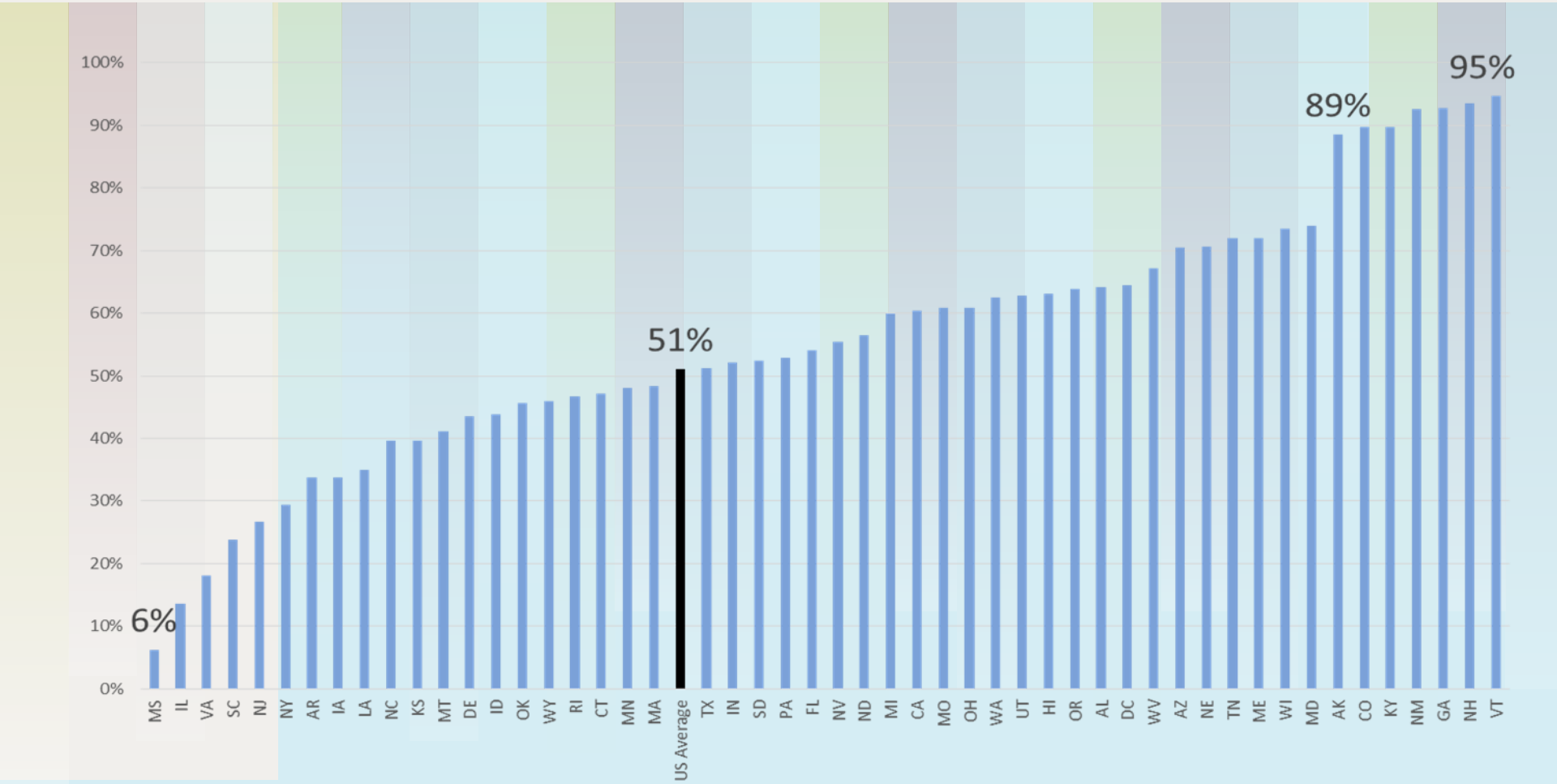
HSRI: John Agosta, Faythe Faiken, Yoshi Kardell
NASDDDS: Mary Sower, Nancy Thayler, Mary Lee Fay

% 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

  53% South Dakota

  *No Institutions

- **6-35%**
  - Mississippi***
  - Illinois***
  - Virginia***
  - South Carolina
  - New Jersey***
  - New York***
  - Arkansas
  - Iowa
  - Louisiana

  *** Among 10 states with largest state institutional populations

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**"

Design Overview

- CMS required alternative to Family Care
- Available where Family Care is offered
  - Began 7/1/2008
- Comprehensive, creative “SDS” waiver
- State-Administered with two primary contracts
  - IRIS Independent Consultant Agency
  - Fiscal Services Agency
- Self-Directed PC (1915 j) added 10/09

Using IRIS

- Begins with an Individual Budget Allocation (**obtained though ADRC**, using Wisconsin LTC Functional Screen) for LTS&S that is managed by the person
- Plan developed and approved with the assistance of an IRIS Consultant and the IRIS Consultant Agency
- Ongoing support through an IRIS Consultant
- "Bills paid" by Financial Services Agency

IRIS Services List

- Adaptive Aids
- Adult Day Care
- Adult Family Home
- Certified Residential Care Apartment Complex
- Communication Aids/Interpreter Services
- Community-Based Residential Facility (CBRF/Group Home)
- Consumer Education and Training
- Counseling and Therapeutic Resources
- **Customized Goods and Services**
- Daily Living Skills Training
- Day Services
- Home Delivered Meals
- Home Modifications
- Housing Counseling
- Personal Emergency Response Services
- Prevocational services
- Relocation Services
- Respite
- Support broker
- Skilled Nursing Services
- Specialized Medical Equipment and Supplies
- Supported Employment
- Supportive Home Care
- Transportation
- Vocational Futures Planning
- **Self-Directed Personal Care**

IRIS Participants

- Enrollment, July 1, 2011; 4,154 people
- Make their own decisions within their allocated budget about the goods, supports and services they will receive;
- Make their own decisions about who provides these supports and services;
- Make their own decisions about when and where supports and services are received;
- Infrequent supports (e.g. housing modification, adaptive equipment) are funded through a separate exceptional expense fund on an as-needed basis.

Wisconsin Long Term Support RESPECT Values

- **R**elationships
- **E**mpowerment to make choices
- **S**ervices to meet individual needs
- **P**hysical and mental health services
- **E**nhancement and maintenance of a person's value
- **C**ommunity and family participation
- **T**ools for independence

Focus on Member- Personal Experience - Outcomes

- I decide where and with whom I live
- I make decisions regarding my supports and services
- I decide how I spend my day
- I have relationships with family and friends I care about
- I do things that are important to me
- I am involved in my community
- My life is stable
- I am respected and treated fairly
- I have privacy
- I have the best possible health
- I feel safe
- I am free from abuse and neglect


CHANGE
AHEAD

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) SPA for HCBS; and, 1915 (k) Community First Choice SPA
- Extensive criteria for the development of a "person centered plan"
- "Informed choice"
- "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 PCP……

CMS Final Rules: 1-16-2014, cont.

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 and are based on the individual's needs, preferences & for residential settings, resources available for room and board."

"(iv) Optimizes, but does not regiment individual initiative, autonomy, and independence in making life choices, including, BNLT, daily activities, physical environment, & with whom to interact."

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

…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."

- **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:…..

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

CMS
CENTERS FOR MEDICARE & MEDICAID SERVICES
CENTER FOR MEDICAID & CHIP SERVICES

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

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?

Planned activities in the home community within all of life's activity 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
- 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

"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.

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.)

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

Individual Supports

- **Separates housing from supports (legal in HCBS waivers since 1995…….)**
- 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 that the person does not need to be "fixed"
- Built on presumption of "integration"/inclusion
- Kills belief that to "win" is to have more $$$

Supported Living: Key Principles

1. People with disabilities should be supported in living arrangements that are typical of those in which persons without disabilities reside.
2. The **services that a person receives should change as his or her needs change without the person having to move elsewhere.**
3. A person with disabilities should exercise **choice over where and with whom he or she lives.**

Supported Living: Key Principles -2

4. People with disabilities should have control over their own living arrangements.
5. The aim of furnishing services and supports to a program participant is to assist that individuals to take command of his or her life while building critical and durable relationships with other people.
6. The services or supports furnished to an individual should be **tailored to his or her needs and preferences.**

Supported Living: Key Principles - 3

7. Services and supports are more effective when furnished where a person lives and within the context of his or her day-to-day activities.
8. Supports must be extremely flexible, not restricted to particular types or categories of services.
9. People with DD should not be excluded from supported living arrangements based on the nature & severity of their disabilities.

Gary A. Smith, 1990 (tied to CSLA)

Supported Living is NOT……

- Simply offering services in “small residences”
- Synonymous with apartment programs
- A model that rejects training as a valid component of service provision
- An “unsupervised” living arrangement
- **Another residential alternative**.

Community Supported Living:WI.

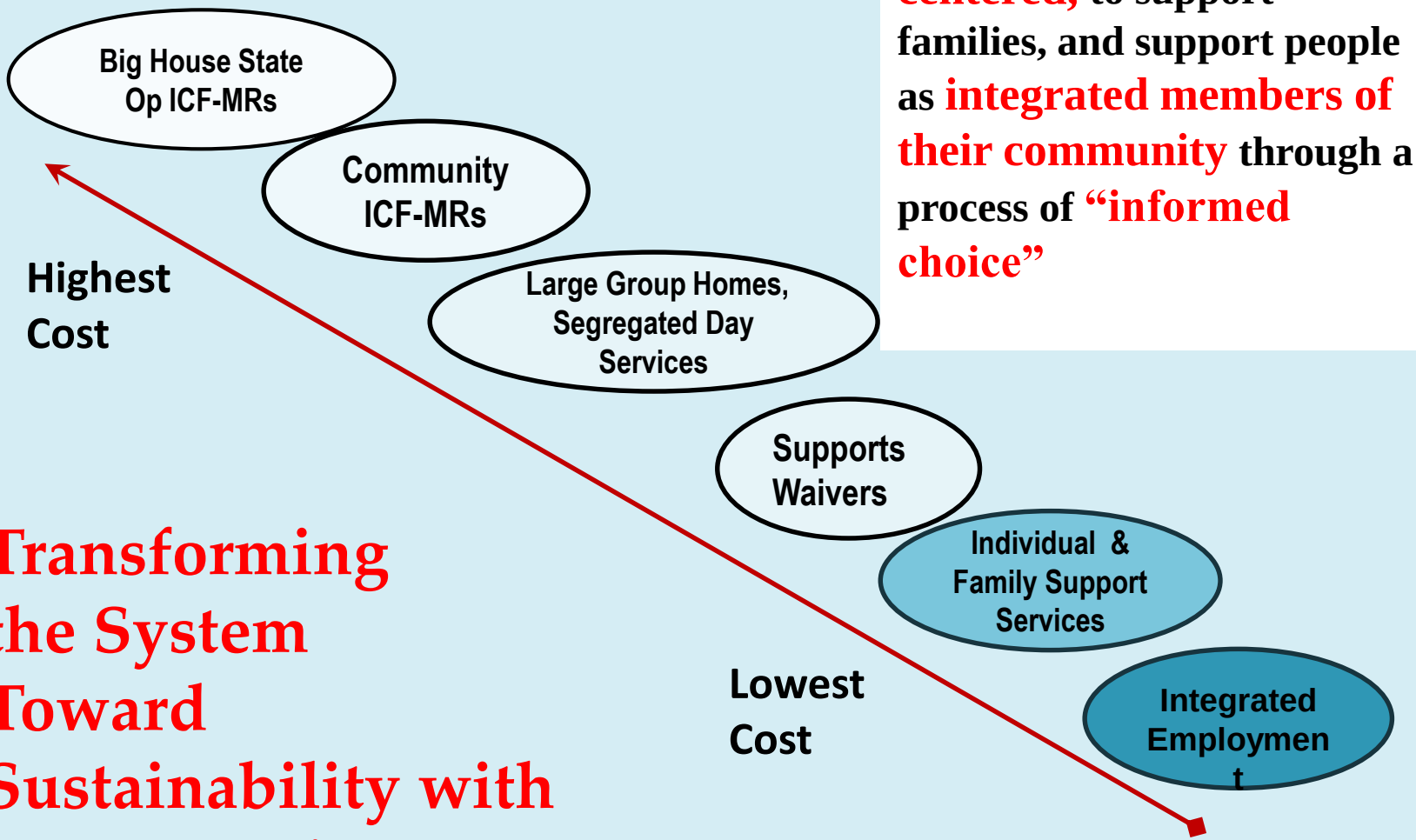
- Separates place from supports
- Presumes that everyone can live in their own "home" with support
- Presumes that everyone can make a valued contribution to community life with support
- Presumes person does not need to be "fixed"
- Built on presumption of "integration"/inclusion
- Community Care of 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)

A Vision that People…..

- Will be healthy, happy and safe
- Will have family and friends in their lives
- Will go to school and be fully involved
- Will work at a good paying job
- Will make decisions about their life – both major and minor
- Will be contributing citizens of their community
- Will have dreams that come true

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"

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

THE ULTIMATE TEST OF POLICY IS YOUR BUDGET

- Many words of law represent hollow promises for individuals with disabilities;
- No incentives or accountability for valued outcomes and results; must develop outcomes and incentives!
- **We need to talk about ROI?**
  - A return on investment to the government and, thus, the tax payer?

Where is the Return on Investment (ROI) for Taxpayers?

- What do we value as outcomes/results?
- What do we owe the taxpayer and society?
- **Are the outcomes and results of our work quantifiable and are they compatible with the valued outcomes of the DD Act, IDEA, WIOA, and the ADA that we espouse?**

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

The Role of Appropriate Data

Every successful enterprise uses outcome data and information to improve results

Adapting to the "New Normal"

- Metrics and measurement; accountability
- All costs must produce clear measurable outcomes; cost effectiveness
- Equity in resource allocation & incentives
- Pockets of excellence must be scalable
- Disparities in outcomes must translate statewide
- Sustainable value that can be quantified
- Transformational policy across state agencies, infrastructure changes and capacity building are essential

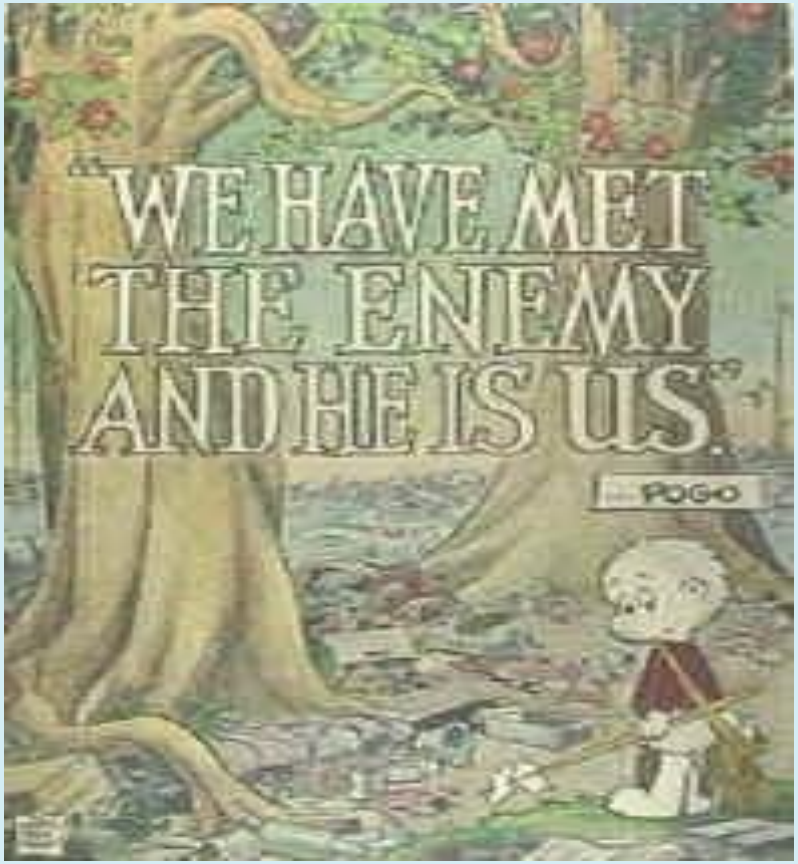
What is Transformation?

- Transformation occurs as a result of a well-orchestrated and well-led change strategy and transition plan.
- The result is an evolution to the desired state in which there is a deep seated adoption of the changes and the associated values, principles, and/or processes.
- Transformation leads to **an internalized change in organizational culture**

Requirements for Data Collection and Performance Measurement

1. Define Goals
2. Define the Metrics to Measure Goals
3. Develop methods to collect/organize data
4. Compare data to goals
5. Assess system strengths/weaknesses
6. Regularly collect, assess and publicly report results
7. Use data to improve performance and outcomes

Formidable Factors Limiting Change



Walt Kelly, Pogo, Earth Day, 1970

- The very practices and systems that need to change are the ones developed, as innovative, by the current generation of leaders.

Change is about people and behavior...

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

Change & Transition

Change

- A shift in the externals of any situation; moving ; restructuring a business;
- Funding changes; setting up a new program
- Is made up of events
- Visible and tangible; technical; structural
- Can happen quickly

- All about the outcomes we are trying to achieve

Transition

- The mental & emotional transformation that people must undergo
- Anxiety; confusion; fear; shock; denial; anger;
- An ongoing process
- A psychological process taking place inside people
- Has its own natural pace like any organic process
- About how we'll get there and how we'll manage things on the way

Resistance to Change

- People are afraid of the unknown; a natural defense mechanism for people who are "losing" something
- Many people think things are fine the way they are; the way I/we've always done it
- Don't understand the need for change.

- Managing the **change process and transition emotions** is critical to the success of a change oriented project.

Possible Reasons for Resistance to Change

- Perceived loss of security
- Money
- Pride or satisfaction
- Friends
- Freedom
- Responsibility
- Authority
- Good working conditions
- Status
- Lack of respect
- Objectionable manner
- Negative attitude
- Personal criticism
- Not having had input
- Bad timing
- Challenge to authority
- Second hand information

Medicaid Employment: Options and Incentives

2015 HCBS Conference
September 3, 2015

Ralph Lollar
Colleen Gauruder
Jeff Clopein
Disabled and Elderly Health Programs Group
Centers for Medicare and Medicaid Services

Serena Lowe
Office of Disability Employment Policy, Department of Labor

Pay for Performance Option

Acceptable:

- Outcome payment for Discovery or SE Assessment Service and Report as a single unit of service which is:
  - Time-limited service
  - Tangible outcome that shows the service was completed (e.g., a report, career plan)
- Payment must be based on the average amount of time it is expected to take to complete the service (based on actual data) and the cost per hour of service determined by the state.

Example: 40 hours of service X $40/hour = $1,600 outcome payment

Pay for Performance Option

Acceptable:

- Outcome payment for Job Development, Placement, Customized Employment Position as a single unit of service
  - Time-limited service
  - Defined outcome that can be identified for payment (e.g. job obtained
- Payment must be based on the average amount of time (based on actual data) it is expected to take to complete the service and the cost per hour of service determined by the state.

Example: 50 hours of service X $40/hour = $2,000 outcome payment

Pay for Performance Option

Acceptable:

- Tiered outcome payments based on level of disability
- Must explain in application the number of tiers and how the state will determine the appropriate tier for each waiver participant
- If state plans to have exception process, this must also be explained
- **If a state doesn't use tiers and instead has one reimbursement rate for everyone, can the state demonstrate that people at all levels of acuity are getting access to the service and using the service to the same degree?**

Pay for Performance Option

Acceptable:

Milestone payments in addition to fee-for-service to reimburse providers when certain employment outcomes are achieved

- Examples:
  - Person secures job that is 20 or more hours per week
  - Person achieves hourly wage that is 20% above state's minimum wage
  - Person retains job for at least 6 months, then one year
- Payment must be based on fair estimate of effort (based on data) a provider must put in to produce these "above average" outcomes.

Pay for Performance Option

Acceptable:

- **Payment per hour worked by the supported employee:**
  - Must be based on average percentage of job coaching time necessary to enable person to retain employment (supported by data at outset and verified at intervals on on-going basis)
  - Can have tiers based on acuity and average percentage can vary based on acuity.
  - **Fading (some decline in percentage) over time must be expected at each acuity tier as the individual develops proficiency at the job.**

Example Model: Job Coaching Percentages for Rate Calculation

SIS Tiers or Similar Acuity Tiers	0-11 Months on Job	12-24 Months on Job	25+ Months on Job
Acuity Tier 1	85%	75%	65%
Acuity Tier 2	65%	55%	45%
Acuity Tier 3	45%	35%	25%
Acuity Tier 4	30%	20%	10%

A world of dignity, opportunity and community for all people

www.c-q-l.org

Personal Outcome Measures® CQL

- Personally defined quality of life outcomes that people want in their lives.
- The set of 21 POMs is a **scientifically valid metric.**

21 Personal Outcome Measures®: Three Factors

My Self: *Who I am as a result of my unique heredity, life experiences and decisions.*

- People are connected to natural support networks
- People have intimate relationships
- People are safe
- People have the best possible health
- People exercise rights
- People are treated fairly
- People are free from abuse and neglect
- People experience continuity and security
- People decide when to share personal information

21 Personal Outcome Measures®: Three Factors

My World: *Where I work, live, socialize, belong or connect.*

- People choose where and with whom they live
- People choose where they work
- People use their environments
- People live in integrated environments
- People interact with other members of the community
- People perform different social roles
- People choose services

21 Personal Outcome Measures®: Three Factors

My Dreams: *How I want my life (self and world) to be.*

- People choose personal goals
- People realize personal goals
- People participate in the life of the community
- People have friends
- People are respected

What really matters?

- No politically correct answers
- Heartfelt answers
- Ask soulful questions
- Treat the information with dignity and respect

SPECIFIC OUTCOMES CORRELATED WITH TOTAL OUTCOMES – PREDICTORS	
HIGHEST	
Exercise Rights	.537
Choose where and with whom they live	.528
Treated fairly	.521
Choose where to work	.507
Interact with other members of the community	.500
Perform different social roles	.487
LOWEST	
Decide when to share personal information	.332
Have the best possible health	.309
Free from abuse and neglect	.287
Experience continuity and security	.276
Are safe	.189

20 Years of Evidence Based Learning from Listening

- Safety, security and health are well supported in organizations.
- Exercising meaningful choice in important life decisions remains a challenge for most people.
- **Community integration and enhanced social roles are least likely to be present in people's lives**

20 Years of Evidence Based Learning and Listening

- Fewer than ½ of the people interviewed were exercising choices in a way that was meaningful to them.
- Participation and interaction in the community were present for about 70%
- 56% reported having friends
- Less than 40% are fully integrated in the community
- 8 out of 10 report being safe and free from abuse and neglect

20 Years of Evidence Based Learning

- 70% experiencing continuity and security
- 70% Best possible health
- **50% report able to exercise their rights**
- 56% Treated fairly
- 70% Accessible environments available to them

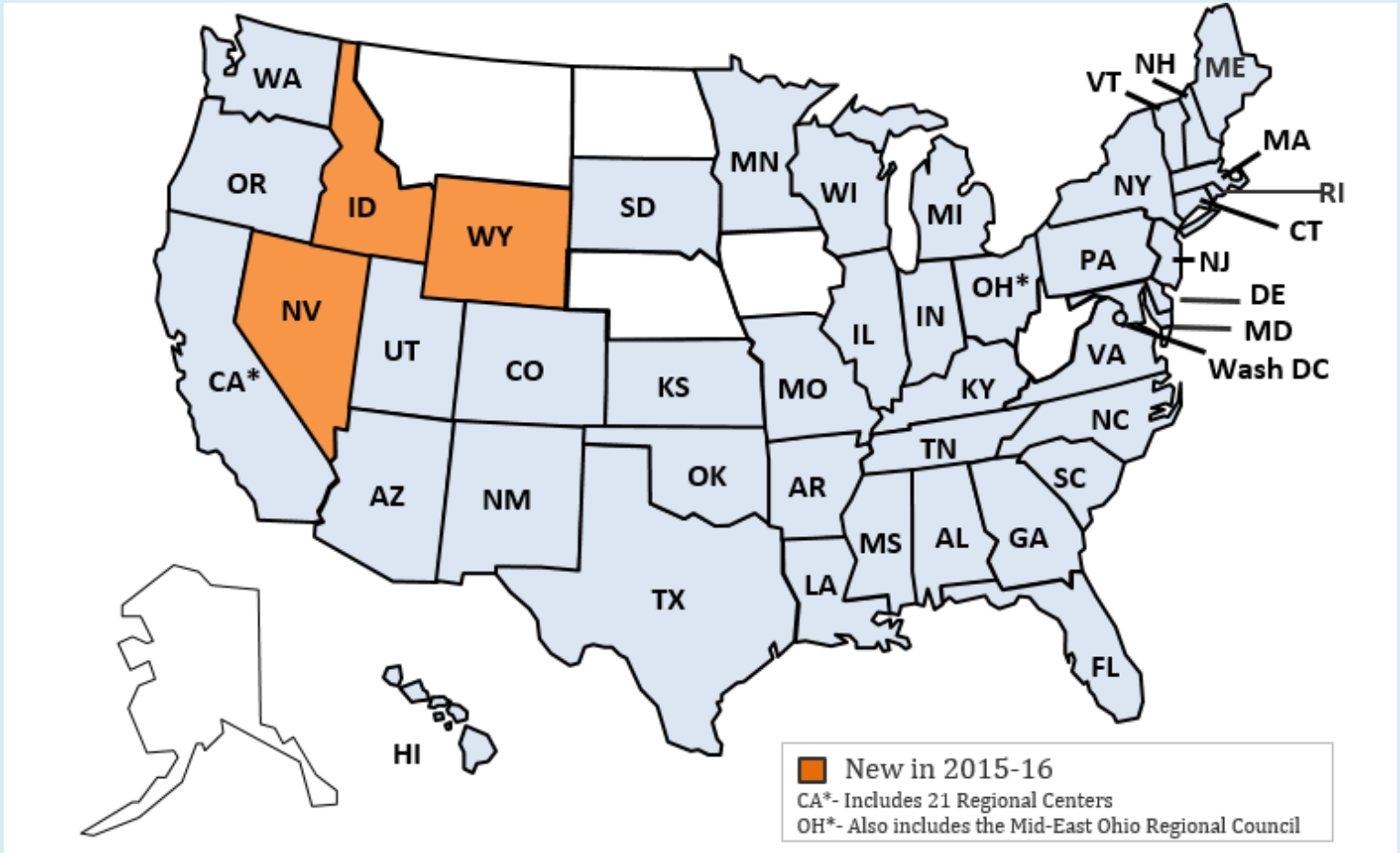
NCI-DD and NCI-AD National Overview

How did NCI Begin?

- NCI began in 1997to measure track state performance in DD systems
- Voluntary effort by public developmental disabilities agencies
- Originally 13 states took part in pilot
  - Currently includes 43 states, Washington D.C., and 22 sub-state entities
- Coordinated by HSRI and NASDDDS

State Participation 2015-16

Includes: 43 states, D.C., 22 sub-state entities



NCI Goals

- Establish a nationally recognized set of performance and outcome indicators for DD service systems
- Develop reliable data collection methods & tools
- Report state comparisons and national benchmarks of system-level performance

What is an “Indicator”?

- Indicators are standard measures used across states to assess the outcomes of services provided to individuals and families. Indicators address key areas of concern including employment, rights, service planning, community inclusion, choice, and health and safety.

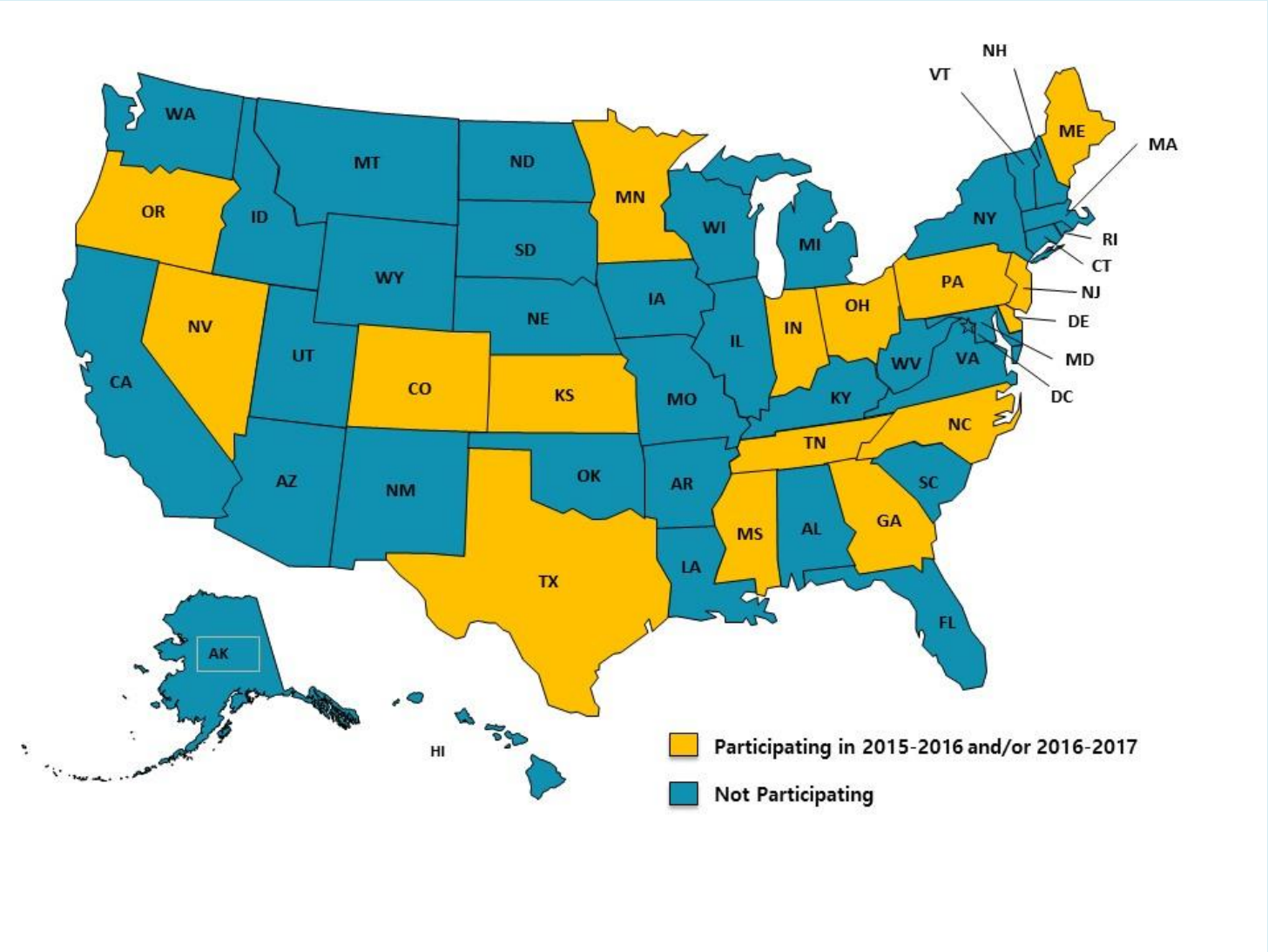
What is NCI-AD

- Collaboration between the National Association of States United for Aging and Disabilities (NASUAD) and Human Services Research Institute (HSRI)
- Focused on older adults and people with physical disabilities being served by state LTSS systems
- Face-to-face survey

NCI-AD Development

- Began in 2013 and took over a year and a half
- Included:
  - Steering committee feedback
  - Expert panel feedback
  - Stakeholder feedback
  - Focus groups with LTSS consumers
  - Large-scale pilot in three states: GA, MN, OH
    - Total of 1600 interviews completed
  - Small-scale pilot in GA

NCI-AD State Participation 2015-2017



NCI-AD Purpose

- Gather feedback directly from service recipients
- Assesses quality of life, service satisfaction, and outcomes of service recipients
- Supports state Aging, Disability, and Medicaid Agencies interested in measuring the performance of their state LTSS systems
- Assists states to improve the quality of services and supports provided to individuals

Consumer Outcomes Measures

Consumer Outcomes:

- Community Participation
- Choice and Decision-making
- Relationships
- Satisfaction
- Service and Care Coordination
- Access
- Self-Direction of Care
- Work/Employment
- Rights and Respect
- Health Care
- Medications
- Safety and Wellness
- Everyday Living and Affordability
- Planning for the Future
- Control

HOW STATES USE NCI DATA

How Data are Used

General Uses

- Setting Priorities
- Quality Councils
- Stakeholder Engagement
- Monitoring People Exiting Institutions

Targeted Outcomes

- Choice
- Health
- Relationships
- Employment
- Medication

Medication

- Statute, policies and procedures in many states affirm that people receiving services cannot be chemically restrained, or prescribed medication that has an impact on behavior, without first conducting an evaluation to determine if there are medical causes for the behavior.
- Some states require functional assessments and positive behavior supports be implemented prior to use of medication.
- Human Rights Councils review restrictive practices and rights violations, including under what circumstance people can be prescribed multiple psychotropic medications.
- Annual service planning allows for review of all treatment regimens and efficacy, and the opportunity to discuss what is least restrictive and most helpful to the person.

Georgia
Community Transition and Medication

- Recognized that medication use was on the rise on a statewide level
  - Reviewed past results and found they tended to be above the national average for people prescribed medications
- Tracked medication use among individuals leaving institutions
- Findings:
  - Overall people who recently moved from institutions were more likely to take medications
  - Among those who recently moved:
    - Males more likely than females to be prescribed medications
    - Those in group homes and host homes versus other setting had higher rates of meds
    - African Americans medicated at higher rates than Whites
    - People with mild to moderate ID compared to profound prescribed medication at higher rates

Georgia
Community Transition

- Next Steps
  - Further Research
  - Increase Human Rights Councils
    - Establish Medication Utilization Board
    - Required pharmacy review for individuals on two or more psychotropic medications
  - Analysis of current transitioning process

Relationships and Employment

- People with friends are more likely to:
  - Have higher rate of satisfaction
  - Tend to be more autonomous
  - Participate in community events
  - Be employed
- People who are employed see many of the same outcomes

Arizona Relationships

- In 2008 set a goal to decrease the percentage of individuals reporting to be lonely, increase support to be engaged with friends, and increase participation in sports and exercise
  - Increased communication and information about activities in the community
  - Worked to increase integrated activities supported by state and advocacy groups
  - Encourage participation in Special

Arizona
Employment

In 2012-13 launched campaign to increase employment

- Employed Employment First messaging
  - Published employment-related articles
  - Updated training for service coordinators
  - Conducted disability training sessions
  - Incentivized employment through providers
- Targeted youth transitioning from high school

Arizona Communication

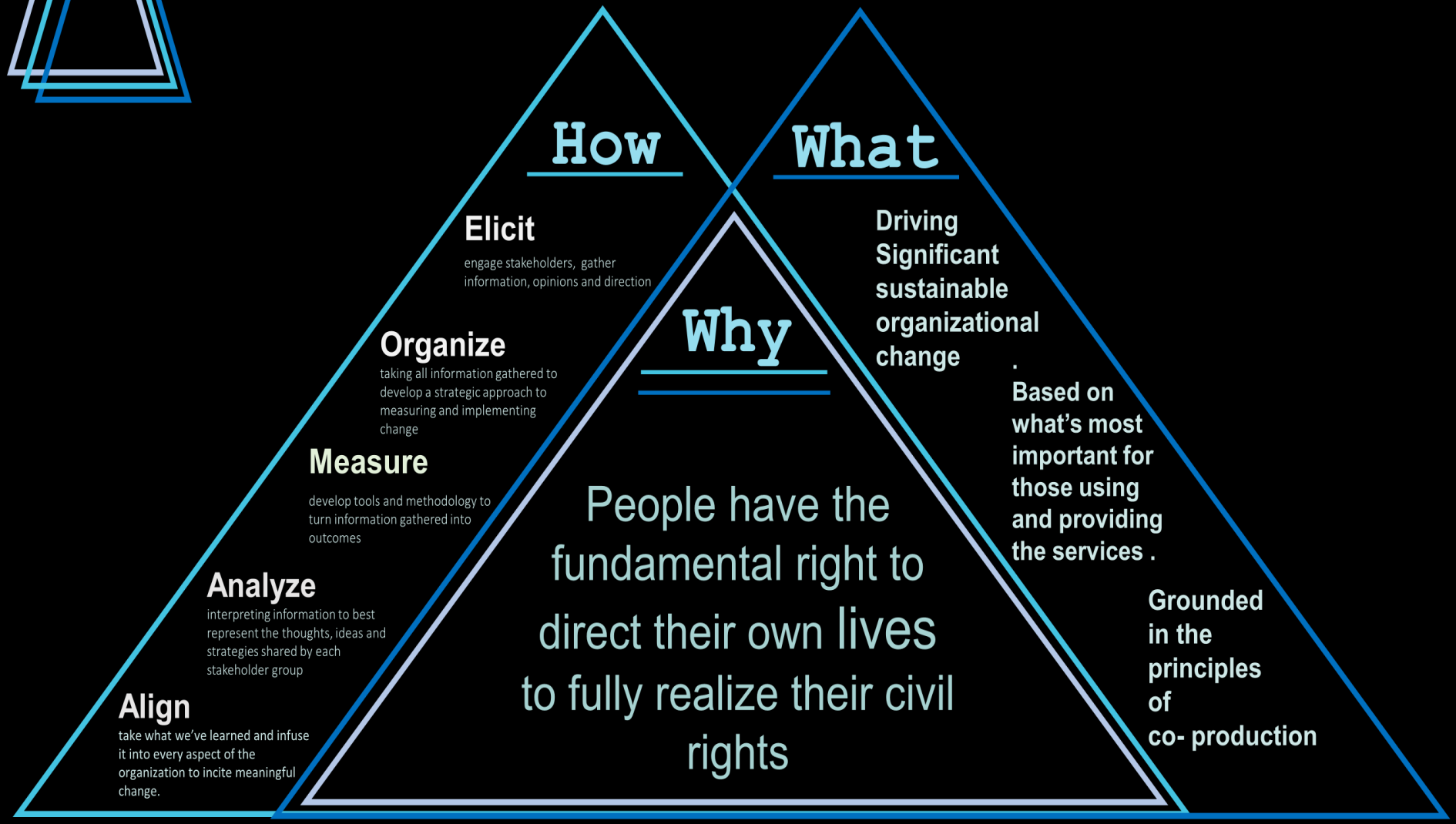
- In both years Arizona had additional goals to increase information to individuals and families
  - 2008 set a goal to increase knowledge of money spent by the state for the individual and family
  - 2013 attempted to increase awareness of activities and programs available to individuals and families
- Similar work done by a number of other states, includes:

California
Self-Advocate Involvement

- Convene a stake-holder group made-up of self-advocates
- Meet bi-annually to:
  - Review data
  - Discuss important issues
  - Make suggestions for the larger state-wide stakeholder group
- Work with NCI data to make improvements in their community
- Has led to creating the User-friendly Report and How to Use Data Guide

Integrated Quality Management Approach

Incite and Ignite Change



Human Services
Research Institute

Bottom Line –
The Train has left the Station……

“Integrated Settings" are inevitable

- We see what is on the horizon and recognize that major reform is underway in the nation
- It is on a very fast track that may be slowed down
- Self advocate and family education must begin and continue
- Provider education, training capacity building, outcome measures and collaboration are essential to thrive……

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

Stakeholder Engagement And Collaboration

"Coming together is a beginning, staying together is progress, and working together is success."

Henry Ford

“Equal Justice Under the Law”

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