

The Employment First Imperative:

“Suit the Actions to the Words”

APSE’S 25TH Anniversary

Annual Conference

Indianapolis, IN.

June 26, 2013

Allan I. Bergman



The Community Imperative Center on Human Policy, 1979

*“ In the domain of Human Rights:
All people have fundamental moral and
constitutional rights.*

These rights must not be abrogated
merely because a person has a
mental or physical disability.

Among these fundamental rights is
the right to community living....

The Community Imperative - 3

Therefore:

In fulfillment of fundamental
human rights,
and

In securing optimum
developmental opportunities,

**all people, regardless of the severity of
their disabilities, are entitled to
community living.**

Why Pursue Employment & The Employment First Imperative?

- ✓ Get out of poverty; pay taxes
- ✓ Increased independence & economic self-sufficiency
- ✓ Opportunities to make friends and expand relationships
- ✓ Make a contribution to the community
- ✓ Positive image and valued role within the family and community
- ✓ Opportunities for learning

What is an “imperative”?

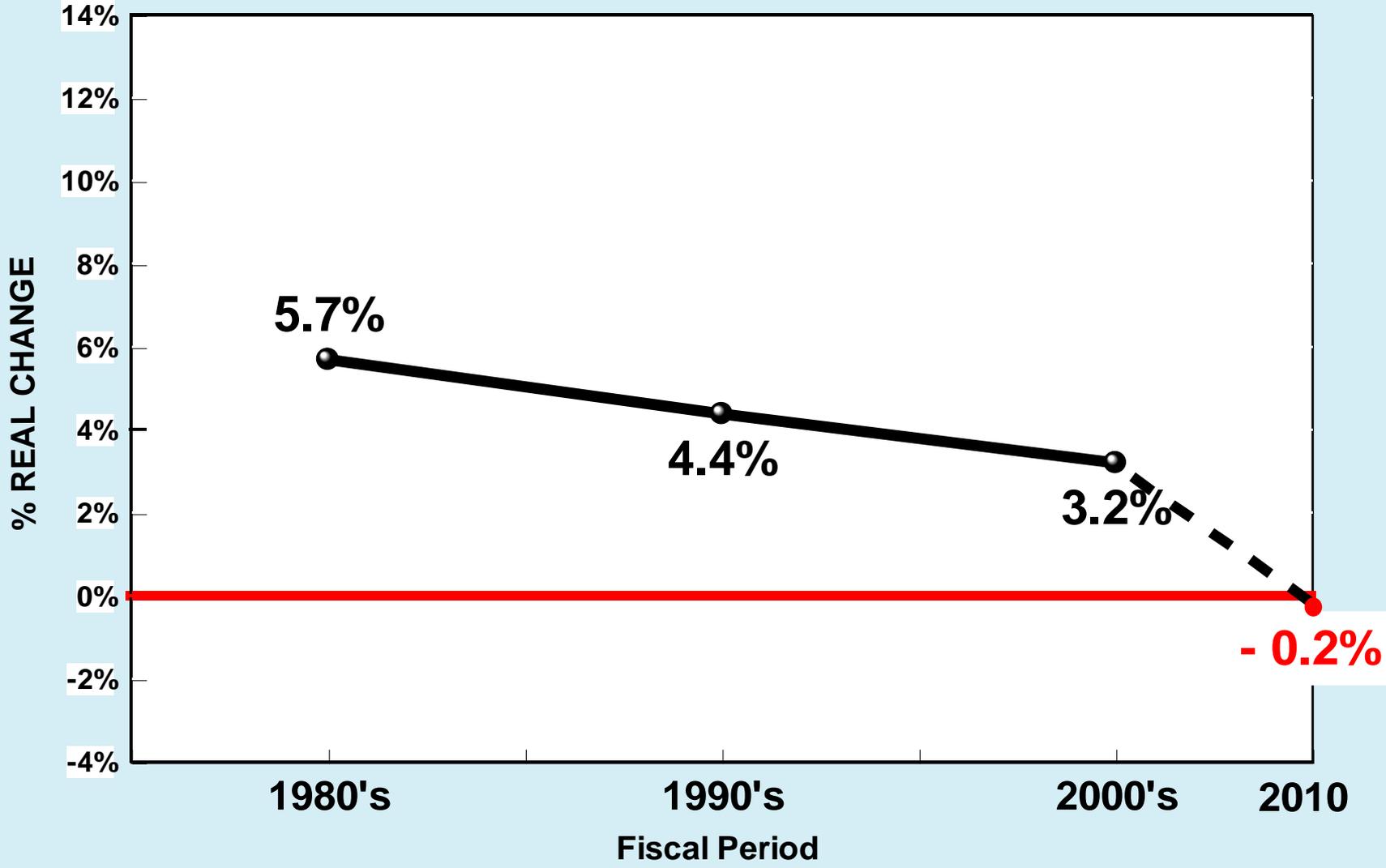
- Something that demands attention or action; unavoidable
- Absolutely necessary or required
- A command

Allan’s Employment First Imperative

"All people, regardless of severity of their disabilities, are entitled to integrated employment with the correct job match and appropriate supports."

(6-26-2013)

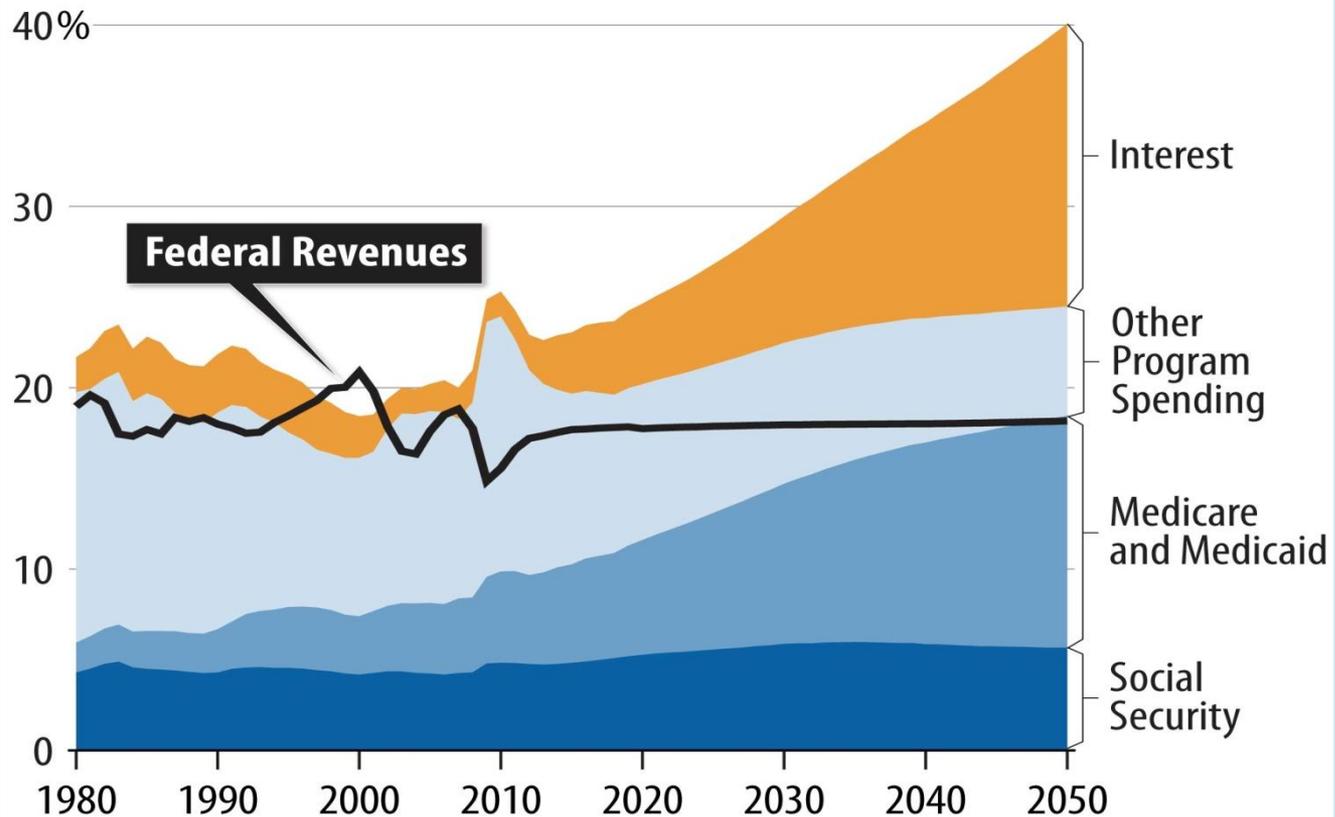
AVERAGE ANNUAL % CHANGE IN INFLATION-ADJUSTED I/DD SPENDING BY DECADE, 77-09



Source: Braddock, D., Coleman Institute and Department of Psychiatry, University of Colorado, 2010.

Current Policies Are Not Fiscally Sustainable

Spending and Revenues as a Share of GDP Under Current Policies



Source: CBPP projections based on CBO data.

2008 Government Expenditures for Working-Age Adults with Disabilities

What's wrong with this picture???

- \$357 Billion, Federal (12% of federal spending)
- Additional \$ 71 Billion, State spending
- Healthcare; 55%
- Income Maintenance; 41%
- Housing & Food Assistance; 3%
- Education, Employment & Training; 1%

- Livermore, Stapleton and O'Toole, *Health Affairs*, 2011

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.

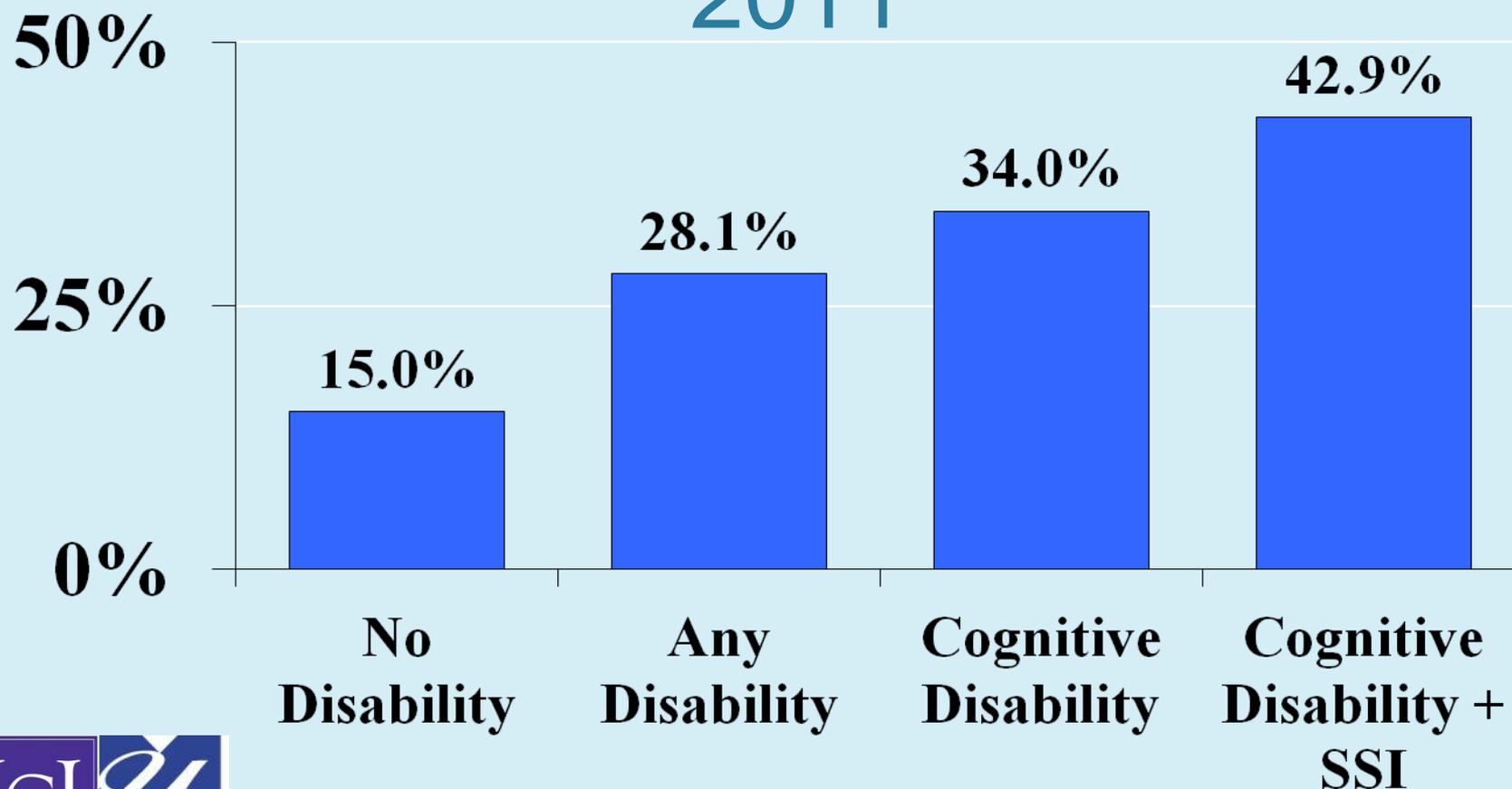
It is expected that SSDI/SSI annual payments will reach over \$1 trillion by 2023.

Data on SSI Beneficiaries, 2010

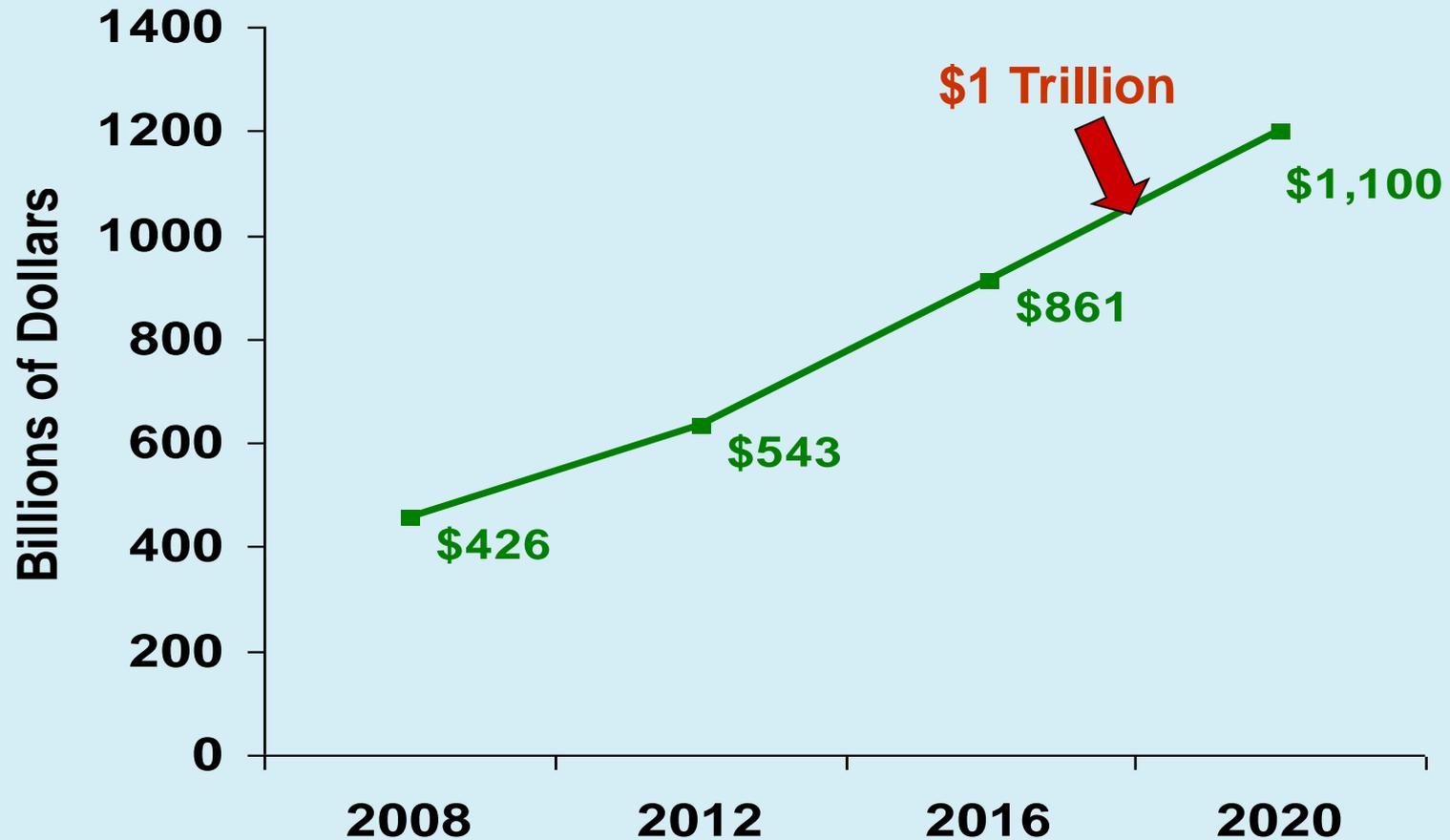
- 4.6 million between ages 18 and 64 years (25% of these beneficiaries also received some type of Social Security payment)
- Only 5% of the SSI beneficiaries of working age reported earned income
- The average earned income is \$286/year (for individuals who are blind, \$460/year)
- Less than 1% leave the rolls per year and only ½ of those for employment

Source: SSA

American Community Survey Lives Below Poverty Threshold 2011



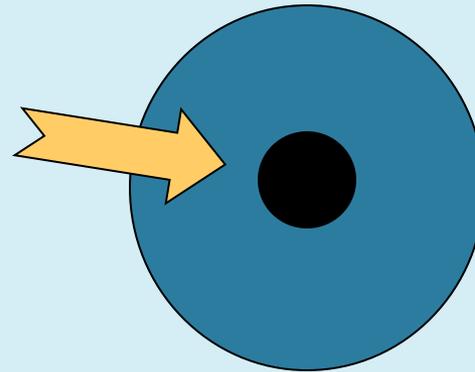
Annual Expenditures for Federal Cash and Health Benefits for Persons With Severe Disabilities FY 2008 – FY 2020



©2008. Institute for Economic Empowerment

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.

Self – Determination

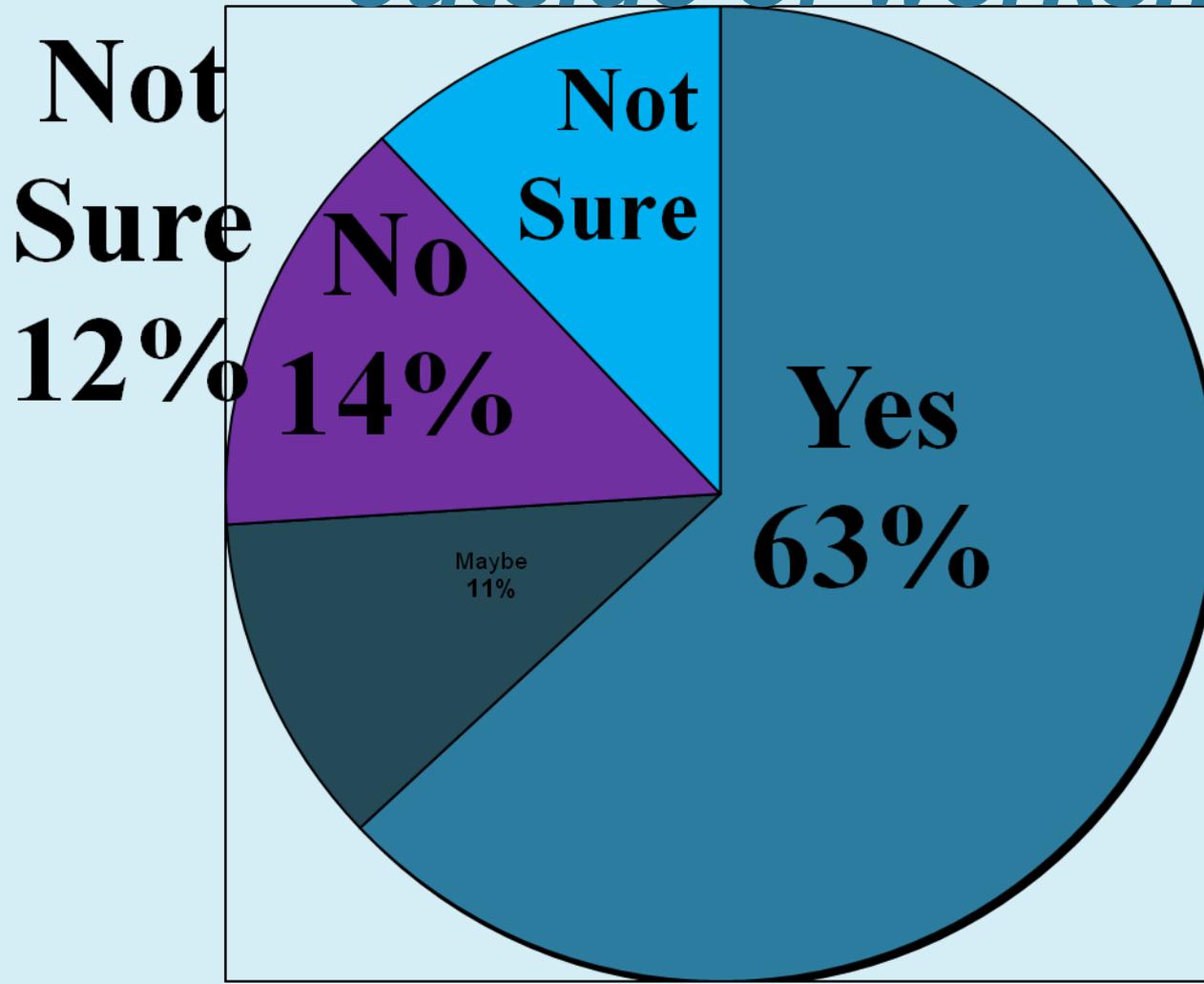
Tom Nerney and Don Shumway, 1996

- 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)

Alliance for Full Participation, 2005.

- We are Americans too!
- We want dignity & respect for all
- We want full participation for all
- We belong in schools, neighborhoods, businesses, government and churches, synagogues and mosques;
- **We do not belong in** segregated institutions, **sheltered workshops**, special schools or nursing homes. Those places must close....
- **We can work in worthwhile jobs.**

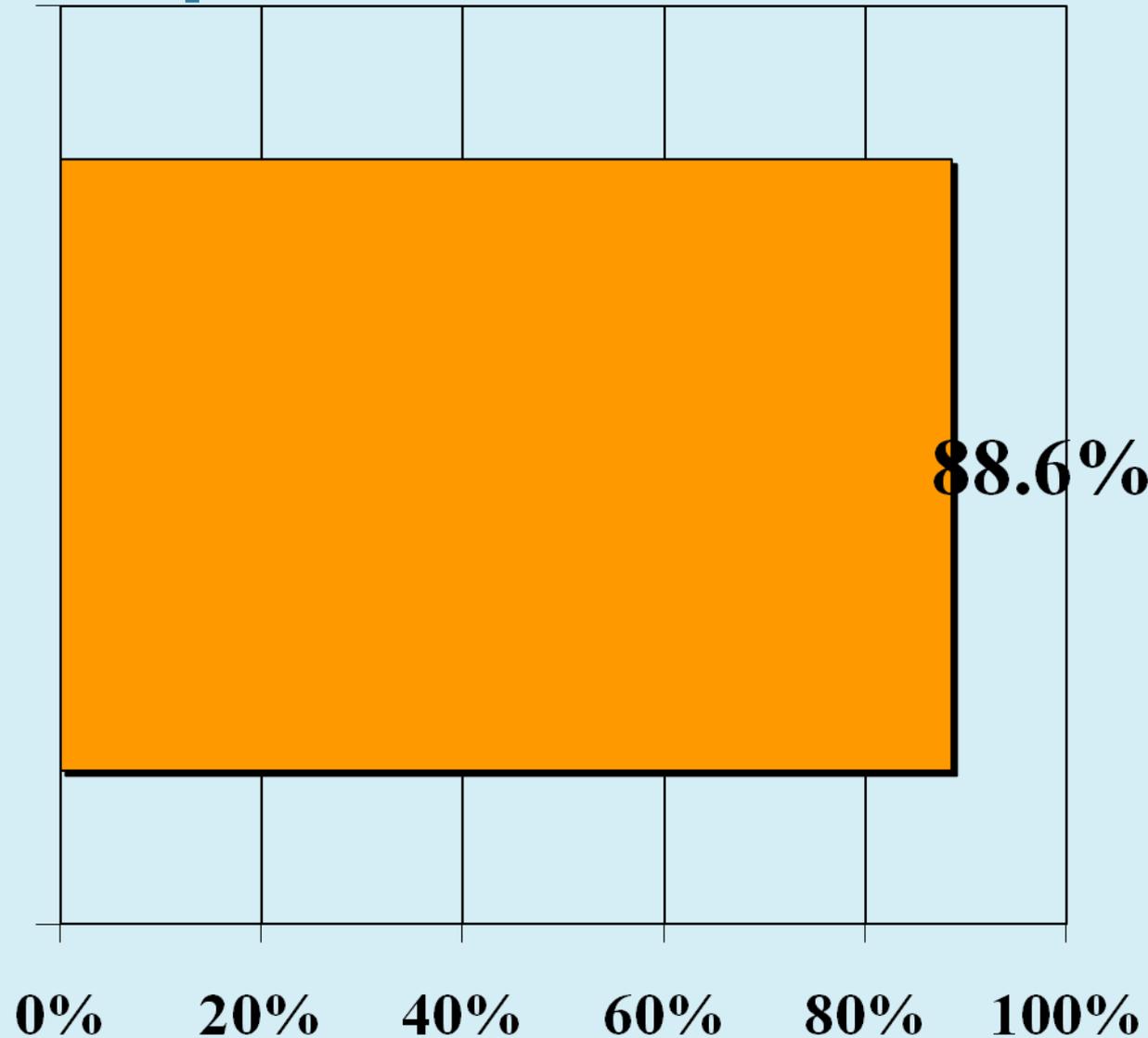
Participant Prefers employment outside of workshop



Migliore
(2006)

Our Expectations

Facility-based programs are needed [for] persons who have difficulty or are unable to maintain employment

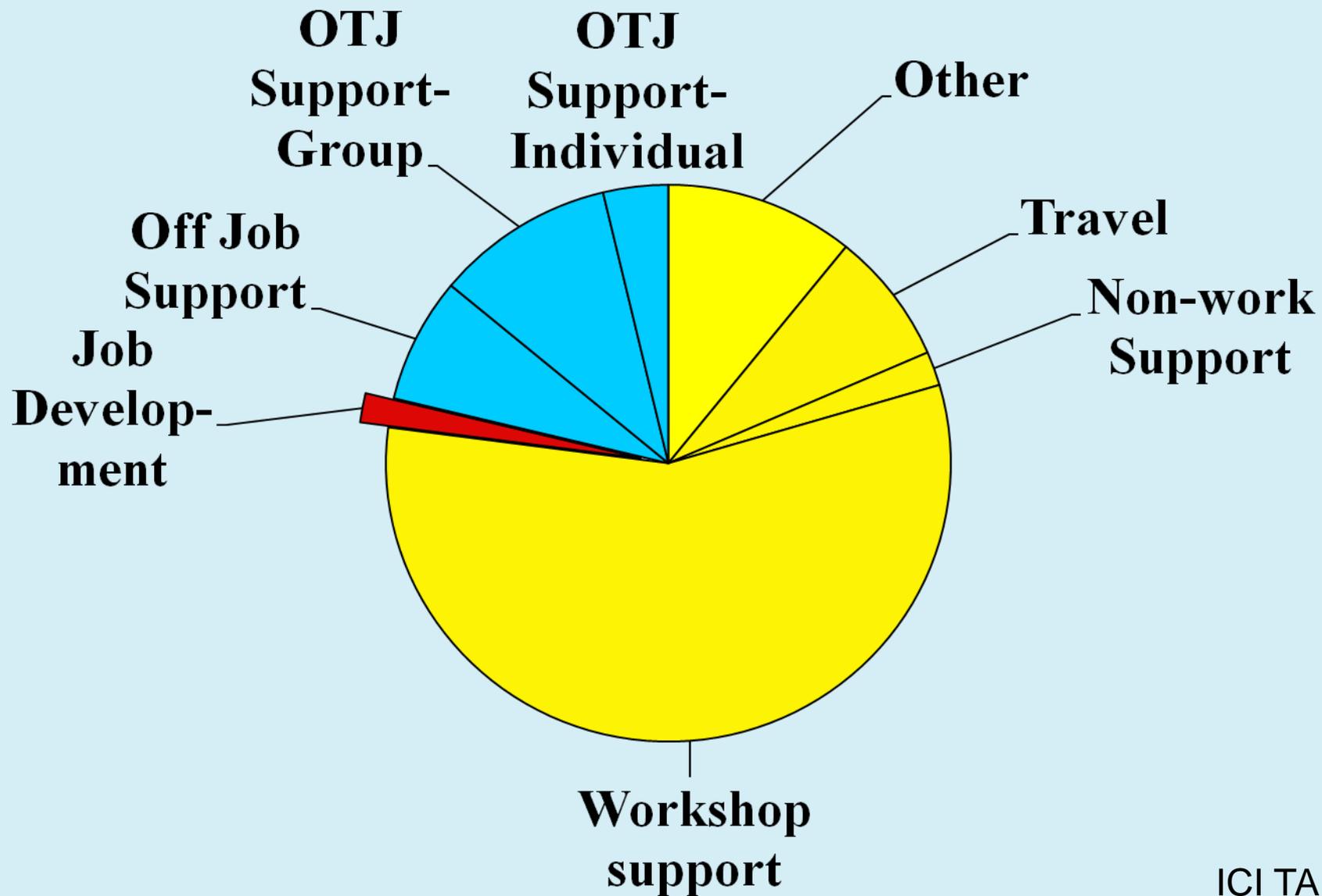


ICI - T-TAP 14c Survey

Wisdom from President John F. Kennedy

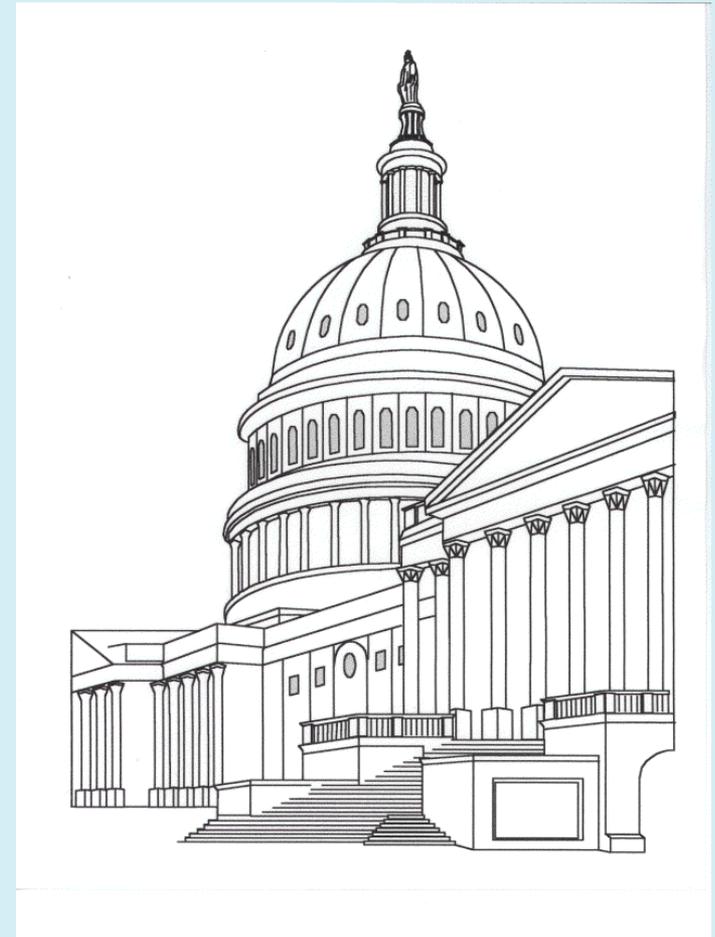
“ The **great enemy of the truth** is very often not the lie – deliberate, contrived and dishonest – but **the myth** – persistent, persuasive, and unrealistic.”

How employment staff use their time



ICI TA data

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



DISABILITY CONSTRUCT IN MULTIPLE FEDERAL 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 & their families participate in the design & have access to needed community services, individualized supports... that **promote self-determination, independence, productivity, and integration and inclusion in all facets of community life**, through culturally competent programs authorized...unique **strengths, resources, priorities, concerns, abilities and capabilities** of such individuals.”

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;**

➤ Identical definition in 4 federal laws:
Assistive Technology Act; DD Act; IDEA;

IDEA Transition Amendments of 2004

“The term ‘transition services’ means a coordinated set of activities for a child with a disability that:

- Is designed to be within a **results-oriented process**, that is focused on improving the **academic and functional** achievement of the child with a disability to facilitate the child’s **movement from school to post-school activities**, including.....

IDEA Transition amends. of 2004, cont.

postsecondary education, **vocational education, integrated employment (including supported employment)** continuing and adult education, adult services, **independent living, or community participation;**

- Is based on the individual child's needs, taking into account the child's **strengths, preferences and interests;** and,

IDEA Transition amends of 2004, cont.

- Includes instruction, related services, **community experiences**, the development of **employment and other post-school adult living objectives**, and, if appropriate, **acquisition of daily living and functional vocational evaluation.**”

Dept. of Ed. to Disability Rights WI.

- January 2012 informal guidance on the **application of LRE to transition IEPs**
- Melody Musgrove, Ed.D, Dir, OSEP
- **Work placement can be an appropriate transition service** and, if determined appropriate by team, it must be in the IEP
- Placement decisions, including those related to transition services (including work placement) **must be based on LRE principles** and made by the IEP team

Youth Employment Data, August 2011, Bureau of Labor Statistics

Youth Without Disabilities

- **29.2%** for youth between the ages of 16 to 19
- **62.9%** for youth between the ages of 20 to 24

Youth With Disabilities

- **13.2%** for youth between the ages of 16 to 19
- **31.2%** for youth between the ages of 20 to 24

Transforming the Front Door to Adult Supports and Services:

"Transition from school to adult life in the community requires a system of seamless, blended and braided supports from Education to Rehabilitation to LTSS in order to prevent regression, and loss of a significant investment in human capital."

WAITING LISTS ARE UNACCEPTABLE!

State V.R. Program Policy...

“(3) It is the policy of the United States that such a program shall be carried out in a manner consistent with the following principles:

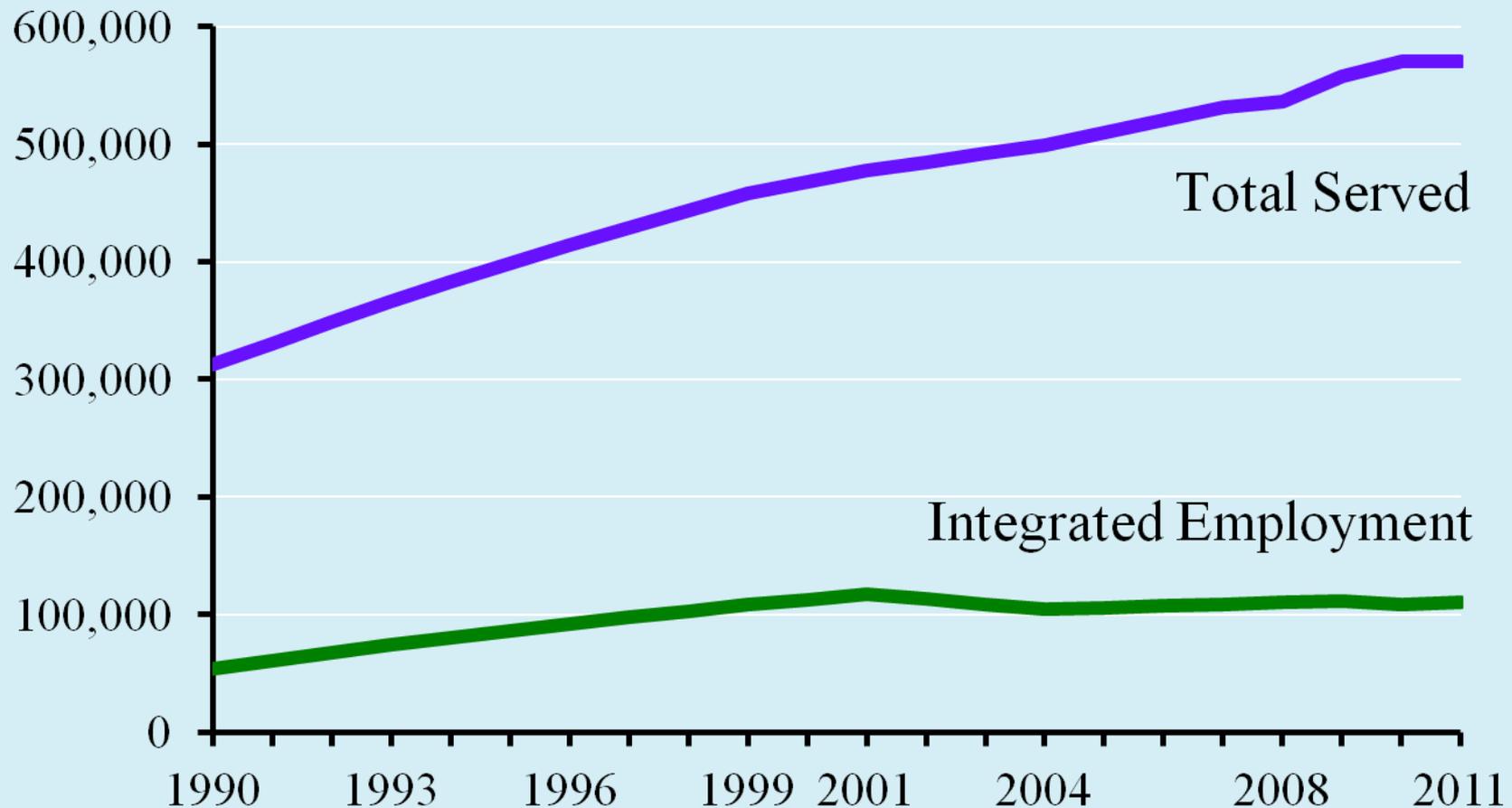
“(A) Individuals with disabilities, including individuals with the **most severe disabilities**, are generally **presumed to be capable of engaging in gainful employment** and the provision of individualized vocational rehabilitation services can improve their ability to become gainfully employed.

“(B) Individuals with disabilities **must be provided** the opportunities to obtain gainful employment in **integrated settings**.

Rehabilitation Act, 1992

Employment & Day Supports, U.S. 2011

Facility-Based & Non-Work Increasing...



ICI National Survey of State IDD Agencies 2011



How are we *Faring Nationally* in Integrated Employment for Individuals with ID/DD?

METRIC	2004	2008	2010
Total Number Receiving Services	499,849	543,257	566,188
Total Number Receiving Services & Supports in Integrated Employment	105,449 (21.1%)	114,395 (21.1%)	113,937 (20.1%)
Total Number Receiving Services in Facility-Based Employment	28.8%	27.1%	26.6%
Total Number Receiving Services in Segregated Non-Work	<u>34.4%</u>	<u>34.6%</u>	<u>37.5%</u>
Total Number Receiving Services in Community-based Non-Work	<u>33.6%</u>	<u>44.4%</u>	<u>46.7%</u>
Total Number Served in Both Settings	83.6%	85.3%	84.9%
Waiting List for Day or Employment Services and Supports	35,739	28,345	47,046

Source: ICI State Data Report, 2011

VAST STATE DISPARITIES IN S.E.P.

- Percentage of individuals in supportive or competitive employment goes from:

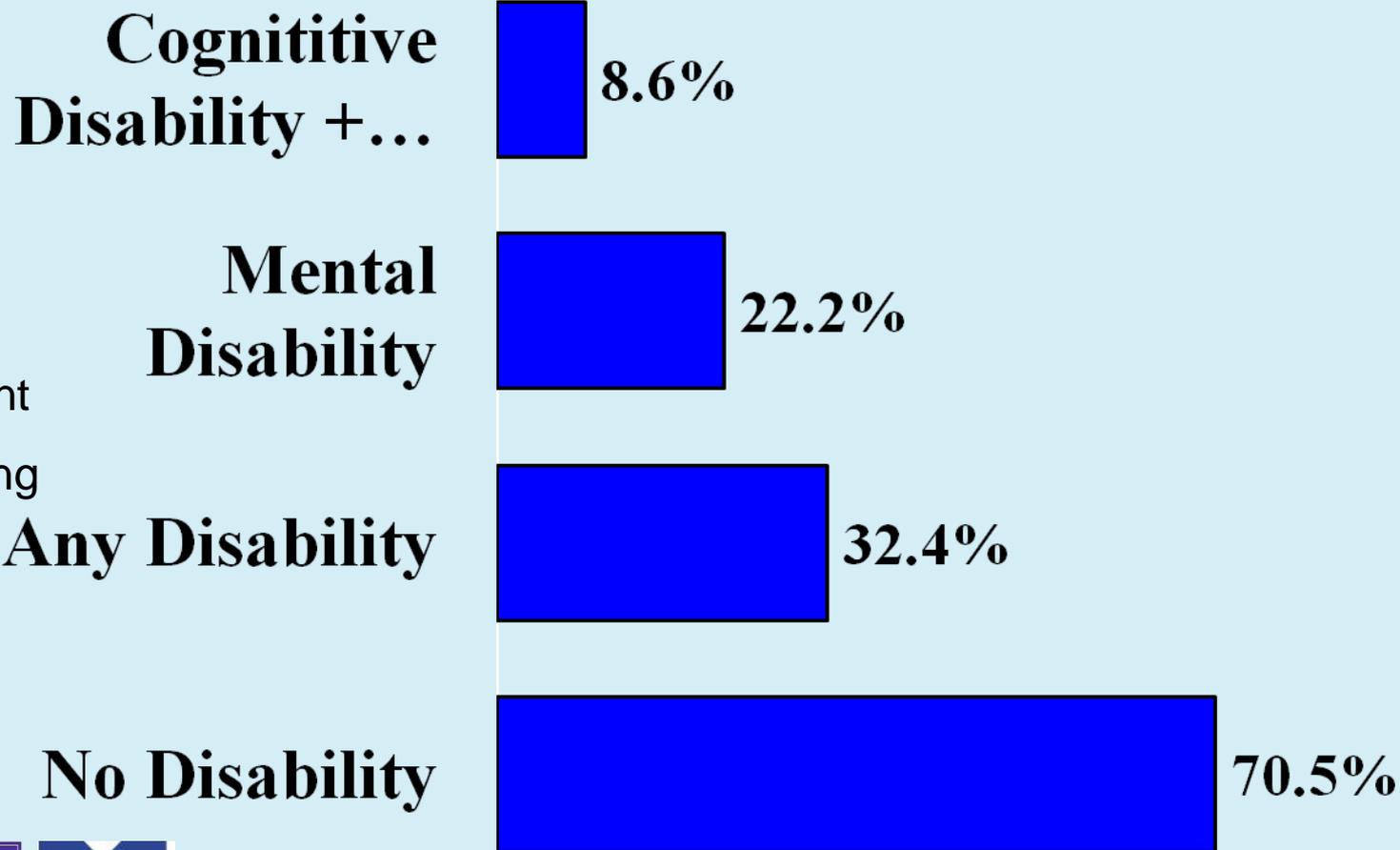
to:

Washington	72%	Arkansas	2%
Connecticut	59%	Missouri	4%
Michigan	55%	Alabama	7%
Delaware	49%	Arizona	8%
Oklahoma	48%	N. Dakota	8%
S. Carolina	40%	Hawaii & Oregon	9%
Vermont	39%	West Virginia	10%
Maryland	36%	Montana	10%
New Mexico	35%	D.C.	11%
Nebraska & Mass.	33%	California	13%
Pennsylvania	31%	N.Y., MN., ID.	14%

State government is a significant policy maker

UCP Case For Inclusion, 2011

Employment participation 2011



American Community Survey



How are we Faring Nationally in State Expenditures for Individuals with ID/DD?

METRIC	2004	2008	2010
Total % I/DD \$\$ spent on Integrated Employment	12%	11%	10%
Total % I/DD \$\$ spent on Facility-Based Employment	21%	28%	21%
Total % I/DD \$\$ spent on Facility-Based Non- Work	39%	31%	42%
Total % I/DD \$\$ spent on Community Based Non-Work	37%	52%	57%

Source: ICI State Data Report, 2011

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

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.

CMS Imposes Special Terms & Conditions on New York State's OPWDD

- “The receipt of expenditure authority for *transformation* for 4/1/13 – 3/31/14, is contingent on state's compliance and CMS' receipt of the following deliverables:”
- Baseline # of people receiving **supported employment services & in competitive employment** for 5/1/12 – 4/30/13
- **Increase that number by 700 people with no exception for attrition, and**
- **Increase by 250 persons by 10/1/13**

CMS & N.Y. OPWDD, cont.

- Effective July 1, 2013, New York will **no longer permit new admissions to sheltered workshops** and must report quarterly enrollment in sheltered workshops
- On 10/1/13, submit a draft plan for review and final plan by 1,1/2014 on **transformation to competitive employment**
- To include detailed work plan (sic) for number of **students exiting educational system moving directly into competitive employment**

CMS & N.Y. OPWDD, cont.

- Plan must include a **timeline for closing sheltered workshops**, and a description of the **collaborative work with the New York educational system** for training/education to key stakeholders on the availability and importance of competitive employment.

SELN : Employment First, since'06

- Alabama
- Arizona
- Colorado
- Connecticut
- Delaware
- D.C.
- Indiana
- Iowa
- Louisiana
- Maryland
- Massachusetts
- Michigan
- Missouri
- Montana
- Nevada
- New Jersey
- New Mexico
- North Carolina
- Ohio
- Oklahoma
- Pennsylvania
- Rhode Island
- South Dakota...Texas
- Virginia
- Washington
- Wyoming

Current Initiatives by Office of Disability Employment Policy (ODEP) in the U.S. Dept of Labor

- Employment First State Leadership Mentoring Project; **Iowa, Oregon, Tennessee and Washington State; more states expected in FY'14**
- Community of Practice webinars with **33 states** participating; more states can apply

AIDD: Partnerships in Employment System Change

- **CA.** Employment Consortium for Youth & Young Adults-I/DD
- **IA.** Coalition for Integrated Employment.
- **MS.** Partners for Employment
- **MO.** Transition to Employment Collaborative: Show Me Careers
- **N.Y.** St. Partnerships in Employment Systems Change
- **WI.** Let's Get to Work Added in 2012
- **AK.** Integrated Employment Initiative
- **TN.** Works Partnership: Changing Employment Landscape Statewide

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

Dept. of Education: PROMISE Grants

Promoting Readiness in S.S.I.

- Competitive aps. due Aug. 19, 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)**.

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

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

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)

The Role of the ADA and Olmstead..

- Cannot be ignored with current DOJ
- **June 22, 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. L.C.

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.”

U.S. v. R.I. & City of Providence; 6/13/13

- **First of its kind** court-enforceable interim settlement agreement tied to ADA Olmstead investigation; **relief for 200 persons with I/DD** at Training Thru Placement, Inc.(TPP), and Harold A. Birch Vocational Program, a segregated sheltered workshop within Providence H.S
- **Unnecessarily *segregated*** individuals with I/DD in a sheltered workshop and ***segregated* day activity** service program;
- Typical "tenure" at TPP of 15-30 years

DOJ & Rhode Island, cont.

- Have placed public school students with I/DD at risk of **unnecessary segregation** in the same program.
- Case begun by DOL, Wage & Hour for violations of procedures, under 14 (c) of FLSA; **payback required @ \$7.25/hr.**
- Providence will no longer fund Birch
- State & City will provide **“robust and person-centered career development planning, transitional services, supported employment and integrated day services.”**

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.**”

Statement by ODEP A.S. Kathy Martinez

“...a collective responsibility to ensure that youth and adults living with significant disabilities have **viable options to seek and gain meaningful integrated employment opportunities and receive real wages for real jobs...publicly funded supports should, first and foremost, help people live healthy, productive lives by getting them employed in community-based jobs that use their talents & abilities & compensate them fairly for their contributions.**”

The Future is Now

- Current programs and service “models” are not sustainable
- We must change how we do our business
- States are looking at efficiency, effectiveness, equity and fairness
- We have an array of “tools” in the toolbox that we did not have in 1988.....
- Must begin with a presumption of competency and employability and no longer allow “blaming the victim”

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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**

Where Do We Go? What Do We Do?



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

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...**

Integrated Employment

-is work compensated by the company at the minimum or prevailing wage,
- Provides similar benefits to all,
- Occurs where the employee with a disability interacts or has the opportunity to interact continuously with co-workers without disabilities,
- Provides chances for advancement, and
- Is preferably engaged full time.

Costs and Outcomes of Supported and Sheltered Employment

Robert Evert Cimera, Ph.D.
Kent State University
rcimera@kent.edu

Supported v. Sheltered Employment

● Cost per Hr. Worked	SE: \$11.88
	SW: \$17.12
● Cost per Dollar Earned	SE: \$2.02
	SW: \$9.39

Individuals in both SE and SW at the same time.

Source: Cimera (2011)

Supported v. Sheltered Employment

- SE is more cost-efficient to taxpayers
SE: \$1.21 SW: \$0.83
- SE is more cost-efficient to workers
SE: \$4.20 SW: \$0.24
- *Regardless of disability or its severity, SE costs less than SW*

Using SW before SE...

No Sheltered Settings

Sheltered Settings

● Earnings	<u>\$137</u>	● Earnings	\$119
● Cost	<u>\$4,543</u>	● Cost	\$7,895

42.5% decrease in cost; 15.1% increase in earnings

Bottom Line – *The Train has left the Station.....*



"System Change"
is inevitable one way or..

- ▶ We see what is on the horizon and recognize that major reform is on the way in the states
- ▶ it is on a fast track \$\$\$\$\$\$
- ▶ Stakeholders must be prepared and engaged throughout the process

▶ APSE must lead

Employment First 2013



- **35+** states have some type of “Employment First” movement; variable impacts
 - About **2/3** of efforts are directed by state policy units or are legislatively based
 - About **1/3** of efforts are grassroots based – i.e., outsiders working to influence state policy and practice
- **23** states have official Employment First legislation and/or policies

Employment First Policies: A Closer Look



- **23 States with a policy:** AR, CA, CO, CT, DE, KS, LA, MD, MA, ME, MI, MO, ND, NJ, OH, OK, OR, PA, RI, TN, UT, VA, WA
- **8** have passed legislation (CA, DE, KS, ND, PA, VA, UT, WA); Remainder are Executive Orders, policy directives, etc.
- **9** state polices are cross-disability; remainder focused on individuals with ID/DD

THE ULTIMATE TEST OF YOUR MISSION IS YOUR BUDGET

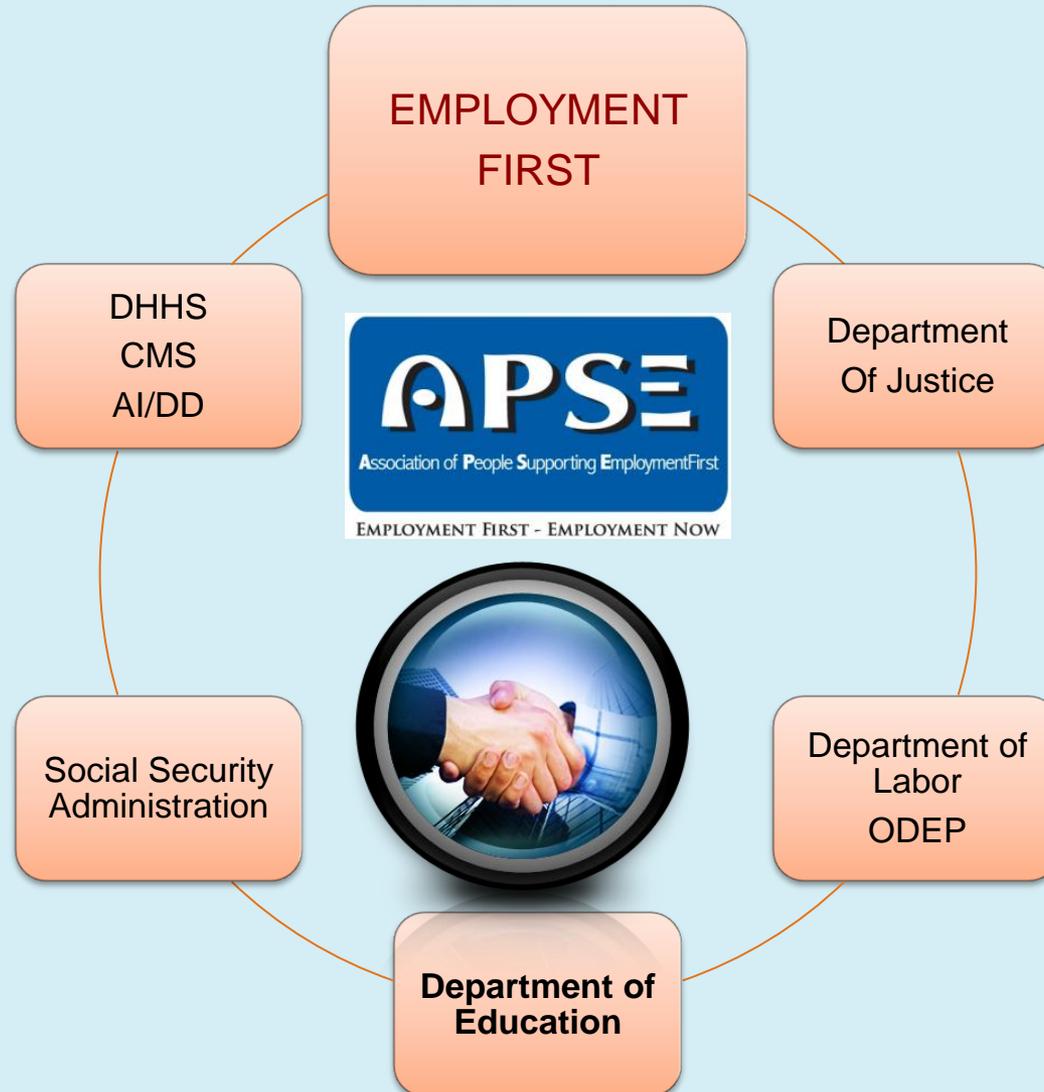
- Most words of law represent **hollow promises** for PWD and their families
- We must **lead by suiting the actions to the words**
- We need incentives and accountability for **valued outcomes** and results
- We need to talk about **ROI** now
- The process of system, organizational and culture change requires **a plan and is hard work.**

Be Passionate about the Mission

“Cowardice asks the question: is it safe?
Expediency asks the question: is it politic?
Vanity asks the question: is it popular? But
Conscience asks the question: is it right?
And there comes a time when one must take
a position that is neither safe, nor politic,
nor popular – but one must take it simply
because it is right.”

Dr. Martin Luther King, Jr.

Aligning Federal Agency Policy & Financing 1988-2013



EMPLOYMENT FIRST IMPERATIVE

“All people, regardless of severity of their disabilities, are entitled to integrated employment with the correct job match and appropriate supports.”

June 23, 2013

For Additional Information, contact

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