

# **“Suit the Actions to the Words”: The Role of the Federal Government in the Lives of People with Developmental Disabilities & Their Families<sup>of</sup>**



**Allan I. Bergman**

**Minnesota Partners in  
Policymaking**

**April 18, 2020**

# 2020: Happy Anniversary

- 6<sup>th</sup> WIOA (Workforce Innovation and Opportunity Act), 2014; Customized Employment; 18-24 years priority
- 21<sup>st</sup> Olmstead SCOTUS (Supreme Court of the United States) Decision, 1999
- 28<sup>th</sup> Rehab Act Amends, 1992; Presumption Employability
- **30<sup>th</sup> ADA (Americans with Disabilities Act), 1990**
- **34<sup>th</sup> Rehab Act Amends, 1986; Supported Employment**
- **45<sup>th</sup> IDEA (Individuals with Disabilities Education Act), 1975**
- **50<sup>th</sup> DD (Developmental Disabilities) Act, 1970**
- 55<sup>th</sup> Medicare and Medicaid, 1965
- 85<sup>th</sup> Social Security, 1935

**What has been achieved???**

# 1978 Amendments to DD (Developmental Disabilities) Act (95-602)

Functional definition of developmental disabilities as having a life-long impact in **3 or more major areas**

- Self-care
- Communication
- Learning
- Mobility
- Self-choice
- Independent living
- Economic self-sufficiency

# Developmental Disabilities Act of 1984 (Public Law 98-527)

- Added new emphasis – persons with developmental disabilities receive services to **achieve their best through living and working in the community**
- **Independence, Productivity and Integration in the Community** added as goals, with terms defined

# **LRE (Least Restrictive Environment) National Data, Fall 2018 (for 2017-18) Students with Intellectual Disability Ages 6-21 years**

> 80% of day included	17.0%
40-79% of day included	26.7%
< 40% of day included	49.2%
Separate school or Residential facility	7.6%

**No real changes over 4-5 years**

# Youth Employment Data, August 2018 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

# **Data: 8.2 Million SSI (Supplemental Security Income) Recipients; 2016 - 1**

- **4.8 million between ages 18 and 64**  
(29.5% of these beneficiaries also received some type of Social Security payment)
- Only 4.8% of the SSI beneficiaries of working age reported earned income: **19/20 ZERO earnings**

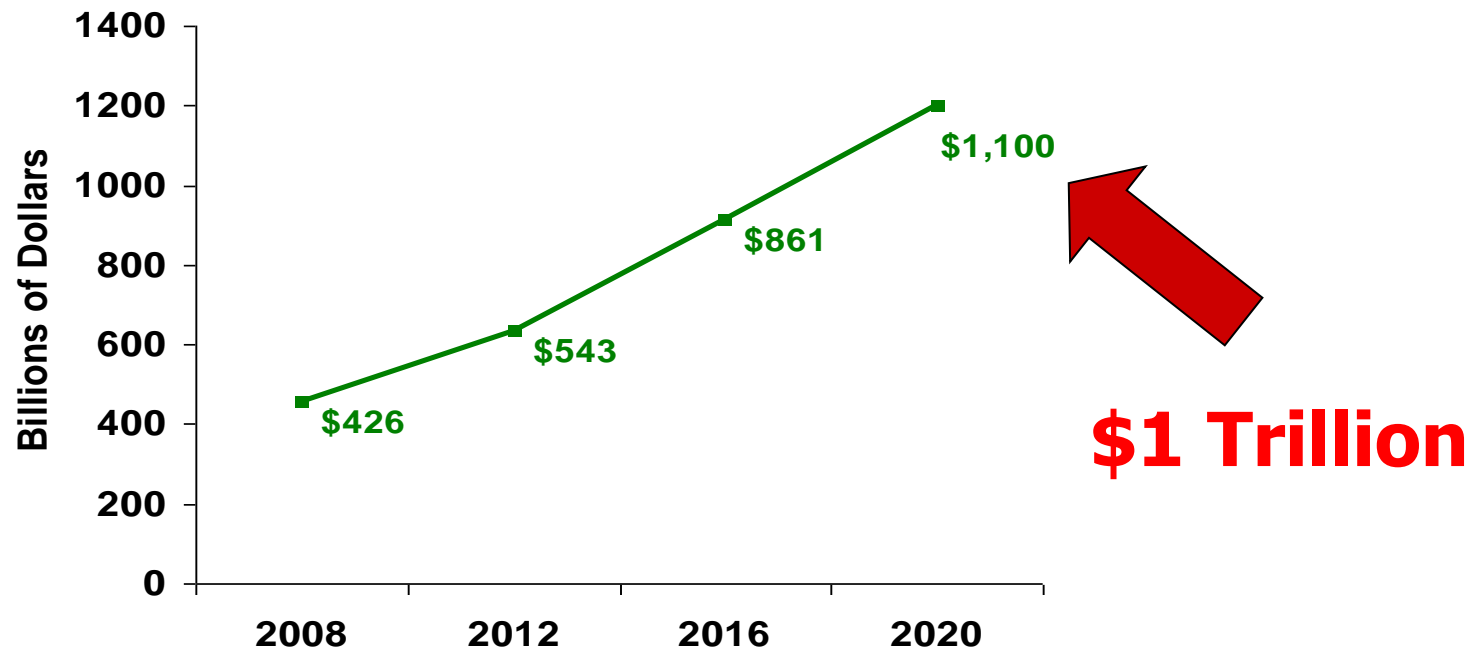
# **Data: 8.2 Million SSI (Supplemental Security Income) Recipients; 2016 - 2**

- The average earned income is **\$396/month** (for individuals who are blind, \$460/month)
- **Less than 1% leave the rolls per year and only 1/2 of those for employment**

Source: SSA

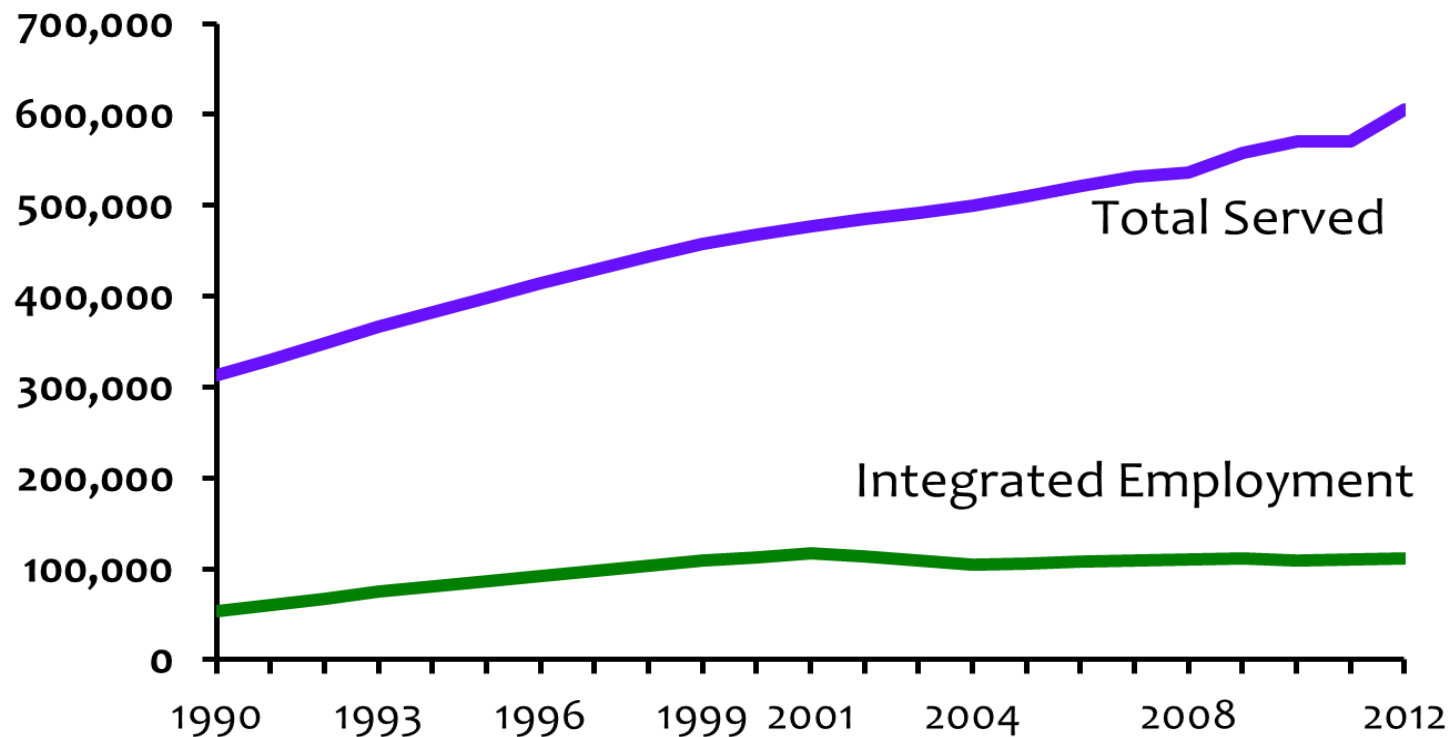


# Annual Expenditures for Federal Cash and Health Benefits for Persons With Severe Disabilities FY 2008 – FY 2020



© 2008 Institute for Economic Empowerment

# Employment and Day Supports IDD (Intellectual and Developmental Disabilities) Agencies: Nation



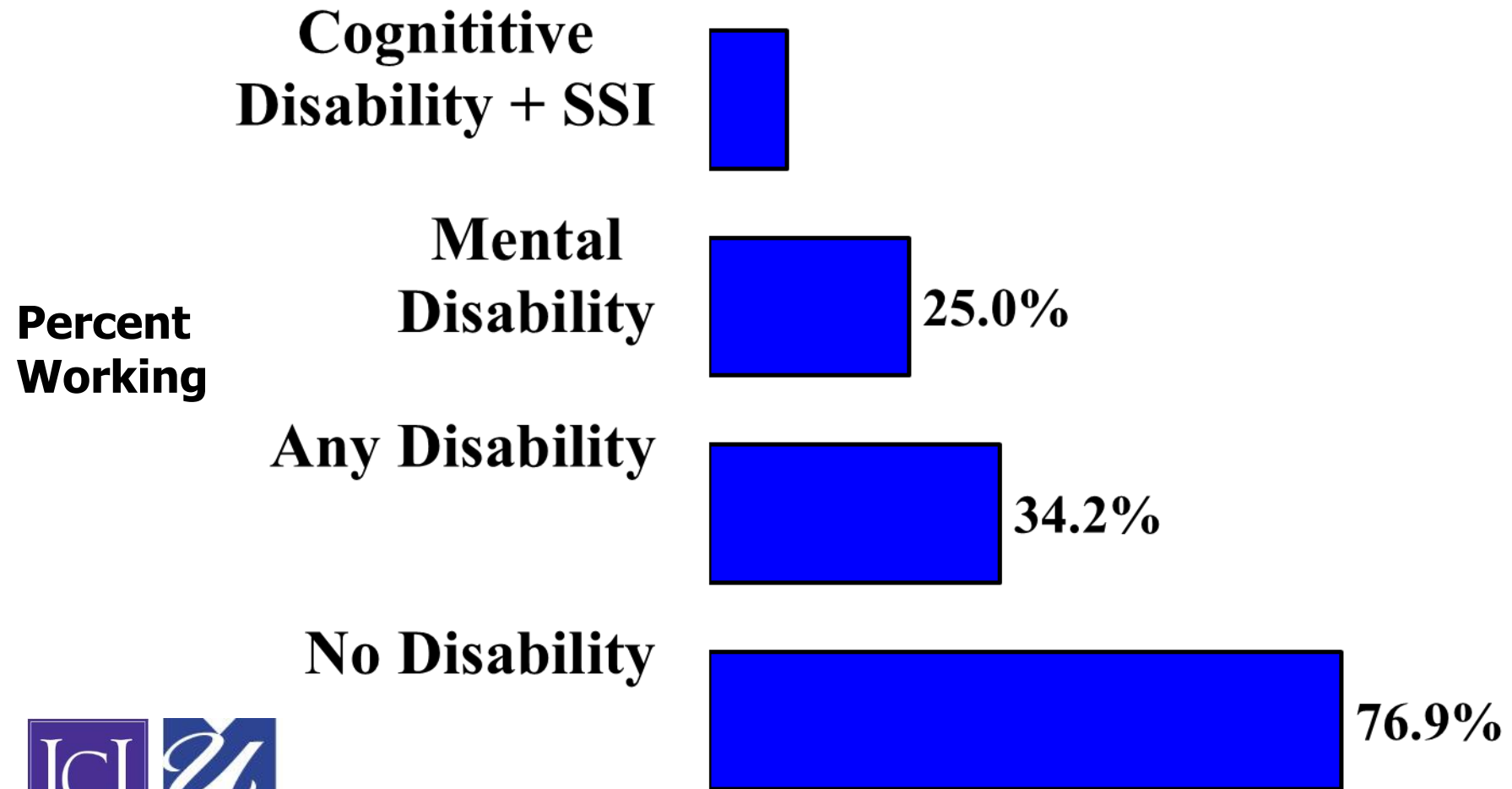
ICI National Survey of  
State IDD Agencies



ALLAN I. BERGMAN High Impact

Mission-based Consulting and Training

# Employment Participation: October 2018



American Community Survey



# Medicaid Overview: 2016 data from Congressional Budget Office; 1-2017

Over 74 million beneficiaries:

- 45 % children; 19% of expenditures
- 36% adults; 34% of expenditures
- **8% seniors; 14% of expenditures**
- **12% PWD (people with disabilities); 33% of expenditure**

**(20 % of population for 47% of \$\$ in 2016)**

Total expenditures for federal governments, FY'16:  
**\$331 Billion...**

# Poverty By The Numbers - 1

SUBPOPULATION	2009 Poverty Rate	2017 Poverty Rate
Children	20.7%	21.1%
African-American	25.8%	22.0%
Hispanic	25.3%	19.0%
Disability	25.0%	24.9%
Total U.S. Population	14.3%	12.3%

U.S. Census Bureau (September 12, 2018)

**39.7 million Americans (of 323.4 million) were living in poverty in 2017.**

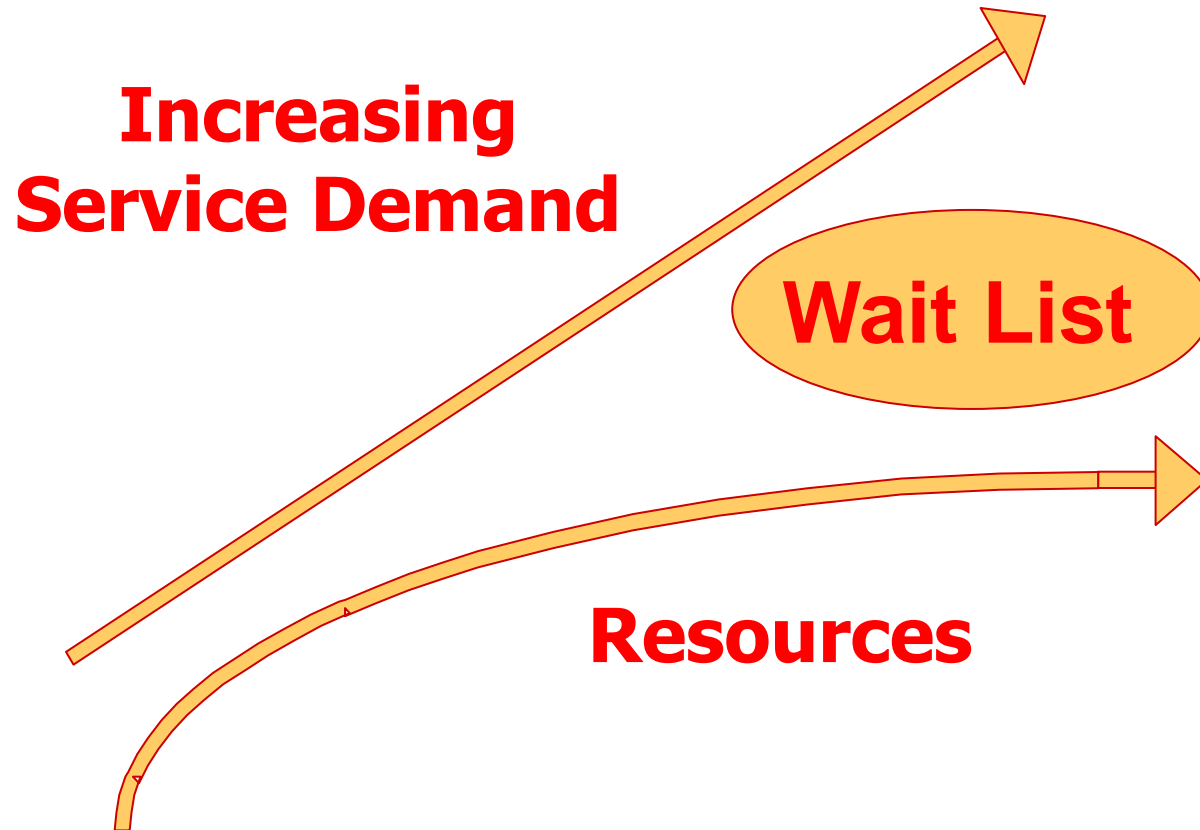
# Longer Lifespans for Individuals with Disabilities Impacts Multiple Public Funding Sources - 1

- Life expectancy **for PW/IDD** (people with disabilities/intellectual and developmental disabilities) has increased **from average of 19 years in the 30's to 66 years in 2010** (Coppus, A.M.W., 2013)

# Longer Lifespans for Individuals with Disabilities Impacts Multiple Public Funding Sources - 2

- Individuals with **Mild ID** (intellectual disabilities) have life expectancies similar to the general population of **74 years** (Coppus, 2013)
- As people with disabilities live longer, the number of years that they require a variety of publicly funded supports.

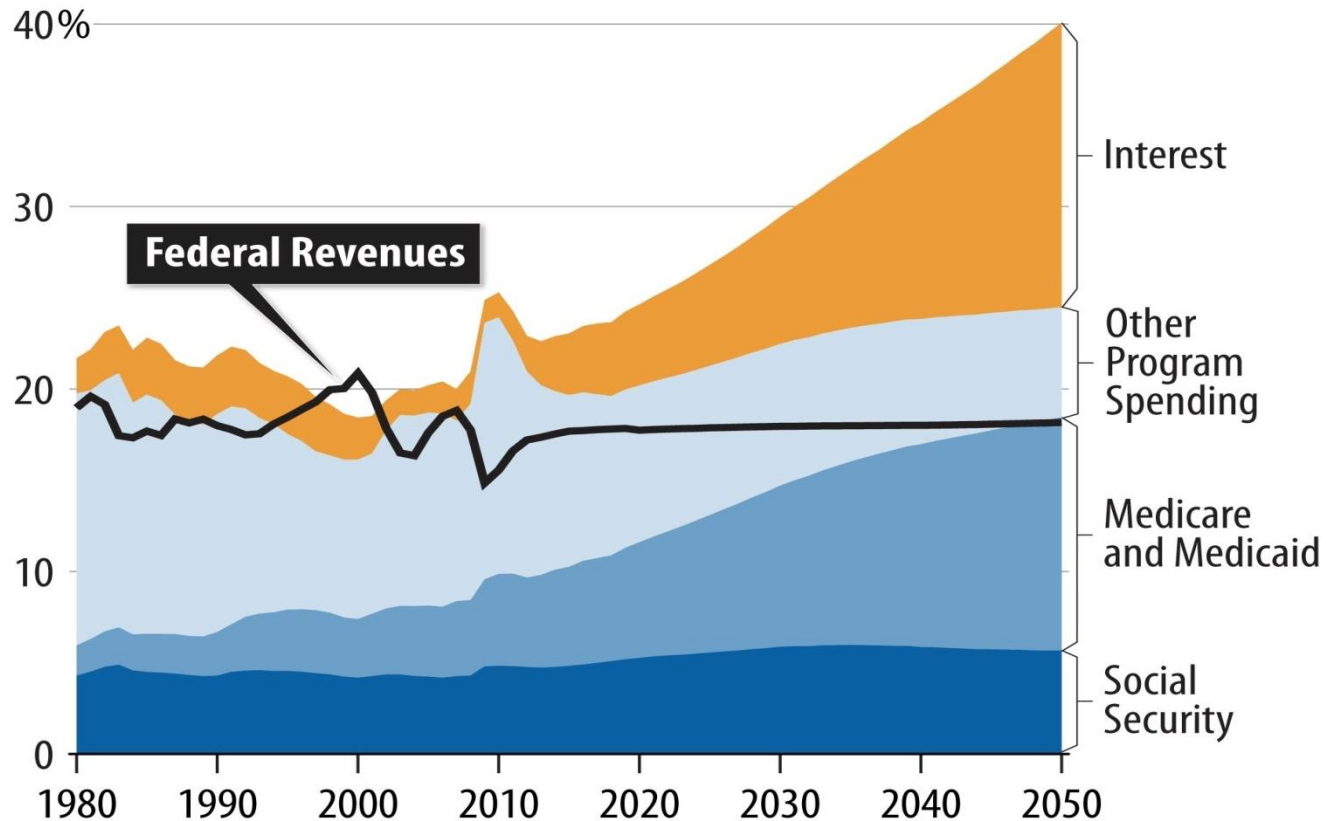
# We Face a Big Problem...





# Current Policies Are Not Fiscally Sustainable

Spending and Revenues as a Share of GDP Under Current Policies



Source: CBPP (Center on Budget and Policy Priorities) projections based on CBO (Congressional Budget Office) data.

# 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”

# 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.”

# Changed Thinking Leads to Changed Public Policy - 1

From Assuming that PWD (people with disabilities):

- Need to be taken care of
- Can't work
- Need Constant Supervision
- Are a burden to families



# Changed Thinking Leads to Changed Public Policy - 2

To Discovering that PWD (people with disabilities):

- Can be self-sufficient
- Can work and pay taxes
- Don't need constant supervision
- Are valued family members

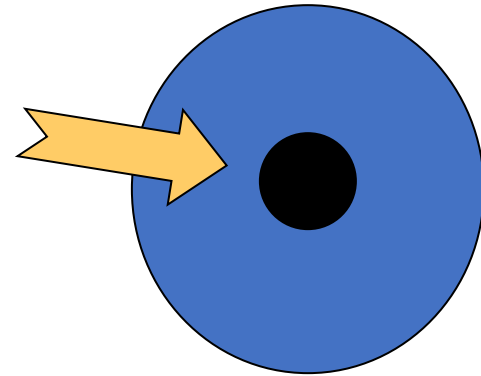


## Key Point:

People need support that **matches their needs.**

# 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.**

# **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)

# Collaboration to Promote Self-Determination (CPSD): Values and Principles for Policy Framework

## Core Values:

- **Equality**
- Choice
- **Competence**
- Community
- Home
- **Work**
- **Dignity of Risk**
- Equity

# Partners in Policymaking Core Values - 1

1. People with disabilities are **PEOPLE FIRST**. They are not “the handicapped” or “the disabled”. Using **People First** Language is a must – no labels!
2. People with disabilities need **REAL FRIENDSHIPS**, not just relationships with paid staff.
3. People with disabilities are entitled to the full meaning of the First Amendment right to free speech. The **ABILITY TO COMMUNICATE**, in whatever form, must be available to every person with a disability.

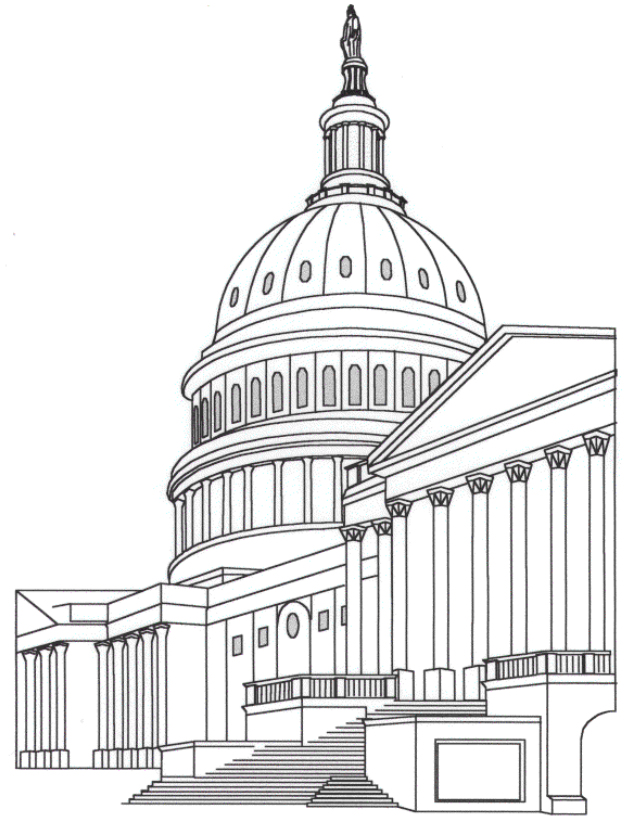
# Partners in Policymaking Core Values – 2

4. People with disabilities must be able to enjoy **FULL MOBILITY AND ACCESSIBILITY** that allows active participation in community life.
5. People with disabilities must be assured **CONTINUITY** in their lives through families and neighborhood connections.
6. People with disabilities must be treated with **RESPECT AND DIGNITY.**
7. People with disabilities need to be IN **POSITIONS TO NEGOTIATE** to have their wants and needs met.

# Partners in Policymaking Core Values - 3

8. People with disabilities must be able to exercise **INFORMED CHOICE** in all areas of their lives.
9. People with disabilities must be able to live in the **HOMES** of their choice with the supports they need.
10. People with disabilities must be able to enjoy the benefits of **TRUE PRODUCTIVITY** through employment and/or contributions as members of their communities.

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





# **"Suit the Actions to the Words"**

## **"Life is not a Program"**

### **A Person is Not a Diagnostic Label**

# Transformation

Moving from Paper Compliance and  
Health, Life Safety to  
**Accountability for Mission Driven  
Valued Outcomes for a Good Life  
as a Valued  
Member of the Community**

# The Power of Language - 1

- Words create images
- Values are formed early in life
- Stereotypes, stigma and prejudice are learned behaviors
- Use terms of dignity and respect to promote citizenship

# The Power of Language - 2

- Watch your language...pity and charity
  - Handicapped
  - Wheelchair Bound
  - Most Vulnerable
  - Special Needs
  - Meltdown
  - High Functioning - Low Functioning
  - Mental age of a ..... year old
  - Crazy, Lunatic, Insane, Psycho

# Purpose of DD (Developmental Disabilities) 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 (Developmental Disabilities) 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...**”

# DD (Developmental Disabilities) Act: Inclusion

Enjoy full access to and active participation in the same community activities and types of **employment** as individuals without disabilities; and,

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.**

# Presumption of Employability and 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



# Individuals with Disabilities Education Act (IDEA)

“to ensure that **all children with disabilities** have available to them a free appropriate public education that emphasizes special education and related services designed to meet their unique needs **and prepare them for further education, employment, and independent living.**”

20 U.S.C. 1400(d)(1)(A)

# IDEA Findings, 2004

“(4) However, the implementation of this chapter has been **impeded by low expectations and an insufficient focus on applying replicable research on proven methods of teaching and learning for children with disabilities.**

(5) Almost **30 years of research** and experience has demonstrated that the education of children with disabilities can be made more effective by-

# IDEA Findings – 2

“(A) **having high expectations for such children** and ensuring their access to the general education curriculum in the regular classroom, to the maximum extent possible, in order to –

(i) meet developmental goals and, to the maximum extent possible, the challenging expectations that have been established for all children; and

(ii) **be prepared to lead productive and independent adult lives**, to the maximum extent possible: ....”

# Introduction to Transition

Transition planning is the student's road map to life after high school...



**Transition is a journey ... NOT a place!**

What will the student achieve and  
how will he/she get there?

# IDEA Transition Amendments of 2004 (identical in Rehabilitation Act) - 1

“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 Amendments of 2004 (identical in Rehabilitation Act) - 2

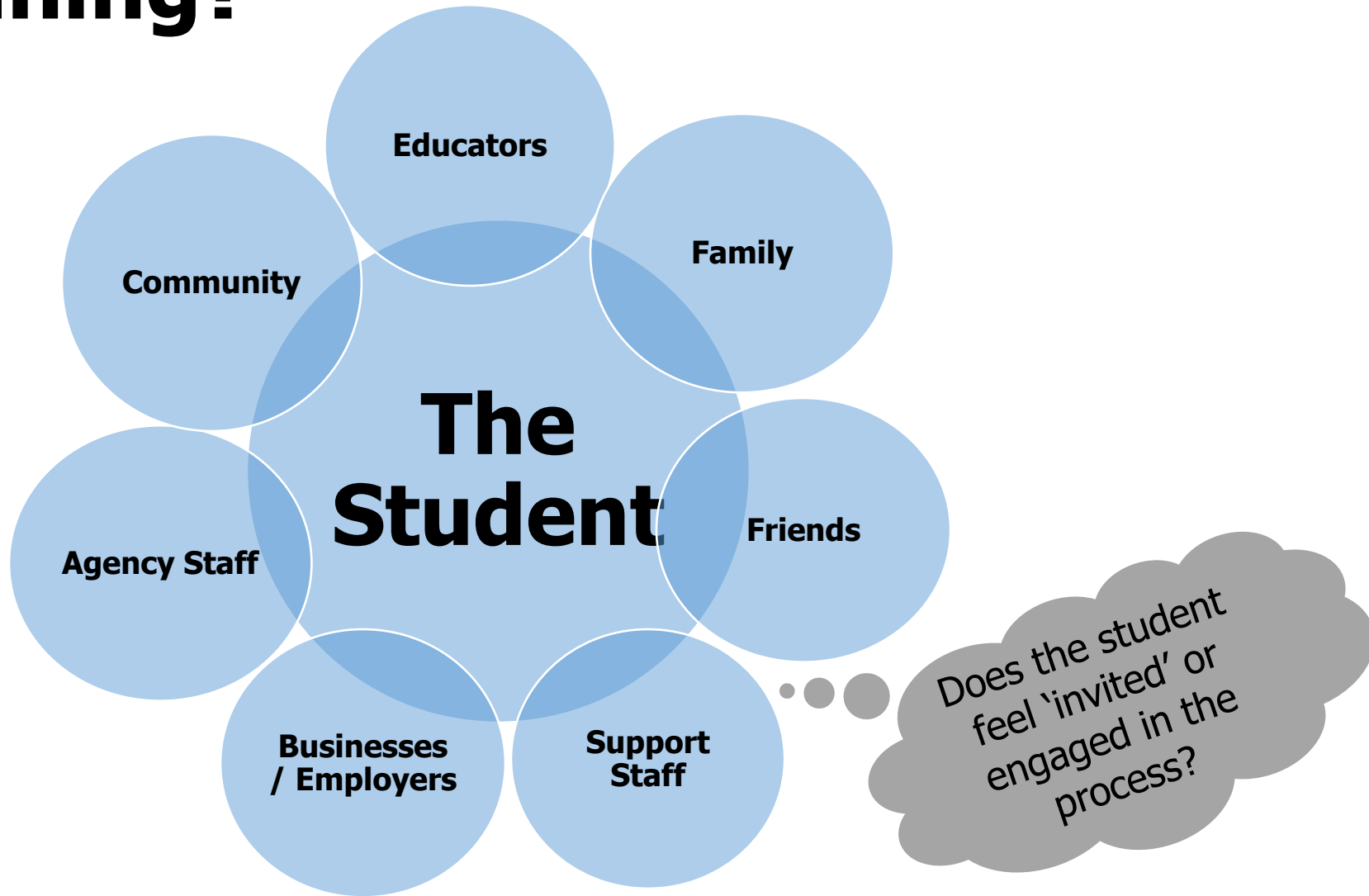
postsecondary education, **vocational education, integrated employment (including supported employment)** continuing and adult education, adult services, **independent living, or community participation;**

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

# IDEA Transition Amendments of 2004 (identical in Rehabilitation Act) - 3

- 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.**"
- Office of Special Education Programs (OSEP) beginning to move towards monitoring for outcomes rather than compliance with paper; a slow process

# Who is Involved in Transition Planning?





# #1 Factor Predicting Post School Career Success

## WORK EXPERIENCE DURING SCHOOL

- Optimum Career Preparation includes:
  - Youth empowerment
  - Family involvement and supports
  - Academic preparation paired with work experience
  - Connections to ancillary services
  - **WORK**

Richard Luecking, Ed.D.

# **Expectations Matter...A Lot!!! - 1**

**“The best predictor of post school outcomes are the following:**

**Parental Expectations**  
**Teachers’ Expectations**

Expectations change the path of what experiences are made available and what is taught to the child/student....”

# **Expectations Matter...A Lot!!! - 2**

**“Changing introductions from deficits and what cannot do, to strengths, preferences, interests, gifts & contributions”**

**Relationships Matter.  
Location Matters.**

Erik Carter, Ph.D. Vanderbilt University, December 3, 2015

# **Andrew F. v. Douglas County School District; SCOTUS (Supreme Court of the United States), March 21, 2017 - 1**

- **Unanimous 8-0 decision regarding educational benefit under IDEA**
- Student with autism; parents pulled from public schools in 5<sup>th</sup> grade and placed in private school; had lost case with state dept. of education and with 10<sup>th</sup> Circuit, Federal District Court
- Chief Justice Roberts wrote the opinion

# Andrew F. v. Douglas County School District; SCOTUS (Supreme Court of the United States), March 21, 2017 - 2

- “When all is said and done, a student offered an education program providing a ‘merely more than deminimis’ progress from year to year can hardly be said to have been offered an education at all.”
- “The IDEA demands more. **It requires an educational program reasonably calculated to enable a child to make progress appropriate in light of the child’s circumstances.**”

# 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 (Developmental Disabilities) Act; IDEA (Individuals with Disabilities Education Act); and Rehabilitation Act

# State Vocational Rehabilitation Program Policy - 1

“(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.

# State Vocational Rehabilitation Program Policy - 2

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

Rehabilitation Act, 1992



# Rehabilitation Act's Presumption of Benefit

“(2) Presumption of benefit

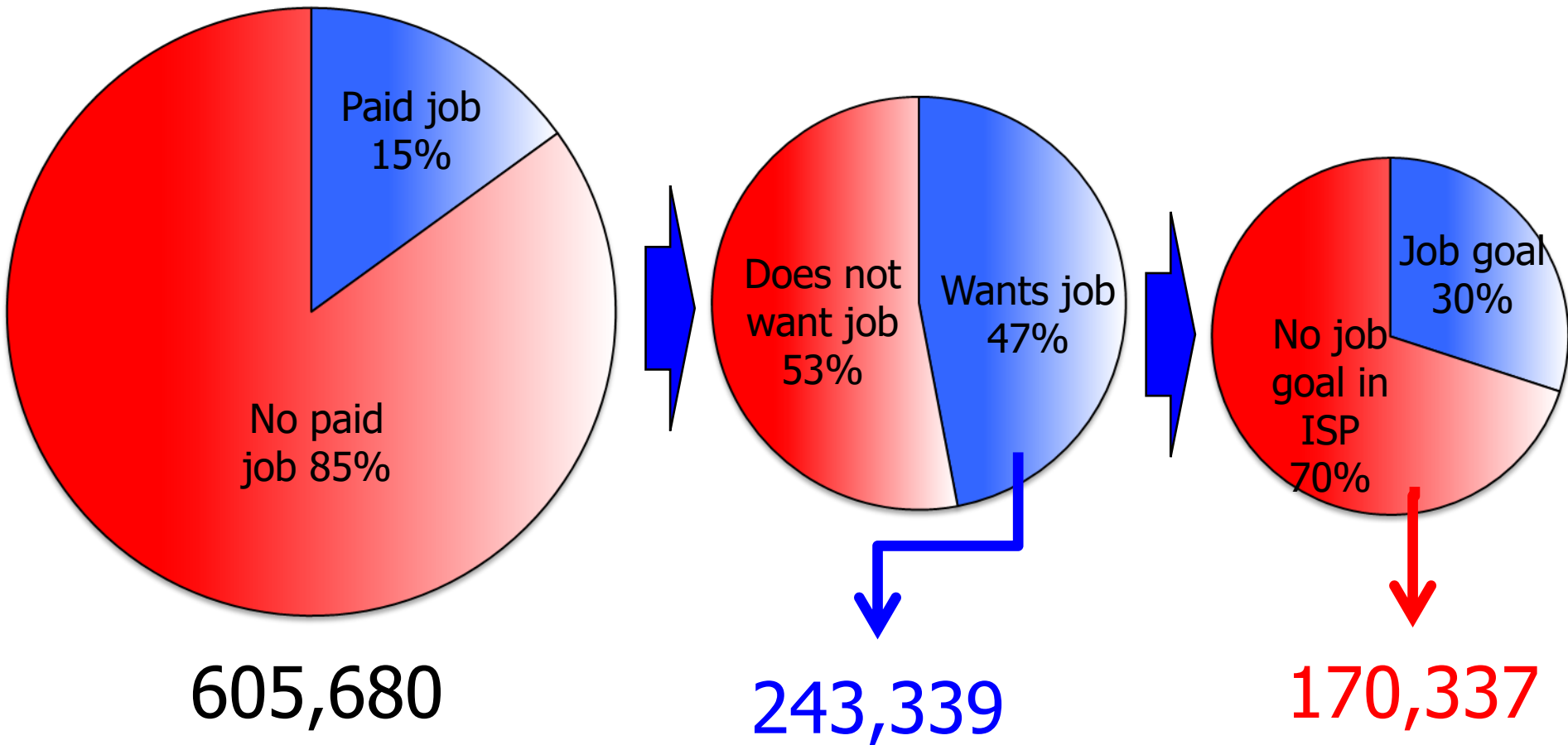
(A) Demonstration: For purposes of this section, an individual shall be presumed to be an individual that can benefit in terms of an employment outcome from V.R. services, ...unless the designated State unit involved **can demonstrate by clear and convincing evidence** that such individual is incapable of benefiting in terms of an employment outcome from V.R. service due to the severity of the disability of the individual.

# Vocational Rehabilitation Employment Outcome, 2001

“Employment outcome means...entering or retaining full-time or, if appropriate, part –time competitive employment as defined in 361.5(b) (11), in the **integrated labor market**, supported employment, or **any other type of employment in an integrated setting**, including self-employment, telecommuting or business ownership, that is **consistent with an individual’s strengths, resources, priorities, concerns, abilities, capabilities, interests & informed choice.**”

34CFR361.5(b)1

# Choice



National Core Indicators Project 2012-2013

# Rehabilitation Services Administration

- **May 6, 2014**; Carol Dobak, Chief, VR Program Unit
- Transition Planning & Services Provided Through the State VR Services Program
- **“...all students with disabilities, including those with significant and the most significant disabilities, are presumed to be eligible for VR services, unless the VR agency concludes , based on clear and convincing evidence..... an employment outcome (integrated employment)”**

Technical Assistance Circular 14-03

# “Significant Disability” in Rehabilitation Act - 1

- Has a “severe physical or mental impairment that **seriously limits one or more functional capacities (such as mobility, communication, self-care, self-direction, interpersonal skills, work tolerance or work skills) in terms of an employment outcome;**”
- Can be expected to require “multiple vocational rehabilitation services over an extended period of time;” and,

# “Significant Disability” in Rehabilitation Act - 2

- Has one or more physical or mental disabilities (e.g. autism, blindness, cerebral palsy, deafness, head injury, intellectual disability) or a combination of disabilities assessed to cause comparable substantial functional limitation.
- **Recipients of SSDI or SSI are presumed to be eligible for VR services as individuals with a significant disability.**

# “Significant Disability” in Rehabilitation Act - 3

- “ ‘**Clear and convincing evidence**’ is defined, in part, as **the highest standard in our civil system of law** whereby VR agencies must have a high degree of certainty before concluding that an individual is incapable of benefiting from services in terms of an employment outcome. The term ‘**clear**’ means **unequivocal**.”

# **The Impact of Early Transition Services on Employment Outcomes for Youth with Disabilities**

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# Do Transition Services Matter? - 1

## Rates of Employment – ASD (Autism Spectrum Disorder)

### By Age 14

2006	80.8%*
2007	77.9%*
2008	75.2%*
2009	69.1%*

### By Age 16

58.9%
60.4%
52.4%
52.2%

# Do Transition Services Matter? - 2

## Rates of Employment – ID (Intellectual Disabilities)

By Age 14		By Age 16
2006	74.3%*	57.8%
2007	61.7%*	57.0%
2008	69.7%*	53.8%
2009	42.8%*	28.2%

7,520 Transition-Age Students with Intellectual Disabilities (Source: Cimera et al., in prep)

# 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.



# 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

# Workforce Innovation and Opportunity Act (WIOA) - 1

- **July 22, 2014**; Public Law 113-128
- **Bipartisan; 95-3 Senate and 415-6 House**
- Major changes in Workforce Investment Act and Vocational Rehabilitation Act
- Joint Performance Measures for the State VR (Vocational Rehabilitation) agency and the State Workforce Agency with one integrated plan
- Emphasis on Transition and Youth with **most significant disabilities for Supported Employment**
- Customized Employment defined in law

# Workforce Innovation and Opportunity Act (WIOA) - 2

- **Pre-employment transition services** are defined as, and **15% of money must be used for:**
  - Job exploration counseling & support
  - Work-based learning experiences
  - Counseling on post-secondary opportunities
  - *Workplace readiness training.....*
  - Training on self-advocacy

**Each local VR (Vocational Rehabilitation) office must engage** in pre-employment transition coordination with all local schools and workforce system

# Workforce Innovation and Opportunity Act (WIOA) - 3

- **Supported Employment in VR (Vocational Rehabilitation) Act:**
  - Definition modified to clarify that **Supported Employment 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)** and they may receive supports for up to 4 years.

# Why Target Transition, Ages 14 –24? - 1

- **Only 26%** of students with intellectual and multiple disabilities were **“employed” two years after high school graduation** (Carter, 2012);
- 400,000 youth with disabilities exit our nation’s schools every year (National Center for Education Statistics); and,



# Why Target Transition, Ages 14 –24? - 2

- Of those students, 40,000 – ID (intellectual disabilities); 15,000 – autism; 9,000 - multiple disabilities; and, 2,500 – TBI (traumatic brain injury).
- **462,000 SSI (Supplemental Security Income) recipients between ages of 14 and 17 in 2014**

# **Costs and Outcomes of Supported Work and Sheltered Employment**

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# FUNDING: Money Matters...and Drives Practice



# What are the Costs of Supported Employment (SE) and Sheltered Work (SW)?

• Cumulative Costs	SE: \$18, 813
	SW: \$46, 855
• Cost per Hour 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)

# What is the Return on Investment (ROI)?

- Is Supported Employment more cost-efficient to workers?

SE: \$4.20      SW: \$0.24

- Is Supported Employment more cost-efficient to taxpayers?

SE: \$1.21      SW: \$0.83

Regardless of disability or its severity, Supported Employment has a better Return on Investment than Sheltered Work.

Cimera, 2010

# Are Sheltered Workshops “Value Added” for People with Intellectual and Developmental Disabilities?

## No Sheltered Settings

Earnings                      \$137

Cost                            \$4,543

## Sheltered Settings

Earnings                      \$119

Cost                            \$7,895

9,808 Supported Employees with Intellectual Disabilities

42.5% decrease in cost; 15.1% increase in earnings (Source: Cimeria, 2011)

# Are Sheltered Workshops “Value Added” for People with Autism Spectrum Disorder?

## No Sheltered Settings

Earnings                      \$191

Cost                            \$4,212

## Sheltered Settings

Earnings                      \$129

Cost                            \$8,346

430 Supported Employees with Autism Spectrum Disorder

48% increase in earnings; 49.6% decrease in costs (Source: Cimeria, 2012)

# Workforce Innovation and Opportunity Act (WIOA) - 1

- **Requires** that the State Vocational Rehabilitation Agency have a **Formal Cooperative Agreement** with the State Medicaid Agency
- **Requires** that the State Vocational Rehabilitation Agency have a **Formal Cooperative Agreement** with the agencies responsible for providing long term services and supports for people with disabilities; intellectual and developmental disabilities; mental health; physical; sensory;



# Workforce Innovation and Opportunity Act (WIOA) - 2

- **Must define the respective roles** in the provision of Vocational Rehabilitation services, including extended services

# 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:

# Vision 2020...

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

Plato

# **The “Flexible Strategies” of Customized Employment in WIOA (Workforce Innovation and Opportunity Act) - 1**

**(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;**

# **The “Flexible Strategies” of Customized Employment in WIOA (Workforce Innovation and Opportunity Act) - 2**

- (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

# **The “Flexible Strategies” of Customized Employment in WIOA (Workforce Innovation and Opportunity Act) - 3**

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

Marc Gold & Associates ©

# Competitive Integrated Employment - 1

“...means **work that is performed on a full-time or part-time basis, including self employment,**

(A) for which an individual is compensated at a rate that shall be not less than the higher of FLSA (Fair Labor Standards Act) or the rate specified in the applicable State or local minimum wage law; and, it **not less than the customary rate paid by the employer for the same of similar work performed by other employees** who are not individuals with disabilities and who are similarly

# Competitive Integrated Employment - 2

**situated in similar occupations by the same employer** and who have similar training, experience and skills, or in the case of an individual who is self-employed, yields an income that is comparable to the income received by other individuals who are not individuals with disabilities, and who are self-employed in similar operations or similar tasks and who have similar training, experience & skills; and is eligible for the level of benefits provided to other employees;



# Competitive Integrated Employment - 3

**(B) that is at a location where the employee interacts with other persons who are not individuals with disabilities – not including supervisory personnel or individuals who are providing services to such employee – to the same extent that individuals who are not individuals with disabilities who are in comparable positions interact with other persons; and**

# Competitive Integrated Employment - 4

(C) that as appropriate, **presents opportunities for advancement that are similar to those for other employees** who are not individuals with disabilities and who have similar positions.”

(Section 7, U.S.C. 705 as amended in WIOA, July 2014)

# **CMS (Centers for Medicare and Medicaid) 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.**”

# Why is Employment Becoming Part of Medicaid's Focus? - 1

## **CMS's (Center for Medicaid and Medicare Services) Commitment:**

- 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.

# Why is Employment Becoming Part of Medicaid's Focus? - 2

- 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.

# Why is Employment Becoming Part of Medicaid's Focus? - 3

- **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

# The Impact of Employment on Medicaid Utilization and Costs

State of Iowa, calendar year 2011, individuals on SSI (Supplemental Security Income) 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

Calendar year 2011, 129,369 MEPD (Medicaid Buy-In) member months produced **\$20,828,409 in Medicaid claims savings.**

Stated another way, the total claims paid for 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 (Supplemental Security Income) related Medicaid beneficiaries.**



# Employment First



“Employment is nature’s best physician and is essential to human happiness.”

Galen, Greek physician

# 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**

# Where is the Future?



# Vision...

“The only thing that is constant  
is change.”

Heraclitis

# **ADA (Americans with Disabilities Act) Findings Public Law 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 resulting from dependency and nonproductivity.**

# Goals of the Americans with Disabilities Act (ADA) 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 (Americans with Disabilities Act) 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. and 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 and institutionalization**



# The Role of the ADA (Americans with Disabilities Act) and Olmstead

- Cannot be ignored with current DOJ (Department of Justice)
- **June 22, 2011** was 12<sup>th</sup> 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 (Department of Justice) on the ADA (Americans with Disabilities Act) (June 22, 2011) - 1**

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

# **DOJ (Department of Justice) on the ADA (Americans with Disabilities Act) (June 22, 2011) - 2**

**Segregated settings** include, but are not limited to:

**(1) congregate settings populated  
exclusively or primarily with individuals  
with disabilities;**

# **DOJ (Department of Justice) on the ADA (Americans with Disabilities Act) (June 22, 2011) - 3**

**Segregated settings** include, but are not limited to:

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

# United States v Rhode Island and City of Providence; 6/13/13 - 1

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

# United States v Rhode Island and City of Providence; 6/13/13 - 2

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

# United States v Rhode Island and City of Providence; 6/13/13 - 3

- Transition Finding: **about 5% of youth with I/DD** (intellectual and developmental disabilities) **leaving school between 2010-2012 transitioned into integrated employment**
- Rhode Island Department of Education 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**

# **United States v Rhode Island and City of Providence; 6/13/13 - 4**

- **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 and non-work hours will total 40 hours/week.**



# 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."

# Department of Justice -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, Department of Justice – Oregon - 1

- 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 (intellectual and developmental disabilities) to work in integrated employment settings for all persons in sheltered workshops who want them;

# Key Provisions, Department of Justice – Oregon - 2

- Ensures that **4,900 youth will receive Employment Services** and that half of those who do receive Employment services will **get an Individual Employment Plan from VR** (Vocational Rehabilitation) **that should lead to competitive employment;**
- Requires that the State issue policies and promote the expectation that all individuals with I/DD (intellectual and developmental disabilities) **work an average of 20 hours/week, consistent with their choice and abilities;**

# Key Provisions, Department of Justice – Oregon - 3

- 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**.

# Statement of Eve Hill, Senior Counselor, to Assistant Attorney General for Civil Rights

“The Supreme Court made clear over a decade ago that **unnecessary segregation of PWD** (people with disabilities) **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 (Training Thru Placement) and Birch is all too **common when states allow low expectations to shape their disability programs.**”

# Employment First as a Civil Right

**“ Access to employment is the most vital civil right because in so many ways, it opens doors to all of the other civil and citizenship rights that most Americans take for granted. This is business we cannot leave unfinished; that we literally cannot afford – morally or financially – to ignore.”**

Patti Killingsworth, Asst. Commissioner & Chief of LTSS,  
TennCare; October 2, 2017; Congressional Briefing

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

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



# Department of Justice on Employment

**“Affirmative steps** may include:”

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

# Employment First: Why Employment First Matters to Self Advocates

“Employment First means that above all else, people with disabilities, people of all abilities, **need to have a purpose in life.** We all have amazing potential to pursue a purpose in life **if given the opportunity.** Employment First is about making that **your top-tier goal in life and really striving to get a job and be a part of your community.**”

John Fenley, People First of New Hampshire; SABE, 2018

# The Administration for Community Living (ACL)

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.**

# Supported Living: Key Principles - 1

- 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.

# **CMS (Centers for Medicare and Medicaid) Issues Final Rules on HCBS (Home and Community Based Services) and the Definition of Community: 1-16-14 - 1**

- Applies to 1915 (c) HCBS waivers; 1915 (I) State Plan Amendment (SPA) for HCBS; and, 1915 (k) Community First Choice SPA
- **Extensive criteria for the development of a “person centered plan”**
- **“Informed choice”**



# CMS (Centers for Medicare and Medicaid) Issues Final Rules on HCBS (Home and Community Based Services) and the Definition of Community: 1-16-14 - 2

- “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 (Centers for Medicare and Medicaid) Issues Final Rules on HCBS (Home and Community Based Services) and the Definition of Community: 1-16-14 - 3**

...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.”

# **CMS (Centers for Medicare and Medicaid) Issues Final Rules on HCBS (Home and Community Based Services) and the Definition of Community: 1-16-14 - 4**

**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 (Centers for Medicare and Medicaid) Issues Final Rules on HCBS (Home and Community Based Services) and the Definition of Community: 1-16-14 - 5**

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

# **CMS (Centers for Medicare and Medicaid) Issues Final Rules on HCBS (Home and Community Based Services) and the Definition of Community: 1-16-14 - 6**

(ii) The setting is selected by the individual from among setting options including...

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

# Qualities of an HCBS (Home and Community Based Services) Settings - 1

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

# Qualities of an HCBS (Home and Community Based Services) Settings - 2

5. There must be opportunities to review, update and change preferences and choices at least annually.
6. There must be sufficient supports to assist an individual in **making informed choices and exercising autonomy to the greatest extent possible.**

# Qualities of an HCBS (Home and Community Based Services) Settings - 3

7. There must be **opportunities for the individual to negotiate work schedules, break times, benefits, etc. same as people without disabilities.**
8. **Tasks and activities are comparable to tasks and activities for people who do not have disabilities.**



# Planned Activities in the Home Community in All Life's Domains - 1

- **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**

# **Planned Activities in the Home Community in All Life's Domains - 2**

- **Joining community organizations**
- **Recreation – swimming, bowling, dancing, movies**
- **Social Life – getting together with family and friends**
- **Peer support groups**

# **Planned Activities in the Home Community in All Life's Domains - 3**

- **Shopping**
- **Maintain health and wellness – walking; gym membership; diet groups; going to medical appointments**
- **Personal care – hairstyling, having nails done**
- **Maintaining home; maintenance and improvement; cleaning; laundry**

# Planned Activities in the Home Community in All Life's Domains - 4

- Caring for others; relatives or friends
- **Spirituality: worship; meditation; yoga classes**
- **Hobbies: Pet care – walking the dog; gardening, painting; photography**
- Going on vacation

# Person-Centered Service Plans

Final rule includes changes to the requirements regarding person-centered service plans for HCBS (Home and Community Based Services) 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**



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

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

# 1915(c) and 1915(i) Home and Community-Based Services Person Centered Service Plans - 1

- **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

# **1915(c) and 1915(i) Home and Community-Based Services Person Centered Service Plans - 2**

- **Identifies the strengths, preferences, needs (clinical and support), and desired outcomes of the individual**
- May include whether and what services are self-directed



# **1915(c) and 1915(i) Home and Community-Based Services Person-Centered Service Plans - 3**

- 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 (Home and Community Based Services) Benefit – Self-Directed Services - 1**

- 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

# **1915(i) State Plan HCBS (Home and Community Based Services) Benefit – Self-Directed Services - 2**

- Person-centered service plan specifies employer authority, limits to authority, and parties responsible for functions outside individual authority

# **Achieving a Better Life Experience**

## **Act: ABLE Act**

**Goal: To help people with disabilities and their families save to meet their long-term ongoing support needs**

- Public Law 113-295; December 19, 2014
- Passed with huge bipartisan support
- Parallels the Section 529 tax free qualified college tuition savings accounts
- Each state must act to make this available
- Up to \$100,000 and no loss of SSI (Supplemental Security Income) or Medicaid benefits
- Regulations expected mid June 2015

# Relationship between ABLE Accounts and SSI (Supplemental Security Income) and Medicaid

- SSI cash payments suspended at \$100,000 in account; SSI eligibility remains intact
- SSI cash payments re-start when account drops below \$100,000 (no re-application)
- Medicaid payback provision included
  - At death (or if disability ceases), funds left in account pay back Medicaid (up to amounts paid on individual's behalf during period account was held).

# 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 (Return on Investment)?  
A return on investment to the government and, thus, the taxpayer?

# 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 (Developmental Disabilities) Act, IDEA (Individuals with Disabilities Education Act), WIOA (Workforce Innovation and Opportunity Act), and the ADA (Americans with Disabilities Act) that we espouse?

# The Importance of Vision

Vision without action is merely a dream;  
action without vision just passes the time;  
**vision with action  
can change the world.**

Joel Arthur Barker



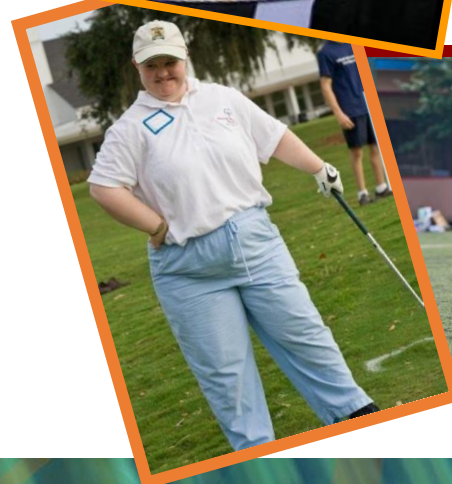
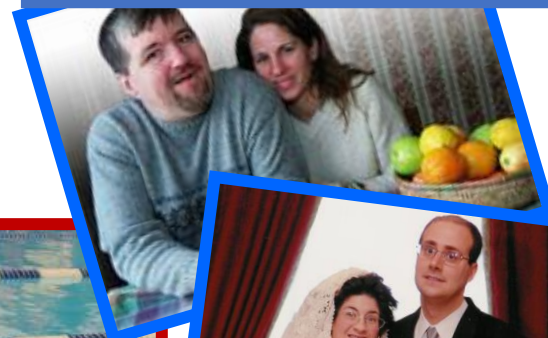
# The Essence of Strategic Planning

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

Peter Drucker

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# 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

# 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.**



# 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**

# “Equal Justice Under the Law”



# For Additional Information

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