

The Impact of Changing Legislation & Court Decisions on Supports for Individuals with Disabilities

AJFCA Webinar

Task Force on Jewish

Residential Alternatives for

Adults with Disabilities

December 16, 2015

Allan I. Bergman



2015: Happy Anniversary

- **25th** **ADA**
- 40th IDEA (Least Restrictive Environment- LRE)
- 45th DD Act
- 50th Medicare and Medicaid
- 80th Social Security

The tough question is:
What has been achieved???

ADA Findings, 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 resulting from dependency and nonproductivity.**"

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 all 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 daytime activities 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.

DOJ Actions on Living Arrangements:

- Virginia
- North Carolina
- Georgia
- Ohio

Why is "Inclusion" an Important Issue for Jewish agencies?

- Spiritual and religious context:
 1. B'tzelem Elohim
 2. Tzedek/kindness, but not Tzedakah/charity or pity or.....
 3. Derech eretz kudmah l'Torah; being a mensch comes even before the Torah
 4. The roles of Moses and Aaron
 5. Parsha Nitzavim; everyone was present at Sinai making the covenant with God; no exclusions

Mishna Sanhedrin 4:5

“A human being mints many coins from the same mold, but the Holy One, Blessed be God, strikes us all from the mold of the first human and each one of us is unique. Therefore, every single person is obligated to say, ‘The world *was created* for my sake.’”

The Meaning of Inclusion

- “Al tifrosh min hatzibur Do not separate yourself from the community”; Hillel, Pirkei Avot 2:5
- **Physical Inclusion**: Access and presence; often seen as the meaning of the Americans with Disabilities Act (ADA)
- **Social Inclusion**: Welcoming, belonging, valued and **being a part of** rather than **apart from and segregated or excluded.**

DISABILITY CONSTRUCT IN 4 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.

Rehab Act, IDEA, DD Act, Tech 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



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**

**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

WHO'S NOT?

LARGEST CENSUS, 2011

1 Texas	4,331
2 New Jersey	2,649
3 Illinois	2,034
4 California	1,774
5 North Carolina	1,572
7 Mississippi	1,333
6 New York	1,313
8 Ohio	1,228
9 Pennsylvania	1,174
10 Virginia	1,105

Private ICF/DD Numbers: Smallest, 2013

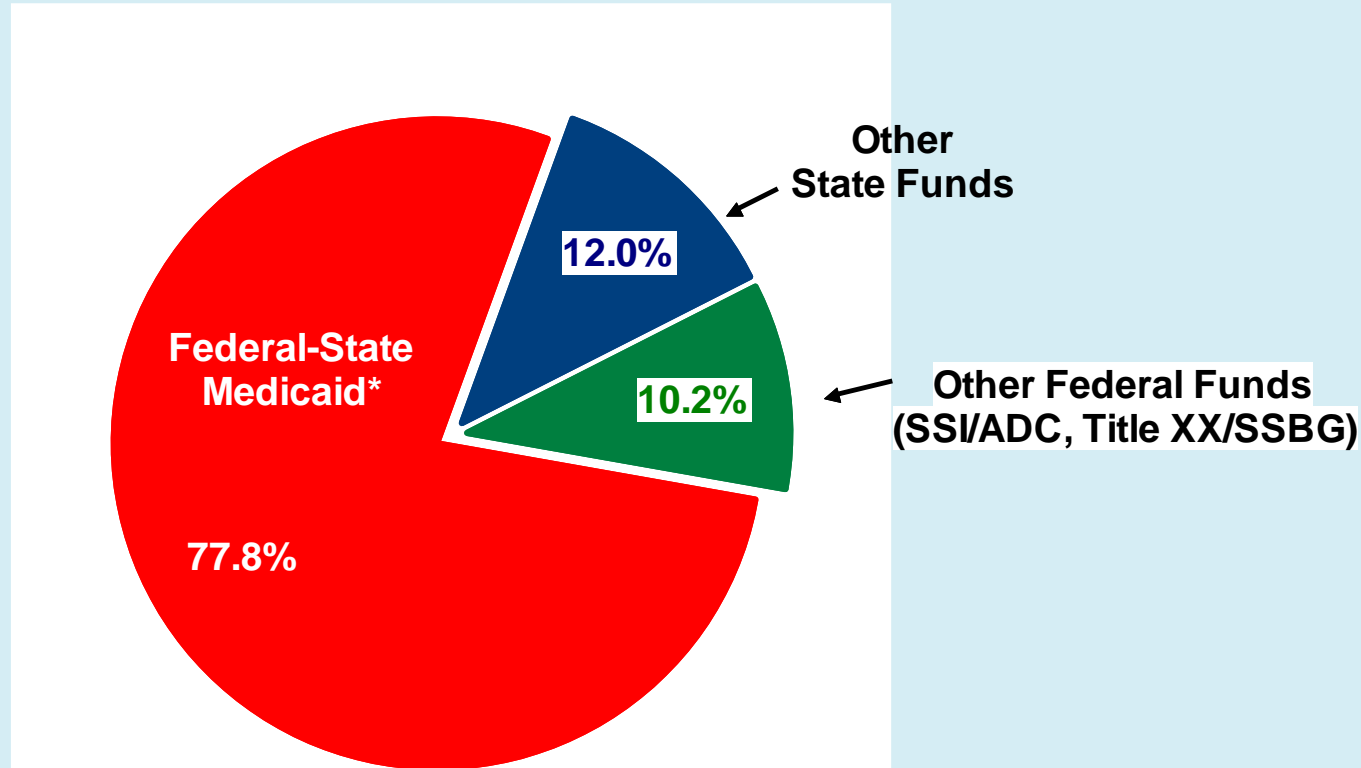
■ <u>MD</u> , MASS, <u>MI</u> , <u>MT</u> ,		■ <u>NV</u> .	54
<u>OR</u> , S.C., <u>WY</u>	0	■ <u>DE</u> .	66
■ <u>VT</u> .	6	■ <u>HI</u> .	87
■ <u>R.I.</u>	18	■ MO.	92
■ <u>CO</u> .	20	■ GA.	108
■ <u>N.H.</u>	25	■ KS.	154
■ <u>AL</u> .	35	■ KY.	154
■ <u>AZ</u>	39	■ <u>ME</u> .	170
■ N.J.	44	Red = no state institutions	
■ <u>S.D.</u>	44		

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

MEDICAID WAS 78% OF TOTAL I/DD SPENDING IN 2013

--66% OF MEDICAID WAS HCBS WAIVER SPENDING



Total I/DD Spending: \$61.65 Billion

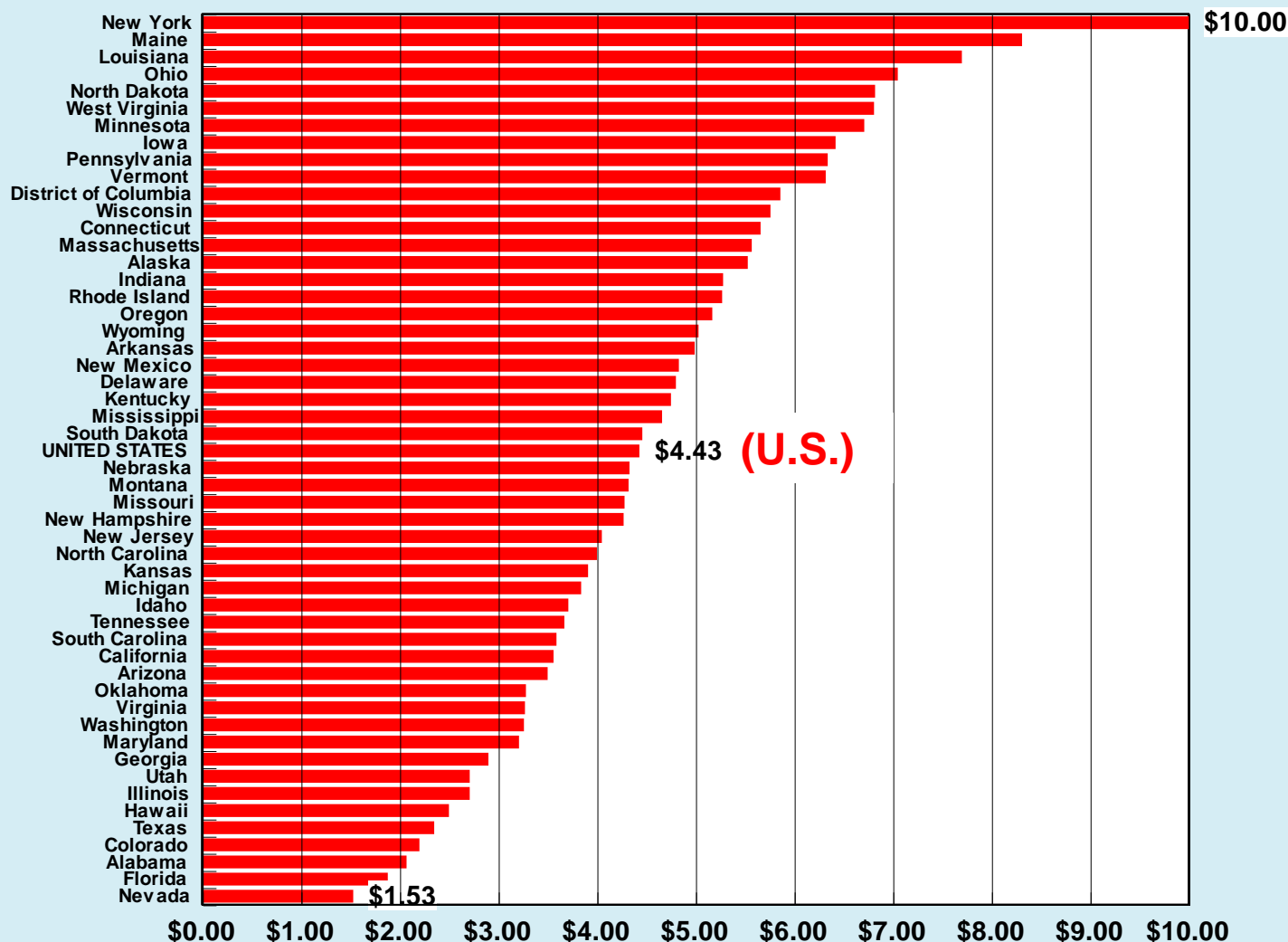
*Total federal-state Medicaid: \$48.0 billion
a) HCBS Waiver (66%);
b) Public & Private ICFs/ID (27%); and
c) Related Medicaid (7%)

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...**

TOTAL I/DD SERVICES FISCAL EFFORT: 2013*



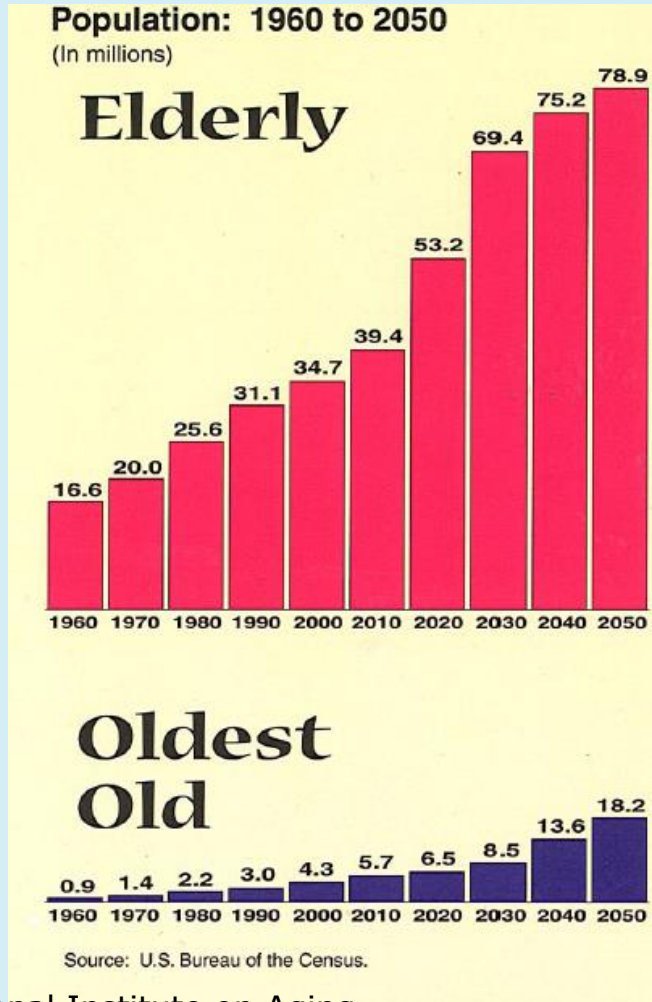
* Dollars per \$1,000 of Statewide Aggregate Personal Income

Source: Bureau of Economic Analysis (2014)

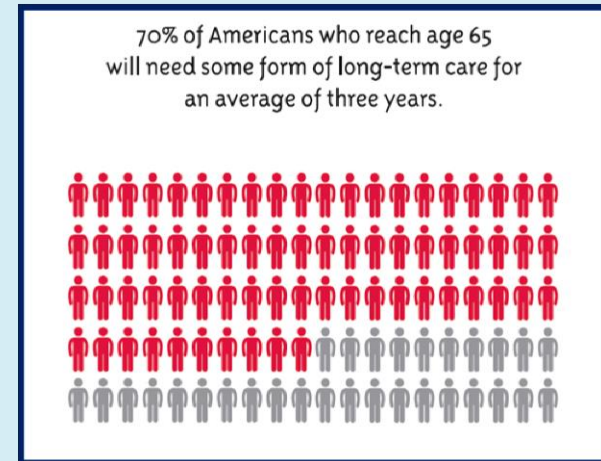
Demographic Climate Change



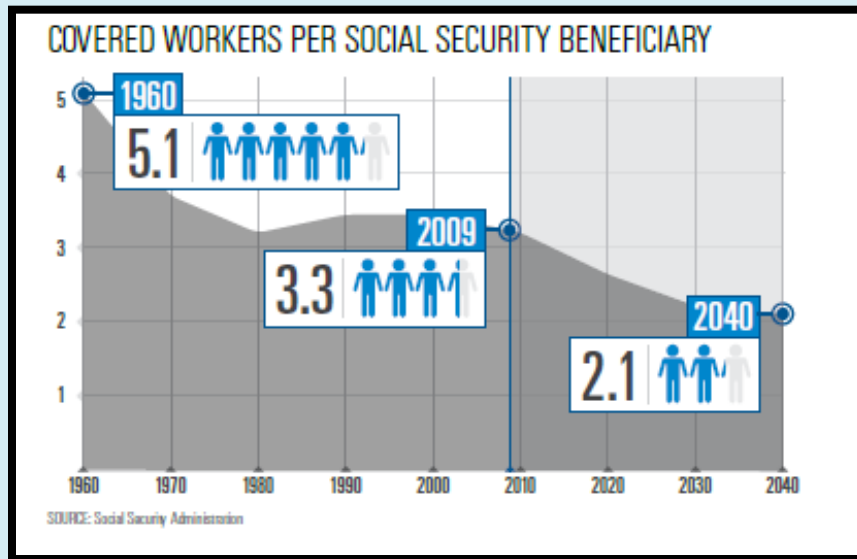
Baby-Boom Generation



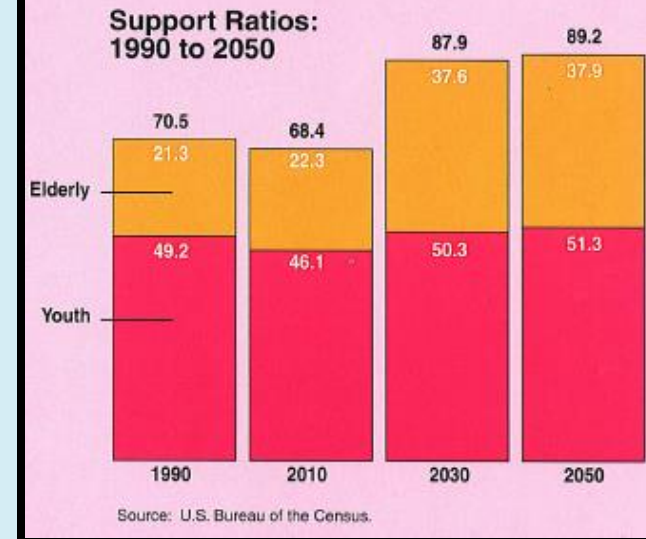
National Institute on Aging



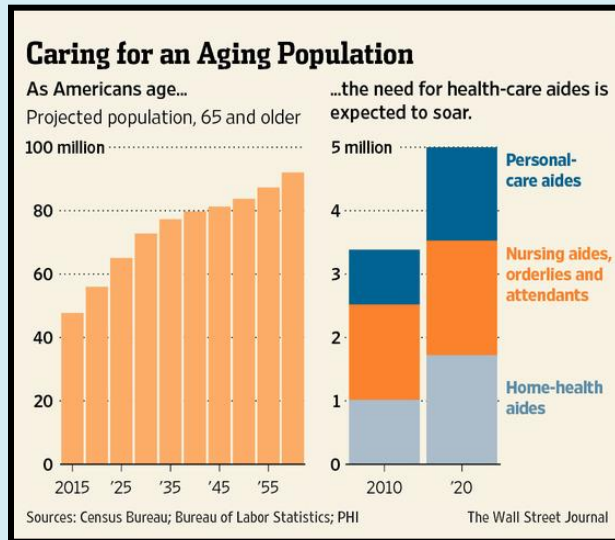
Workers per Social Security Beneficiary



Ratio of Elderly to Working-Age Population to Nearly Double From 1990 to 2050

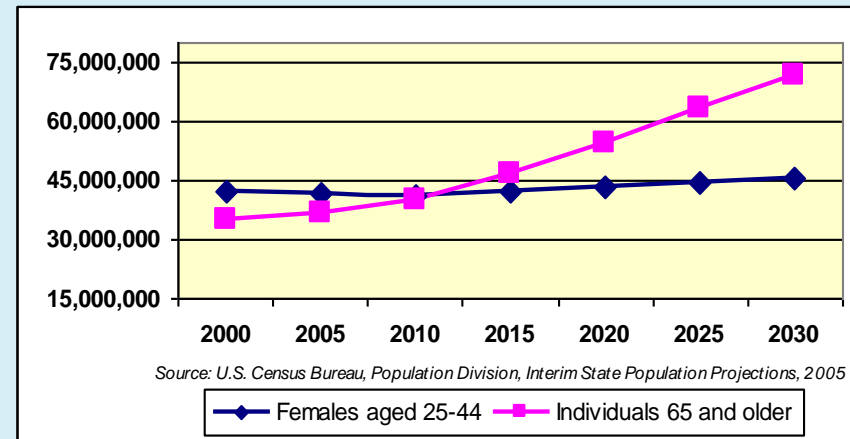


Shortages of Care Givers as America Ages



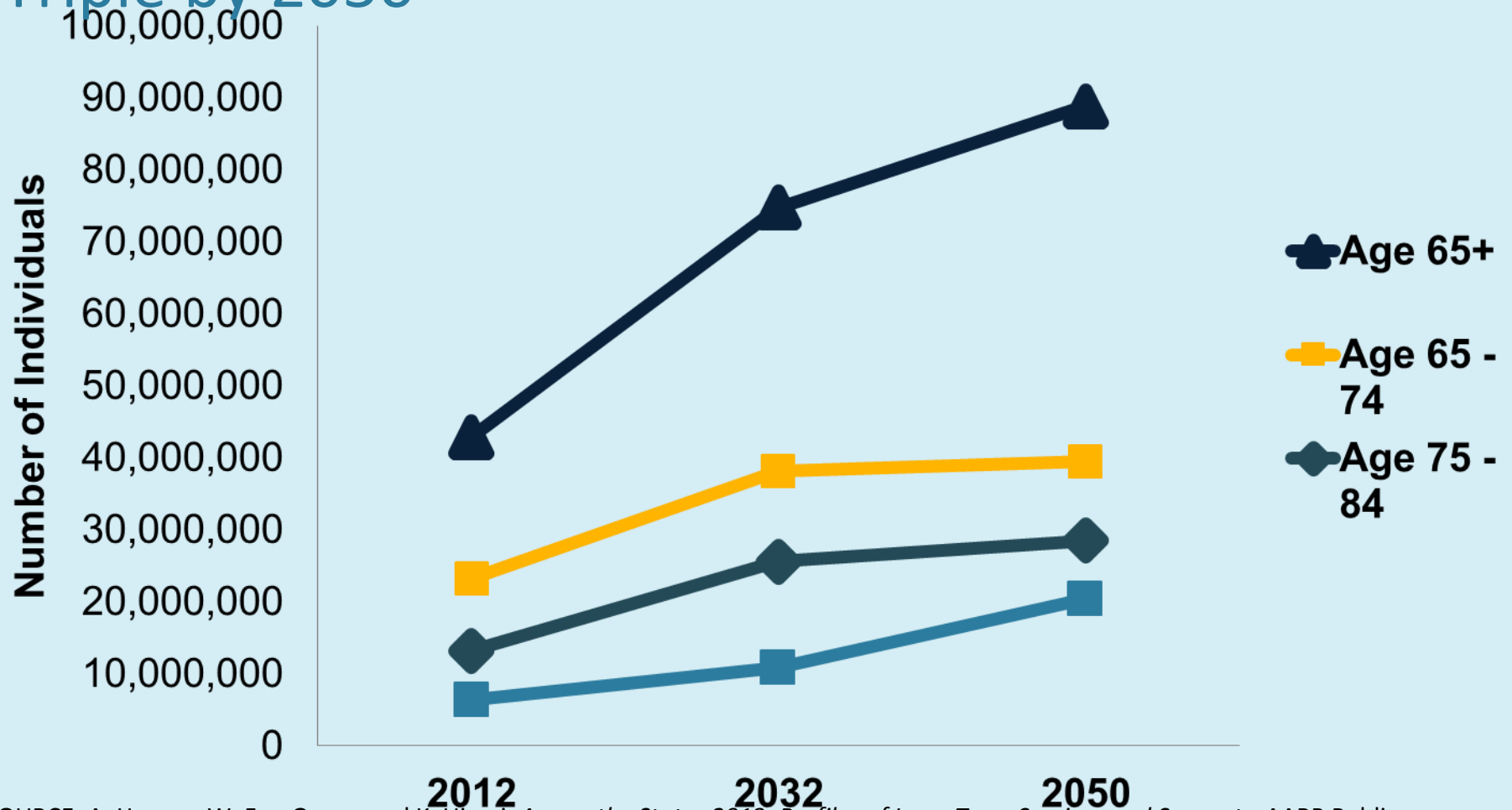
A labor shortage is worsening in one of the nation's fastest-growing occupations—taking care of the elderly and disabled—just as baby boomers head into old age.

Wall Street Journal
April 15, 2013



Larson, Edelstein, 2006

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/lrc/2012/across-the-states-2012-full-report-AARP-ppi-lrc.pdf.

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 your state ???**

Heading for a crash!

Weighty Legacy
Services & Structures



Rising Unmet
Demand



Workforce
Shortages



Fragmentation



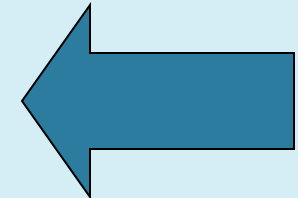
Quality
Problems



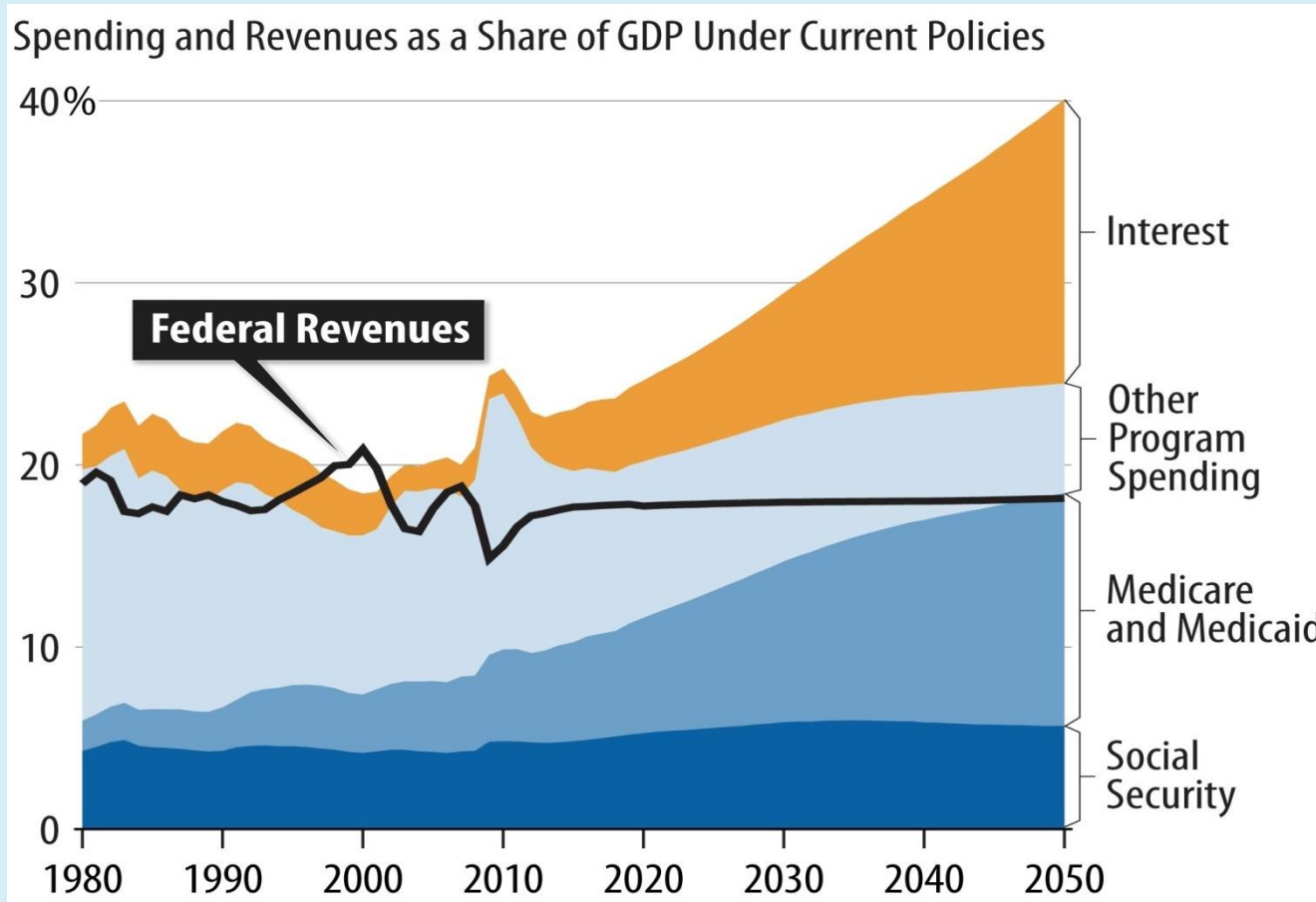
Antiquated
Technologies



**Budget
Shortfalls**

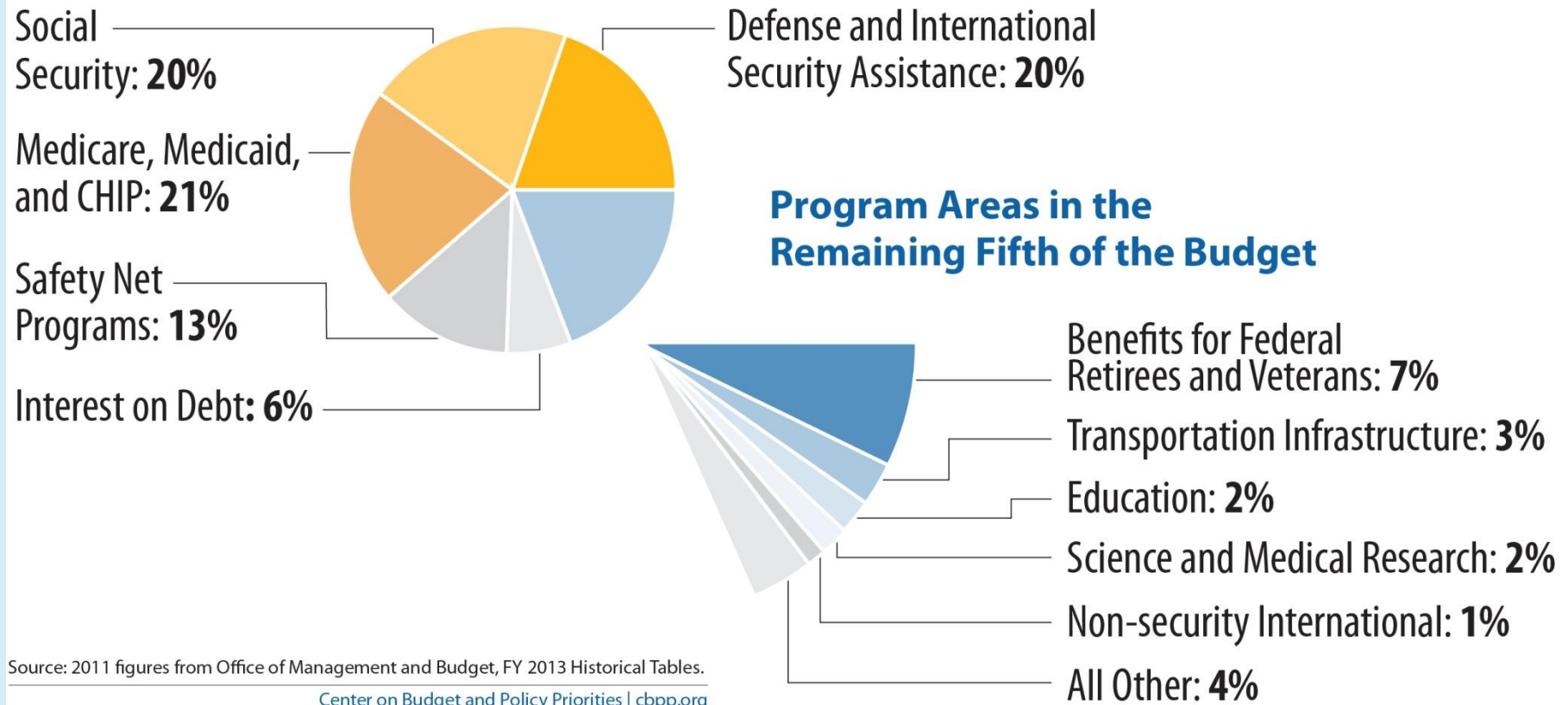


Current Policies Are Not Fiscally Sustainable



Source: CBPP projections based on CBO data.

Most of Budget Goes Toward Defense, Social Security, and Major Health Programs

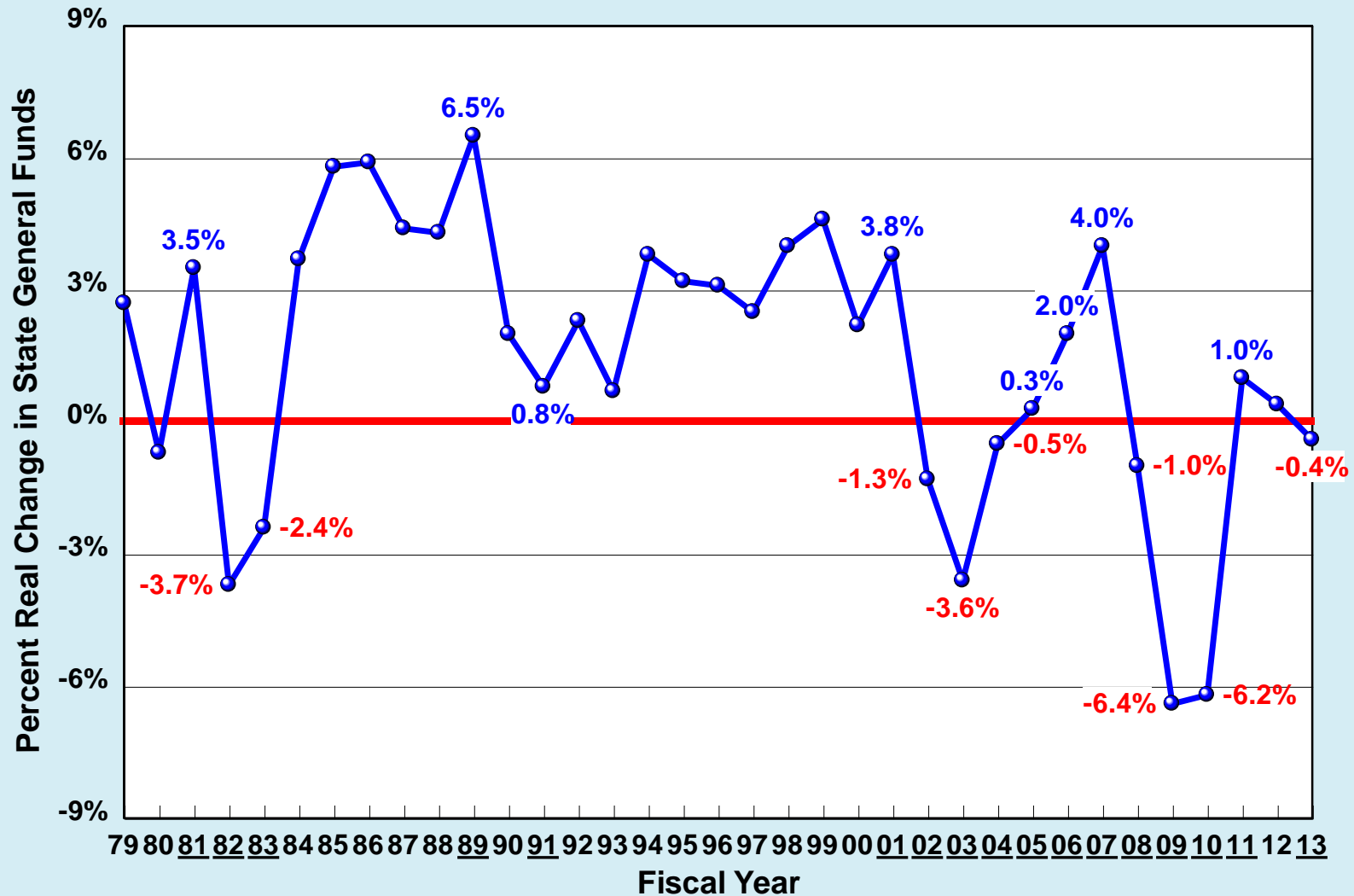


2008 Government Expenditures for Working-Age Adults with Disabilities

What's wrong with this picture???

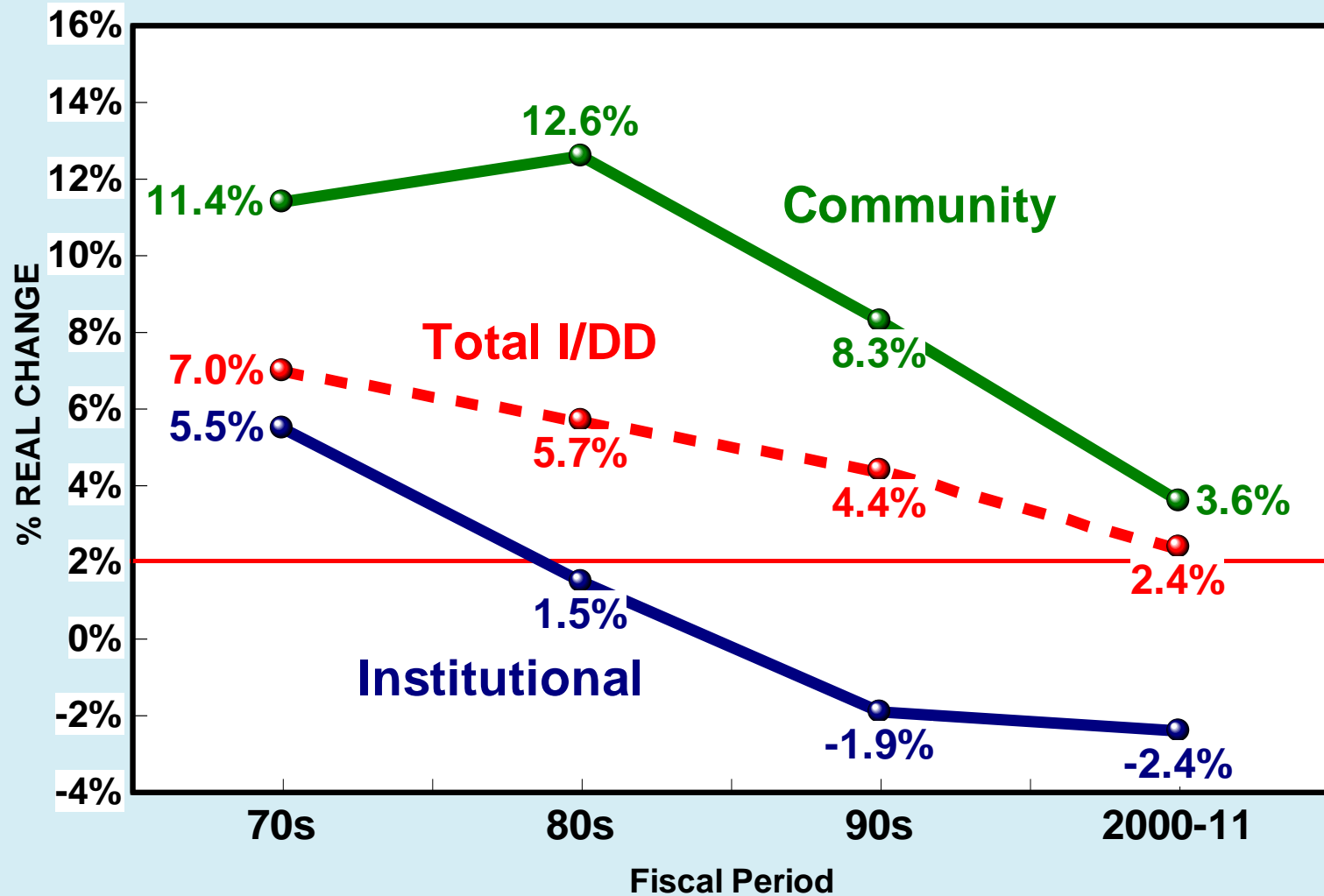
- \$357 Billion, Federal (12% of federal spending)
 - \$ 71 Billion, State spending
 - Healthcare; 55%
 - Income Maintenance; 41%
 - Housing & Food Assistance; 3%
 - Education, Employment & Training; 1%
- Livermore, Stapleton and O'Toole, 2011

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."

AVERAGE ANNUAL % CHANGE IN INFLATION-ADJUSTED I/DD SPENDING BY DECADE, 77-11

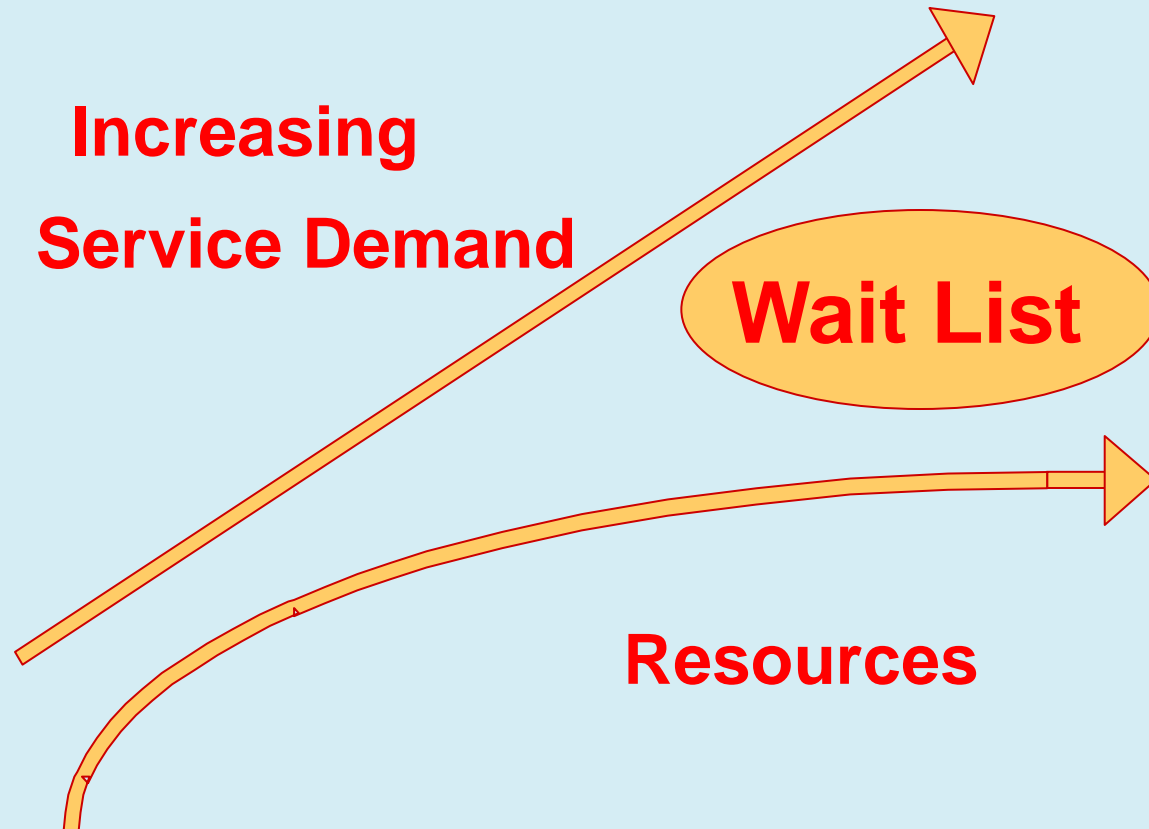


Source: Braddock, D., Coleman Institute and Department of Psychiatry, University of Colorado, 2013.

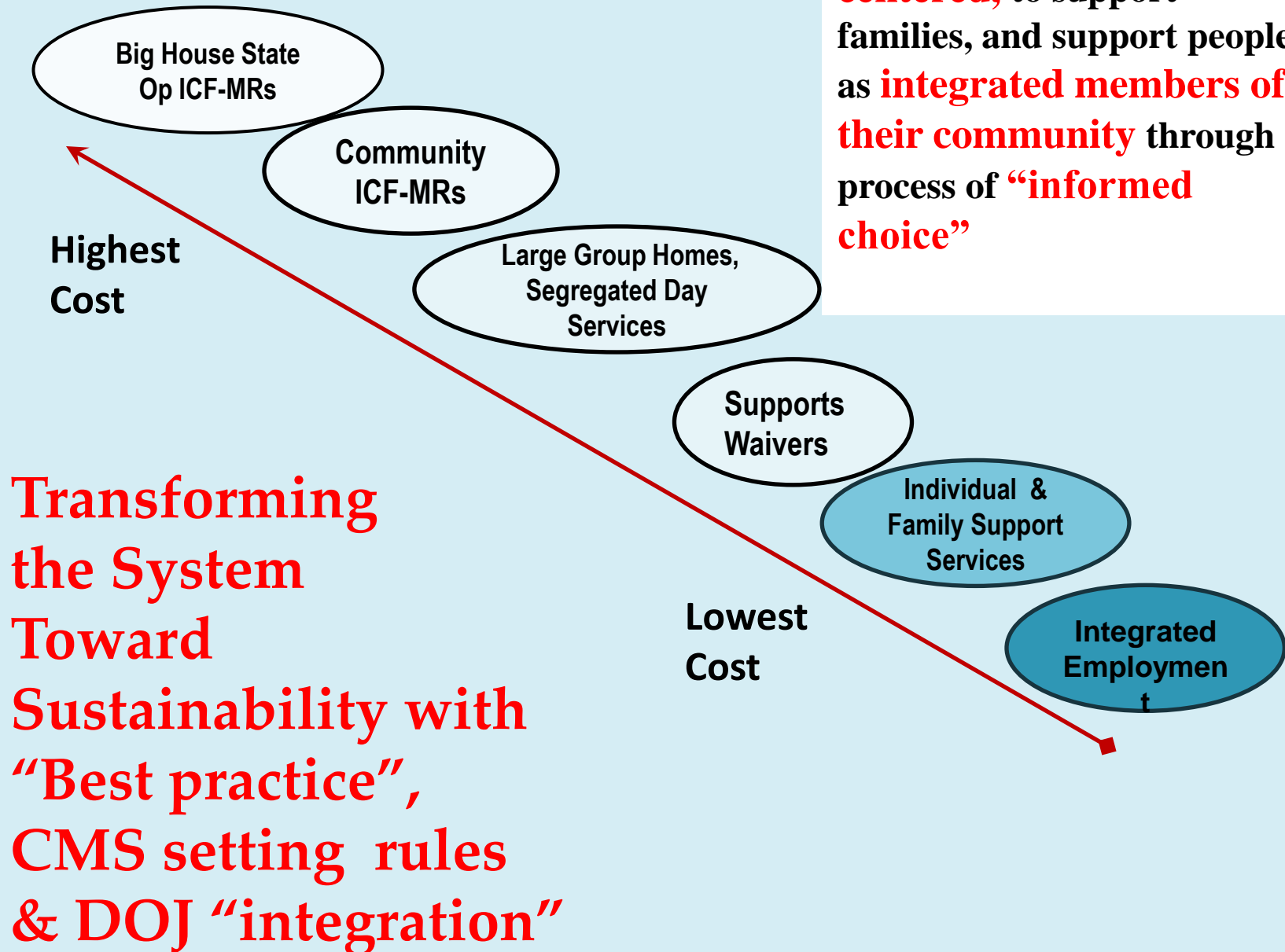
New York OPWDD Age Distribution of Individuals Getting Medicaid Services, 09-10

■ 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

We Face a Big Problem...



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**”



Poverty *By The Numbers*

SUBPOPULATION	2009 Poverty Rate	2011 Poverty Rate
Children	20.7%	22.0%
African-American	25.8%	27.4%
Hispanic	25.3%	26.6%
Disability	25.0%	27.9%
Total U.S. Population	14.3%	15.1%

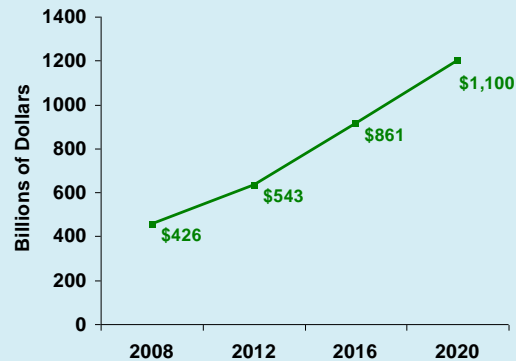
U.S. Census Bureau (13 September 2012)

46.2 million Americans were living in poverty in 2011.

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

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

Annual Expenditures for Federal Cash and Health Benefits for Persons With Severe Disabilities FY 2008 – FY 2020

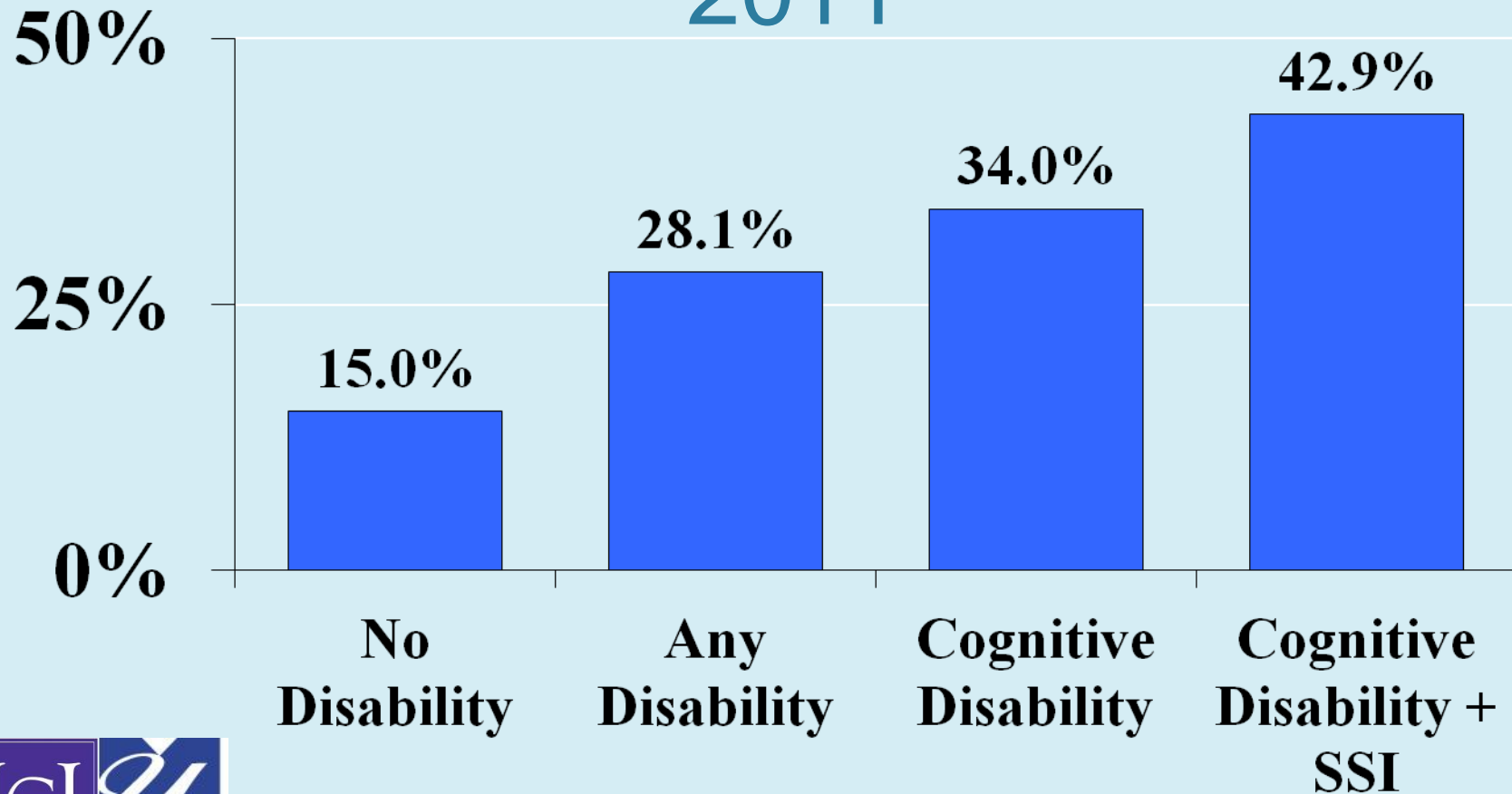


\$1 Trillion

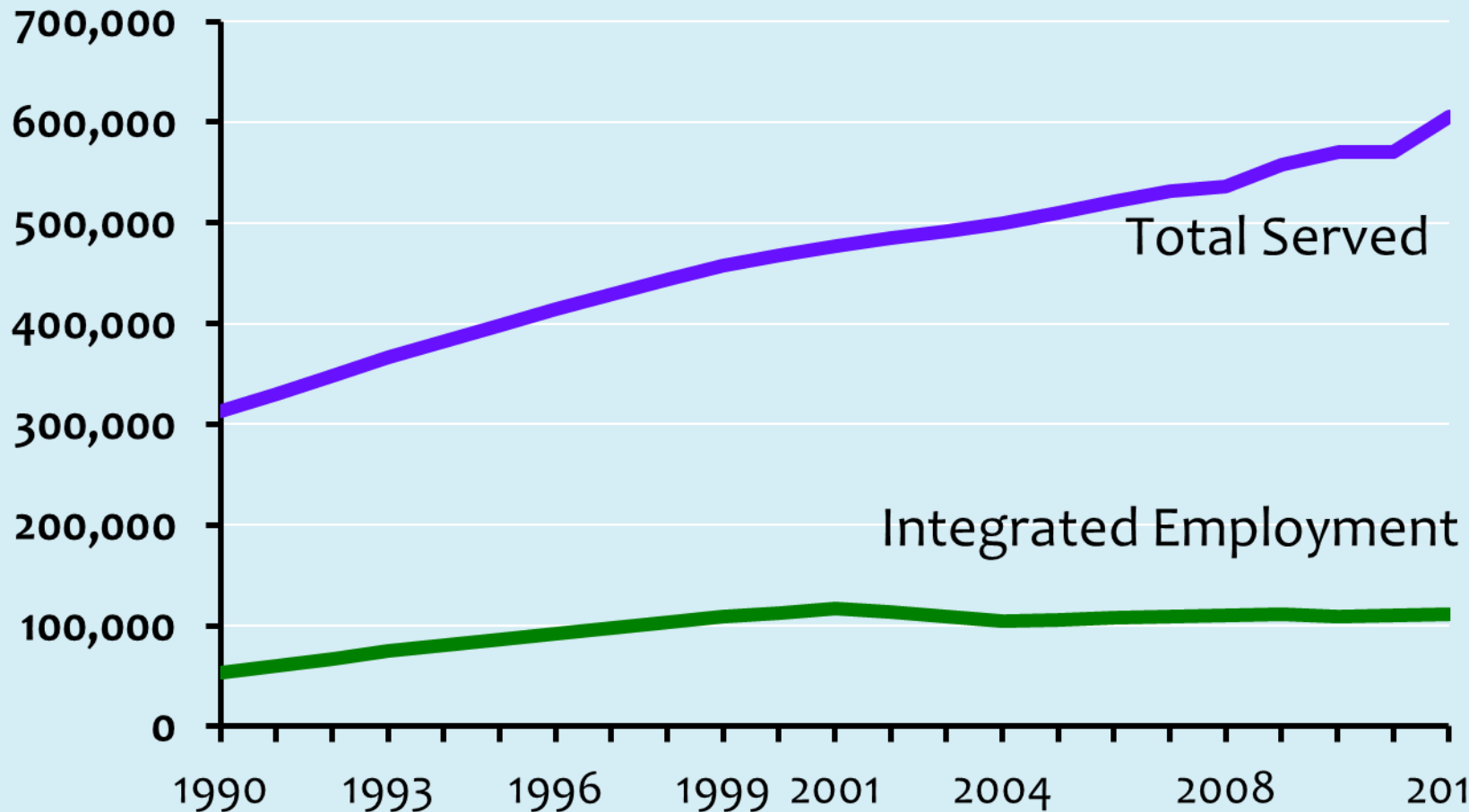


©2008. Institute for Economic Empowerment

American Community Survey Lives Below Poverty Threshold 2011



Employment and Day Supports IDD Agencies: Nation



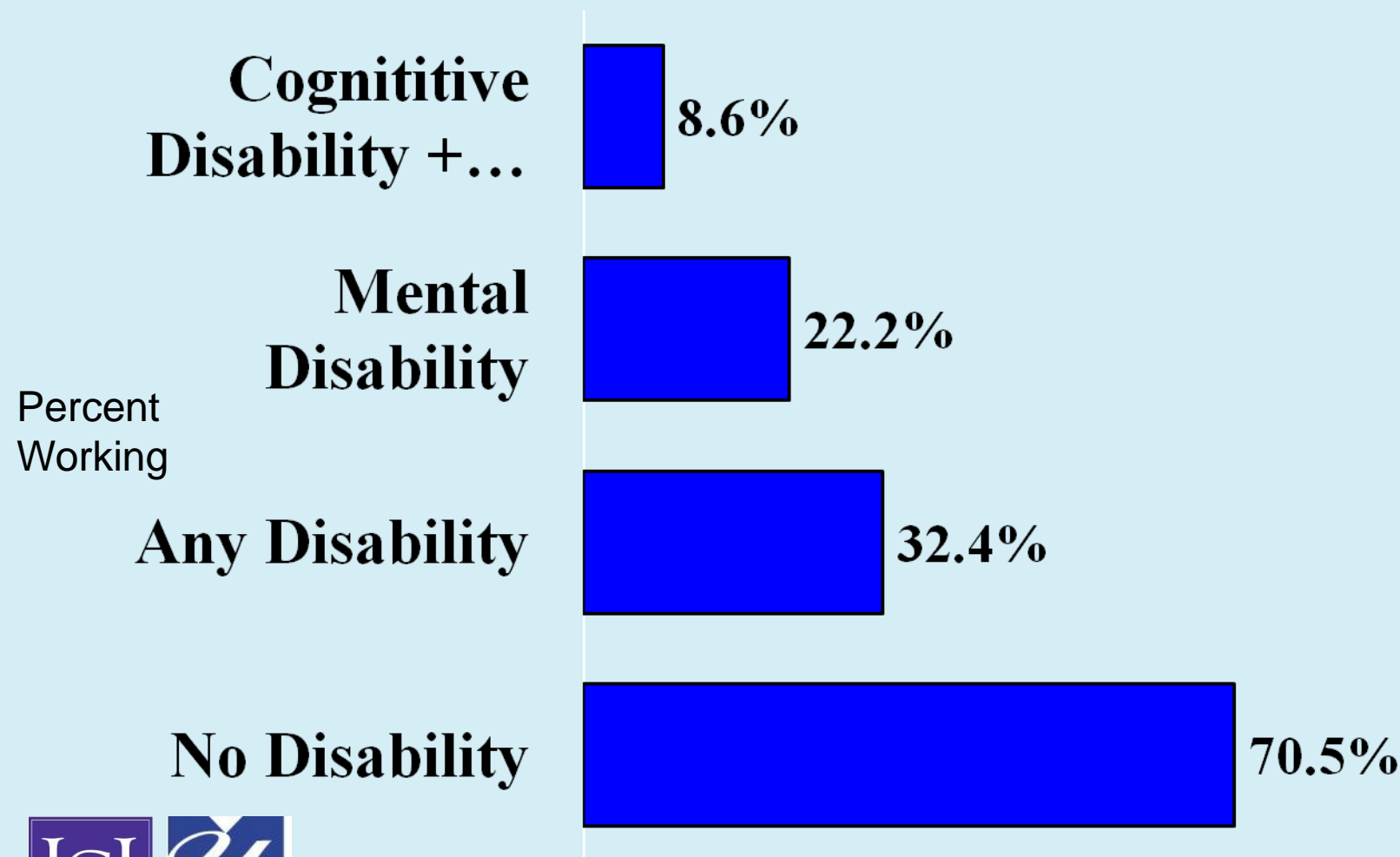
ICI National Survey of State IDD Agencies



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 economic productivity
- Supported Employment; Bellamy/Mank
- Refined by Callahan to Customized Employment; Self Employment by Hammis and Griffin

Employment participation 2011



American Community Survey



**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 Complaint, cont.

- “2. A sheltered workshop is a segregated facility that exclusively or primarily employs persons with I/DD. Sheltered workshops are usually, large, institutional facilities in which persons with I/DD have little to no contact with non-disabled persons besides paid staff. Persons with I/DD typically earn wages that are well below minimum wage.”

DOJ-OREGON Complaint, cont.

- “...Oregon’s system has so ingrained the expectation that all individuals with I/DD will work in such sheltered workshops, that students from local high schools receive scholarships/stipends to participate in the workshop provider’s programs while still in school. Some other high schools “life skills” programs operate sheltered workshops in school or have students with I/DD perform workshop tasks.”

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 choice 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**

Key Provisions: DOJ-Oregon, cont.

- Establishes a defense if Oregon cannot meet a job metric as a result of a factor outside of its control;
- Appoints **an Independent Reviewer** who is responsible for determining progress and compliance in implementing the Agreement, including coordinating meetings with the parties and communicating with the Court; and,
- Establishes a dispute resolution and judicial enforcement procedures in the event of an allegation of noncompliance.

Employment First is the Imperative

- **General theme:**

Employment in the community is the first/primary service option for individuals with disabilities

APSE Statement on Employment First

Employment in the general workforce is the **first and preferred outcome** in the provision of **publicly funded services** for **all** working age citizens with disabilities, **regardless** of level of disability.



Employment First is
not just about
“best practice”.

It is about
clear public policies
that employment is
the priority

**A critical focus of
Employment
First must be on
shifting public
resources to be
in alignment
with our values...**

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.**

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.
- Section 511 proposed rules require an annual review of everyone earning sub-minimum wage.
- Sen. Tom Harkin & Rep. Pete Sessions

++

Senator Tom Harkin on WIOA

- “It will help prepare a new generation of young people with disabilities to prepare for, **to obtain and succeed in competitive, integrated employment, not substandard, subminimum wage, dead-end jobs**, but jobs in which people with disabilities can learn and grow to their maximum potential. Basically, we’re going to give persons with disabilities the same supports and experiences that everyone else expects and receives which they haven’t had in the past.”

Thinking for the Long Term: "ROI"

Type of Service	1 yr. Cost	3 yrs. Cost	10 yrs. Cost	Experience
Sheltered Work /Day Habilitation	\$15,000	\$45,000	\$150,000	No money Segregation Dependence
Employment Services	\$20,000	\$50,000 (\$20,000 yr. 1 \$20,000 yr. 2 \$10,000 yr. 3)	\$75,000 (\$50,000 1-3 yrs. \$25,000 3-10 yrs.)	Makes money Pays Taxes Meets People Sense of Independence and Accomplishment

Estimated figures – use your own figures and do the math; ICI, Boston

Social Security's Mixed Message to People with Disabilities



Yes you can go to work:
Work Incentives,
Ticket to Work,
Medicaid Buy-In

Entitled to benefits due to disability and inability to obtain gainful employment

Data on SSI Beneficiaries, 2010

- 4.6 million between ages 18 and 64 years (25% of these beneficiaries also received some type of Social Security payment)
- Only 5% of the SSI beneficiaries of working age reported earned income
- The average earned income is \$286/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

Impact of Work on SSI

If you get a job making **\$8.25** per hour and you work **30** hours per week, earnings are **\$1,072** per month

Monthly Earned Income would be	\$1,072.00
Subtract two exclusions totaling	\$ 85.00
(General disregard \$20, Earned Income Disregard \$65)	
	<hr/>
	\$ 987.00

Disregard another 50% of earned income	x 50%
	<hr/>
Countable wages are:	\$ 493.50

●

If your SSI amount is:	\$ 733.00
You subtract your countable wages from that amount:	- 493.50
	<hr/>

Your SSI check would then be:	\$ 239.50
Plus....income from job:	\$1,072.00
	<hr/>

Your total monthly income is now:	\$1,311.50
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That is \$578.50 more per month; \$6,942.00 per year!

Why is Employment Becoming Part of Medicaid's Focus?

CMS's commitment to the importance of work for Medicaid LTSS participants:

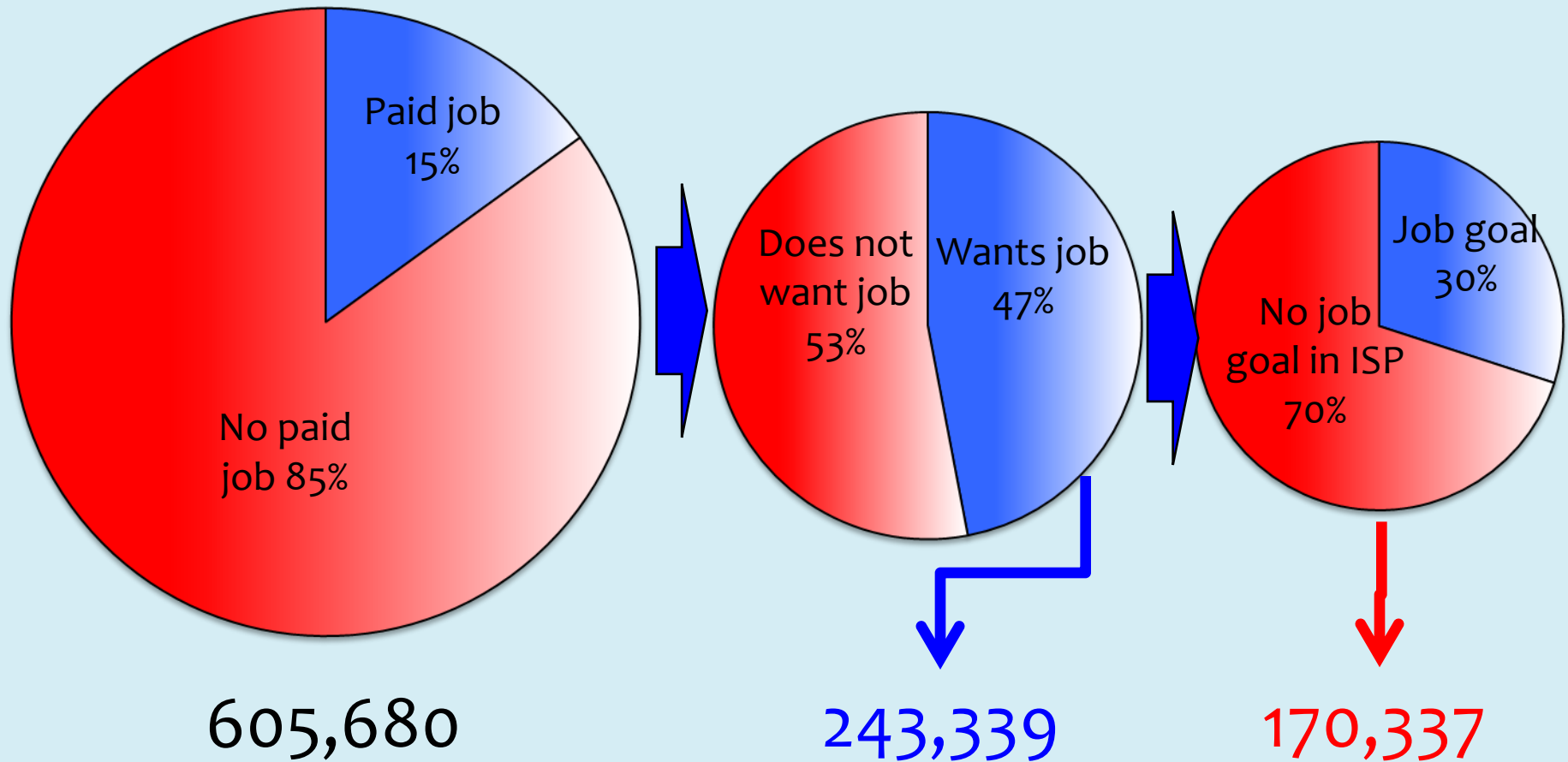
- “Work is a fundamental part of adult life for people with and without disabilities. It provides a sense of purpose, shaping who we are and how we fit into our community. **Meaningful work has also been associated with positive physical and mental health benefits and is a part of building a healthy lifestyle as a contributing member of society.** Because it is so essential to people's economic self sufficiency, as well as self esteem and well being, people with disabilities...who want to work should be provided the opportunity and support to work competitively within the general workforce in their pursuit of health, wealth and happiness. **All individuals, regardless of disability and age, can work – and work optimally with opportunity, training, and support that build on each person's strengths and interests.** Individually tailored and preference-based job development, training, and support should recognize each person's employability and potential contributions to the labor market.”
- Highlights CMS's goal to promote integrated employment options

➤ September 15, 2011

Why is Employment Becoming Part of Medicaid's Focus?

- Medicaid costs associated with unemployment (employment is a social determinant of health)
- **Physical and mental health maintained and improved by participation in employment**
- Employment mitigates health disparities and poverty's negative impact on health and well-being.
- **Employment brings potential for independence, natural supports and real inclusion.**

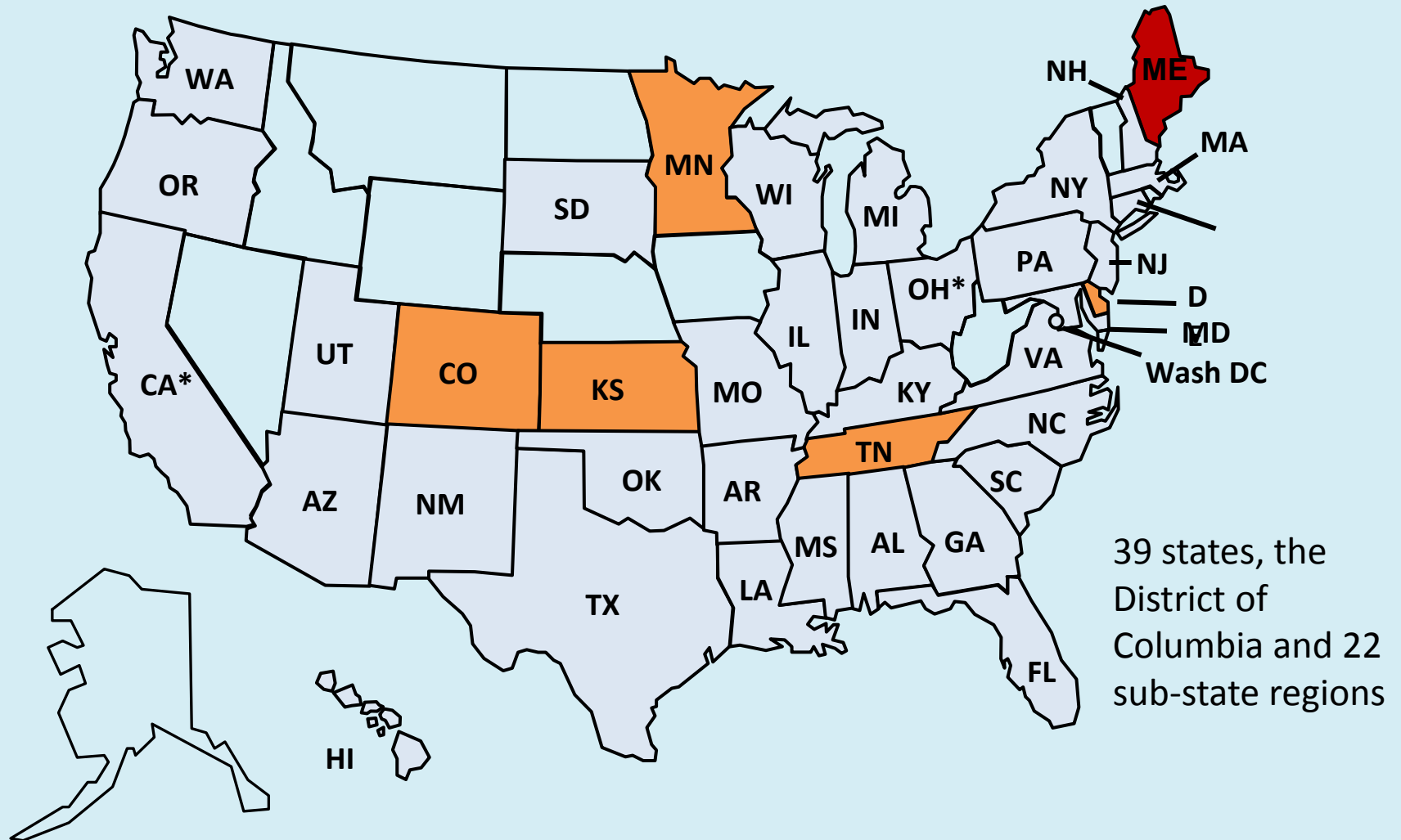
Choice



National Core Indicators (NCI): A must see to compare your state with other states on Quality

- NCI is a voluntary effort by public developmental disabilities agencies to measure and track their own performance.
- Coordinated by HSRI and NASDDDS
- Collaboration began in 1997
- Support from ACL to expand NCI – now currently 41 states including Washington D.C. plus 22 sub-state entities
- Most recently, ACL funding NCI-AD for older adults and people with physical disabilities

NCI State Participation 2013-14



■ State contract awarded in 2013-14 through AIDD funding

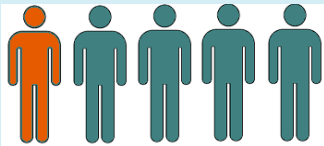
CA*- Includes 21 Regional Centers

OH*- Also includes the Mid-East Ohio Regional Council

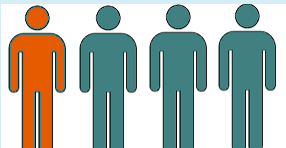
Medication Use

Medco Health Solutions 2010 data

- 1 in 5 took at least 1 psychiatric medication in 2010



- 1 in 4 women took at least 1 psychiatric medication in 2010

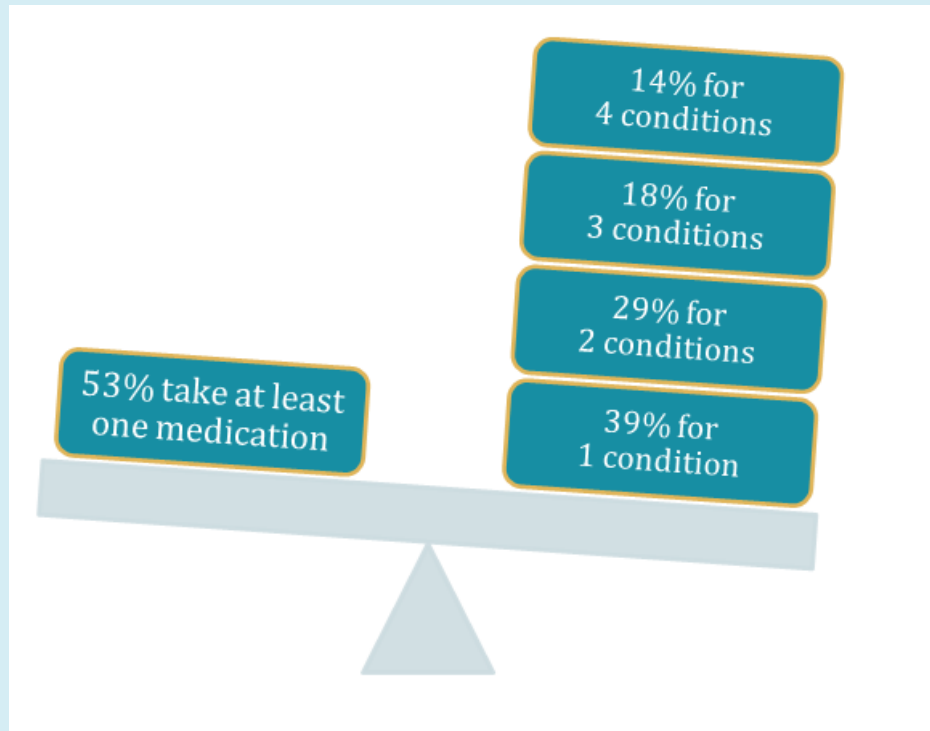


Source:

<http://www.medscape.com/viewarticle/753789>

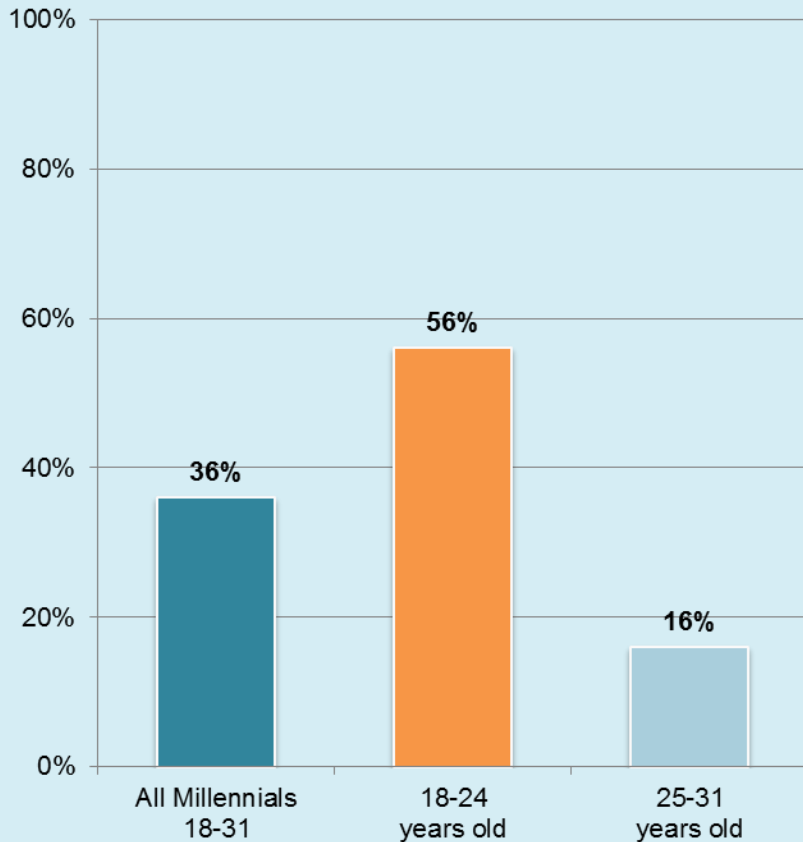
NCI

takes medication for mood, behavior, anxiety, and/or psychotic disorder and number of conditions medication treat

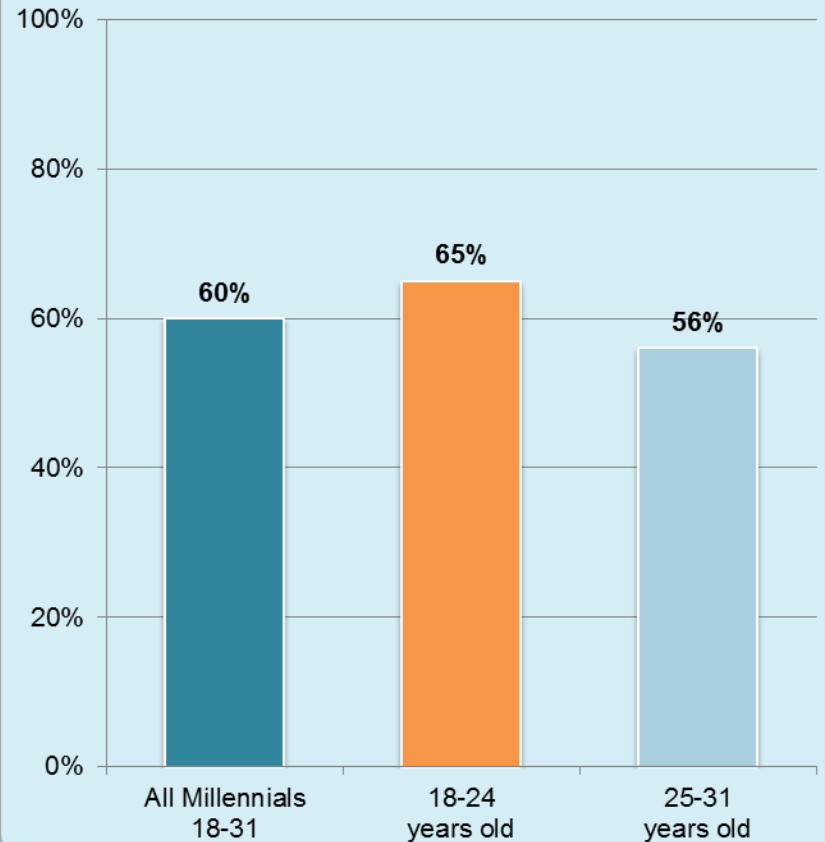


Millennials at Home

Pew Research



NCI



Contacts

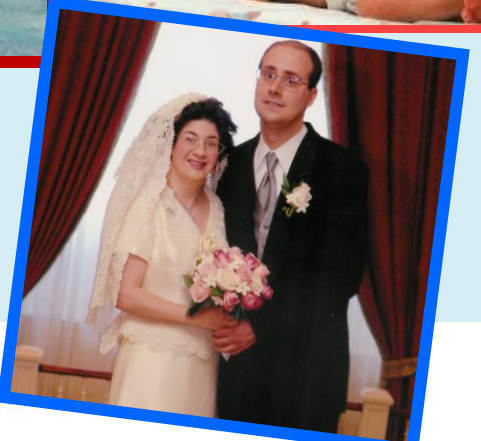
- HSRI
 - Julie Bershadsky: jbershadsky@hsri.org
 - Dorothy Hiersteiner: dhiersteiner@hsri.org
- NASDDDS
 - Mary Lee Fay: MLFay@nasddds.org
- NCI website: www.nationalcoreindicators.org



NASDDDS

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 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?

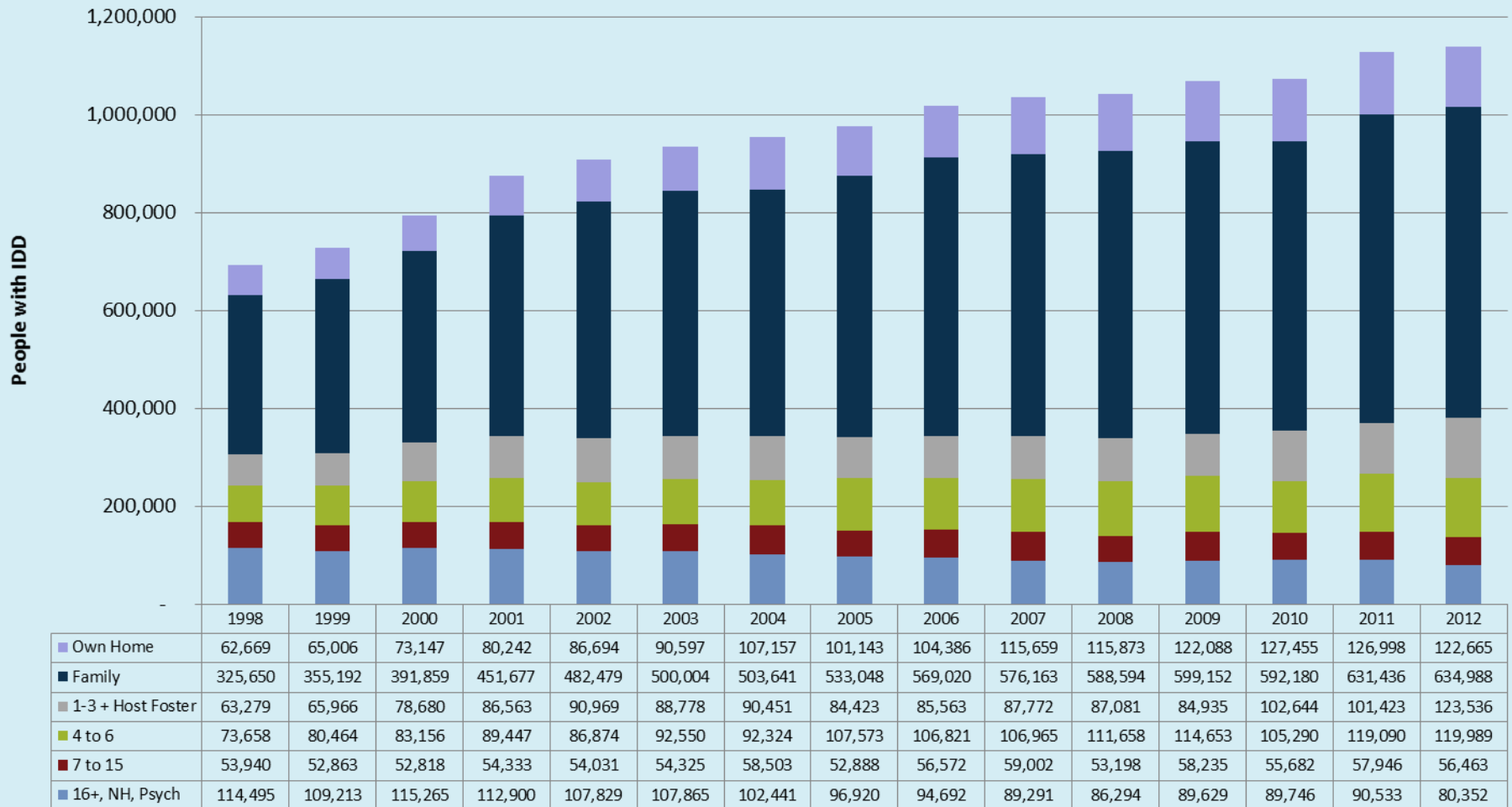
Contact Information

Sheryl Larson, Ph.D. Principal Investigator
612.624.6024 larso072@umn.edu

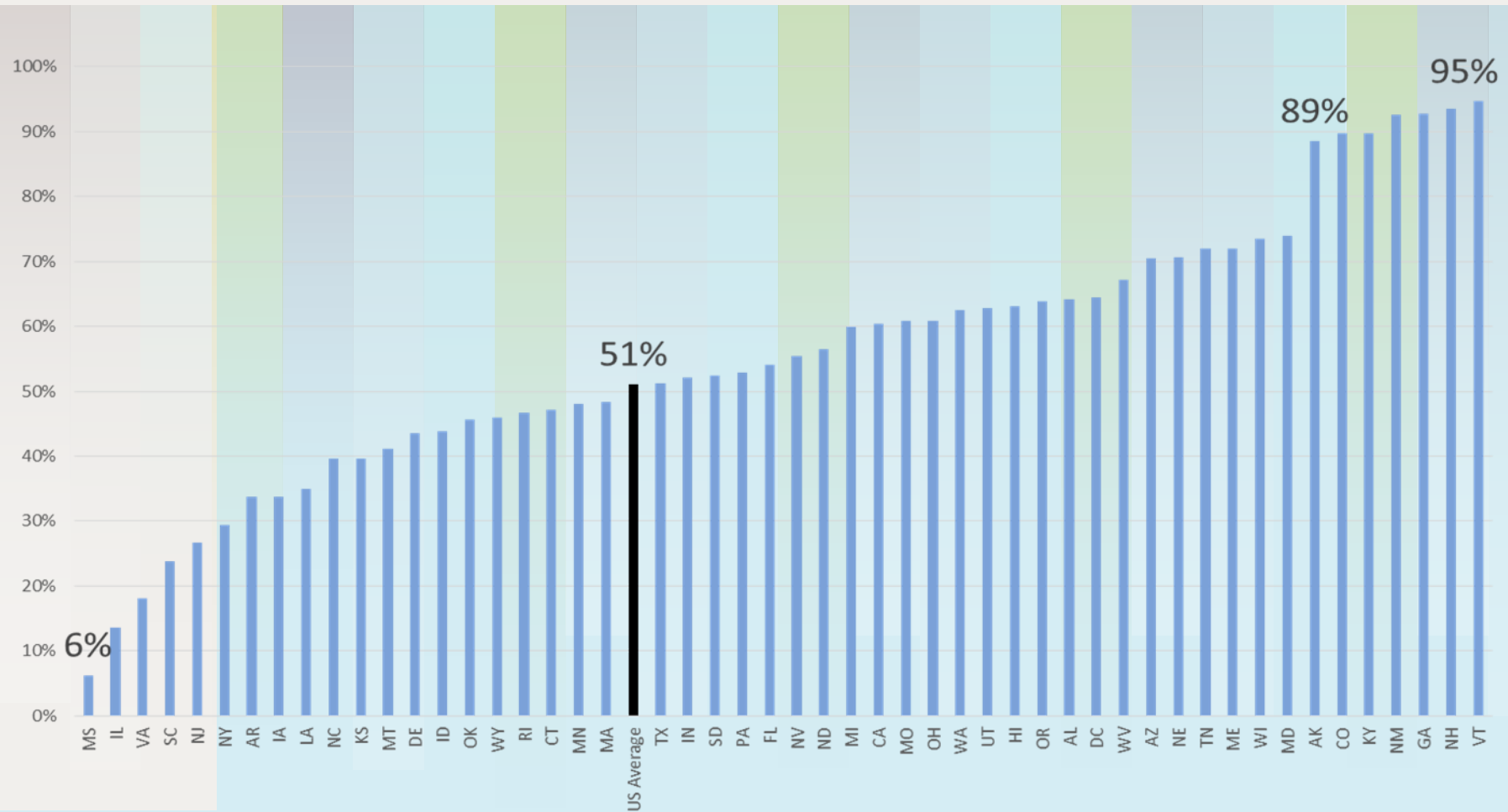
RISP/FISP Research and Training Center on Community Living
Institute on Community Integration (UCEDD)
University of Minnesota, Twin Cities
214 Pattee Hall, 150 Pillsbury Drive SE
Minneapolis, MN 55455

RISP/FISP Data MN: Amy Hewitt (Co-PI), Libby Muchow-Hallis, Lynda Anderson, Sandy Pettingall, Kristin Dean, John Westerman, Jonathan Walz, Shawn Lawler, John Smith
HSRI: John Agosta, Faythe Faiken, Yoshi Kardell
NASDDDS: Mary Sower, Nancy Thayler, Mary Lee Fay

Change in Residence Size and Type



% 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

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



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%

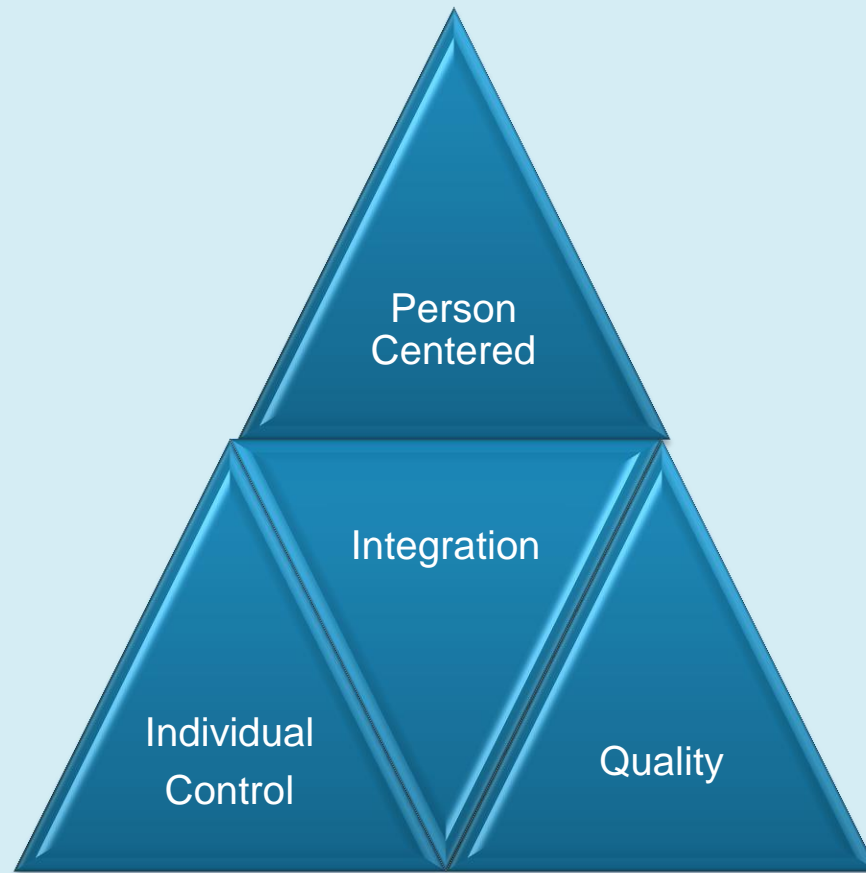
Money Follows the Person

- 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**

“Qualified Residence” under MFP Size Matters!

- “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”**

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



Leveraging the HUD Section 811 Program

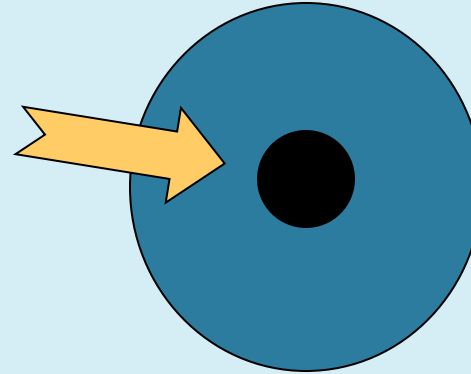
- **Critical need** for safe, decent, affordable and accessible housing
- Frank Melville Supportive Housing Investment Act of 2010; P.L. 111-374
- Reduce reliance on segregated, restrictive settings for people with disabilities
- 14,000 vouchers shifted to section 8 targeted to people with disabilities
- **State Housing Finance Authorities** are the primary applicants

Section 811, as amended

- **Project Rental Assistance Contract (PRAC)** for “reasonable project costs” including...**service coordinators...**”
- Shall be operated for no less than 40 years as **supportive housing for PWD**
- **Prescriptive tenant/landlord leasing including choice of provider for supports, including no supports**
- Multifamily units include condominiums and cooperative housing
- **Occupancy preference for PWD may not exceed 25%**

What To Do???

We can't stay on
this spot



We need to rethink what
we do – affirm our
values but resolutely
search for “value”

System Centered

- Deficit Based
- Segregation/Isolation
- Professional/Provider Control
- Rejecting Community/Loneliness
- Paper Compliance
- 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 (not the diagnosis)
- 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.

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.”

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 and 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.

Self – Determination

Tom Nerney and Don Shumway, 1996

- **Freedom**

To Plan a Real Life

- **Authority**

To Control a Limited Amount of Resources

- **Support**





For Building a Life in One's Community

- **Responsibility**

To Give Back to One's Community

Confirmation (added in 2000)

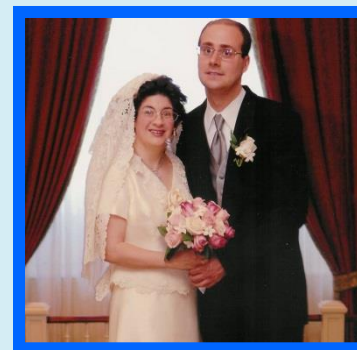
Evaluating service models in I/DD

Type of Service	Cost per Person	Cost to Serve the Waiting List 122,870	People Served with \$5 M
ICF/MR	\$128,275	\$15,761,114,925	 39
Non-family HCBS	\$70,133	\$8,617,241,710	 71
Host Family	\$44,122	\$5,421,270,140	 113
Own Family	\$25,072	\$3,080,596,640	 200

Data Source: Lakin, K.C. MSIS and NCI data from 4 states (1,240 Individuals)

Focusing on Relationship Based Living Options

- ✓ Living with siblings
- ✓ Living with other relatives
- ✓ Living with Friends
- ✓ Living with a partner
- ✓ Supported Living – supports provided in the person's own home
- ✓ Shared Living – the person matched to live with another



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 PRINCIPLES

- ✓ CHOICE
 - Where to live, with whom and which lifestyle
- ✓ OWNERSHIP BY OTHER THAN THE SERVICE PROVIDER
 - Individual owns or rents;
 - Family owns or holds lease;
 - Housing cooperative owns
- ✓ INDIVIDUAL SUPPORT
 - Focus on individual's changing needs over time;
 - Individualized support plan or support contract

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.....

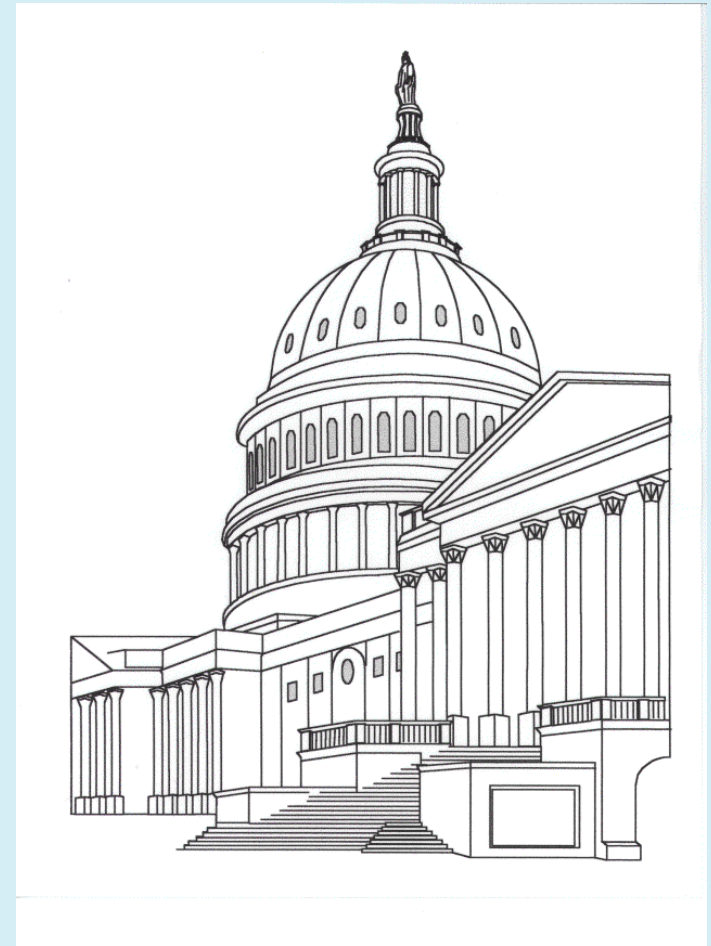
- Simply offering services in “small residences”
- Synonymous with apartment programs
- A model that rejects training as a valid component of service provision
- An “unsupervised” living arrangement
- **Another residential alternative.**

Presumption of Competency

**“ 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

Key Federal Policies and Court Decisions for Systems Change: **The Context**



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;

Policy of DD Act, cont.

“(1) individuals with DD, including those with the most severe DD, **are capable of self-determination, independence, productivity, and integration and inclusion in all facets of community life**, but often require the provision of community services, individualized supports, and the other forms of assistance;

Policy of DD Act, cont.

“(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...**”



Historical Events

Created as State Mental Health Agency in 1983

Purpose: Close Plymouth State, DD Institutions and Nursing Homes

Plymouth Center closed 1986, Southgate 1991, all in 2010

Transfer: State Agency to Wayne County CMH as Non-Profit 1991

Robert W Johnson Self-Determination 400 Individual Budgets 2001

Now 1400 directly control budget all other PC Plans have budgets

Became Wayne CMH MCPN in 2002 providing Managed Care

Only MCPN that also Provides Support Coordination

RFP Awarded from Oakland County CMHA in 2004

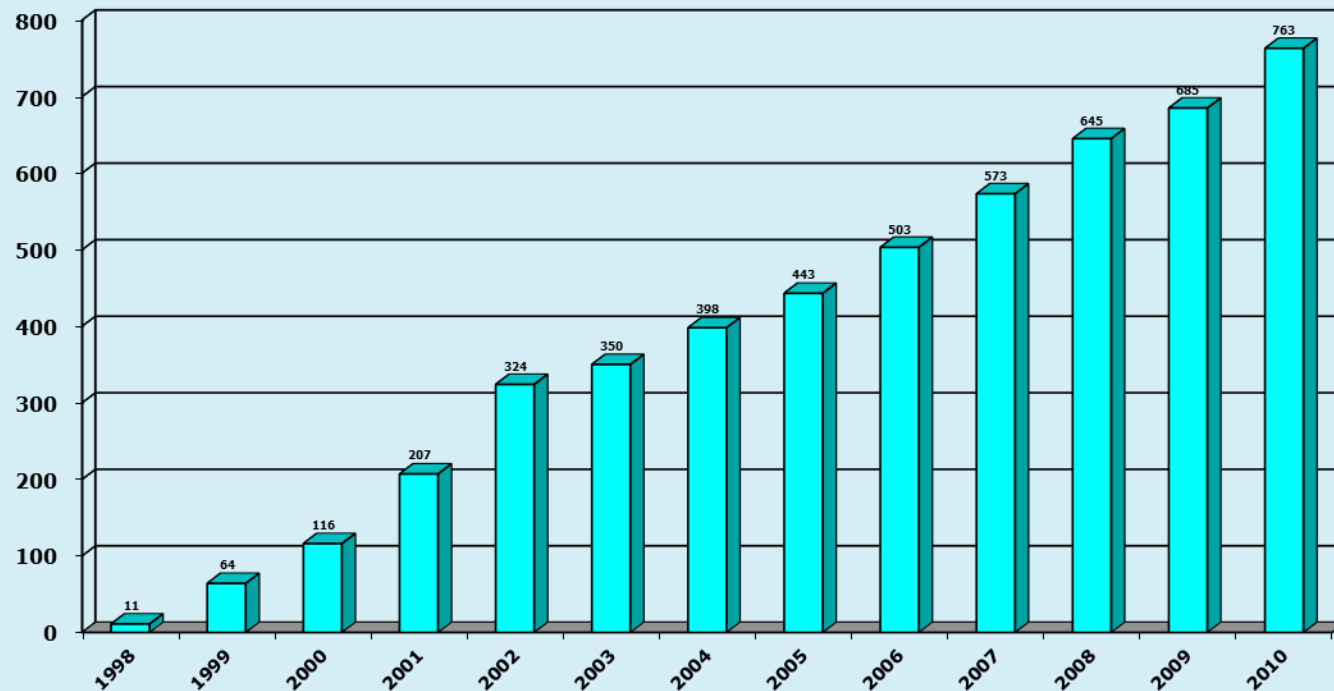
Currently serve over 4000 with DD, MI/DD and Seniors

Medicare Home Health and Advantage Programs now in place

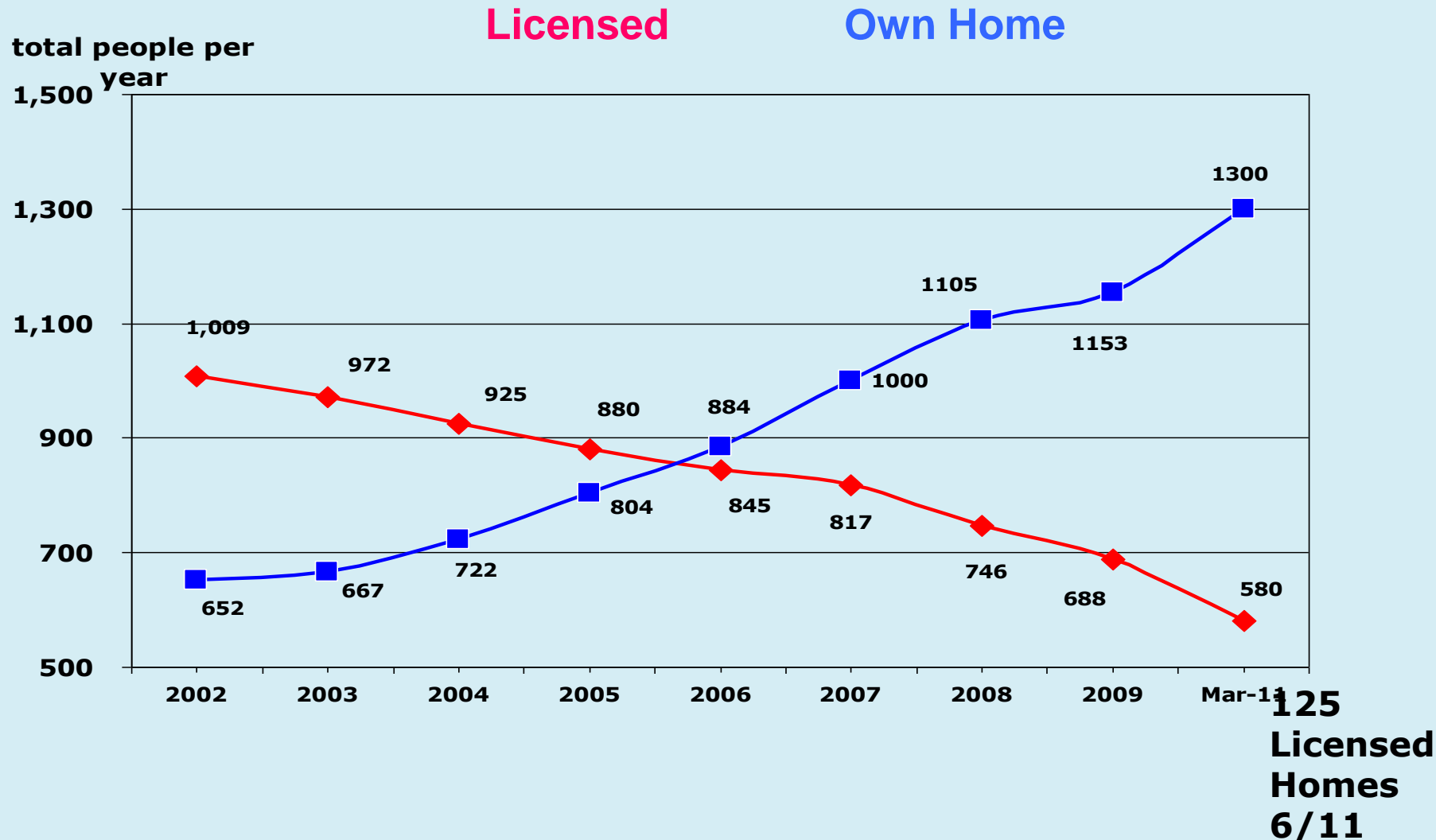
Proven lower unit costs, fewer per home, integration in Health Care

Jim Dehem, CEO

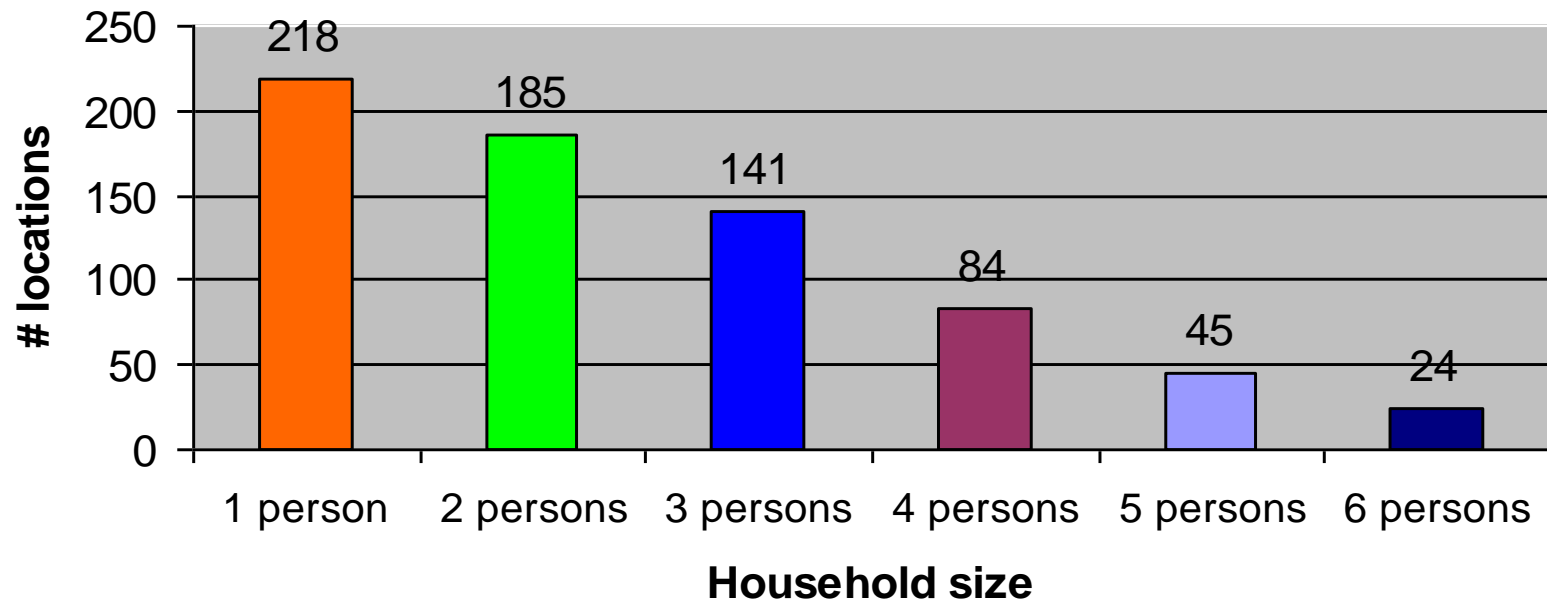
Total number of Individuals with Self-Determination and Individual Budgets in Wayne County



Number of People Living in Licensed vs. Own Home



Number of locations by household size varying from 1 to 6 persons



My Perspective from Michigan

“The future is here. It's
just not evenly
distributed.”

William Gibson
Science fiction writer

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

- Applies to 1915 (c) HCBS waivers; 1915 (l) 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:.....**

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

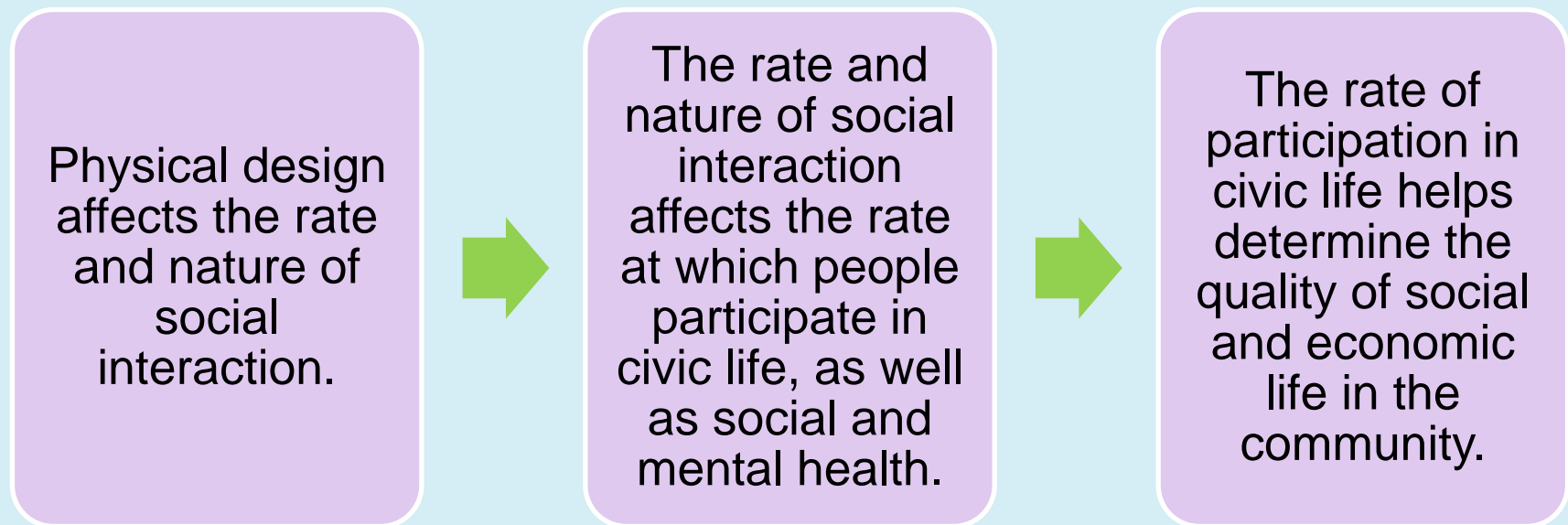
“ (i) The **setting is integrated** in and supports **full access** of individuals receiving Medicaid HCBS **to the greater community**, including opportunities **to seek employment and work in competitive integrated settings**, **engage in community life**, control personal resources, and receive services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

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.)

Healthy Communities



*Restoring Community through Traditional Neighborhood Design: A Case Study of Diggs Town Public Housing, Housing Policy Debate • Volume 9, Issue 1 89, Fannie Mae Foundation 1998, Stephanie E. Bothwell, Raymond Gindroz, and Robert E. Lang

Factors to consider in establishing Service Standards and Requirements

- **Is there a setting type or size or location at which integration is less likely to occur?**
 - Settings are designed exclusively or primarily for individuals with disabilities;
 - Settings provide multiple types of services and activities on-site in a manner that creates barriers to participation outside the setting
 - Regimentation in daily activities, lack of privacy or autonomy, policies limiting visitors, or limits on individuals' ability to engage freely in community activities
 - Homes and apartments are the size typical of family home in the area
 - People living in their own homes have full access to the greater community and opportunities to engage in community life
- **Is there a setting location in which integration is less likely to occur?**
 - Enables unplanned interaction with non-disabled peers throughout the day
 - Requires planned interaction with non-disabled individuals throughout the day

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; photography²⁷
- 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.

Factors to consider in establishing Service Standards and Requirements

- If activities are conducted in groups, is there a size at which integration is less likely to occur?
- What is the frequency of activity in the community needed to meet the standard?
- Should standards differ by age of individuals?
 - Children – children typically live with a family. Services for children would be home based, supportive of families and include options when children cannot live with their birth family including kin-care and shared living.
 - Working age adults - are typically out and about in their communities
 - Elderly – a time of decreasing activity and choice of living options that allow easy contact with peers

Assess Person-Centered Planning Practices

- **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**
- **Offers choices** to the individual regarding services and supports the individual receives and from whom
- Provides **method to request updates**

Assess Person-centered Planning Practices cont.

- 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**
- **Requires “Informed Choice” (experientially-based)**
- May include whether and **what services are self-directed**

Assess Plan Documentation Requirement

- **Written plan reflects –**

- **Setting is chosen** by the individual and **is integrated** in, and supports **full access to the greater community**
- Opportunities to seek employment and work in **competitive integrated settings**
- Opportunity to **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
- Includes **individually identified goals and preferences related to relationships, community participation, employment, income and savings, healthcare and wellness, education and others**

Assess Plan Documentation Requirement cont.

- Includes risk factors and plans to minimize them
- Documents that any modification, when a safety need warrants a restriction, is supported by a specific assessed need and is justified in the person-centered service plan (*this means using positive behavioral intervention supports – PBIS*)
- Is signed by all individuals and providers responsible for its implementation and a copy of the plan must be provided to the individual and his/her representative
- Distributed to the individual and others involved in plan
- Includes purchase/control of self-directed services
- Exclude unnecessary or inappropriate services and supports

The State Transition Plan

- **Assess infrastructure and need for modifications:**
 1. Service definitions
 2. Service standards and requirements
 - Regulations
 - Provider qualifications
 - Training requirements
 - 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**

Where is the Future?



135

The Essence of Strategic Planning

“Long range planning does not deal with future decisions, but with the future of present decisions.”

Peter Drucker

The Future is Now

- Current programs and service “models” are not sustainable even in a recovering economy
- We must change how we do our business
- States are looking at efficiency, effectiveness, equity and fairness
- A Variety of “tools” in the toolbox
- The median family household income in the United States in 2011 was \$50,054.00

Belonging

be-long, v. 1: to feel and be a part of
...i.e. of a community, a workplace, a
neighborhood or school 2: to enjoy a
sense of contribution, value, self-worth
3: to truly believe one is a natural and
equal part of the whole 4: comfortable,
safe, cared for, welcome.

“Equal Justice Under the Law”



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