Federal Update: Challenges and Opportunities; Keeping Your Compass on "True North" **Consumer Advisory Council, CT. UCEDD** A. J. Pappanikou Center **Farmington, Connecticut** June 13, 2019 Allan I. Bergman

2019: Happy Anniversary

- Olmstead Supreme Court Decision
- 29th ADA, 1990
- **44**th **IDEA, 1975**
- **49**th **DD Act, 1970**
- 49th CRIPA, 1970
- 54th Medicare and Medicaid, 1965
- 84th Social Security, 1935

What has been achieved???

LRE National Data, Fall 2016 (for Fall 2014) Students with Intellectual Disability Ages 6-21 years

- > 80% of day included
- 40-79% of day included
- < 40% of day includedSeparate school or

Residential facility

16.9% 26.3% 49.2%

7.6%

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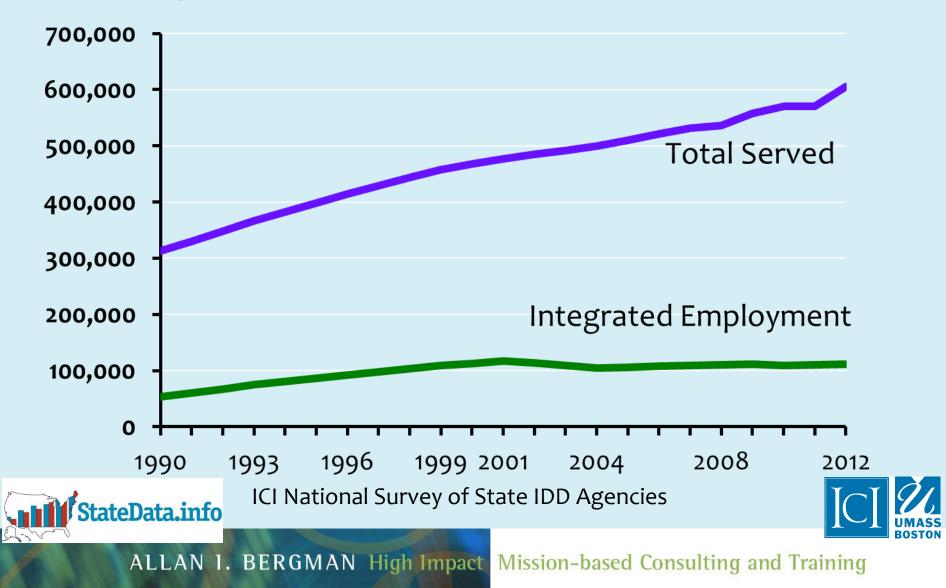
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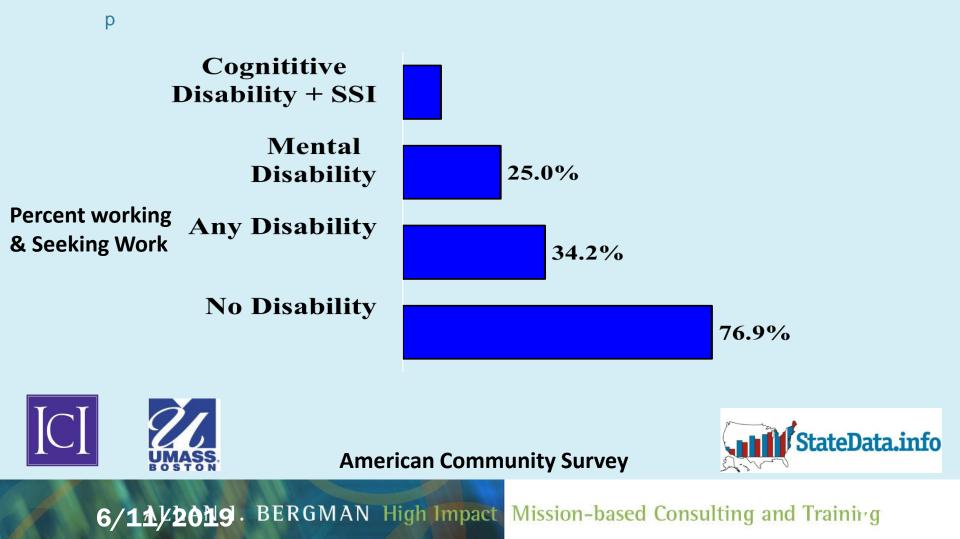
No real changes over 4-5 years

- Data: 8.2 M.SSI Recipients;2016
 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: <u>19/20 ZERO earnings</u>
- The average earned income is <u>\$396/mo</u>.
 (for individuals who are blind, \$460/mo.)
- Less than 1% leave the rolls per year and only ½ of those for employment

Employment and Day Supports IDD Agencies: Nation



Employment participation Oct. 2018



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; 33% of expenditures (20 % of population for 47% of \$\$ in 2016)

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

Poverty By The Numbers

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%

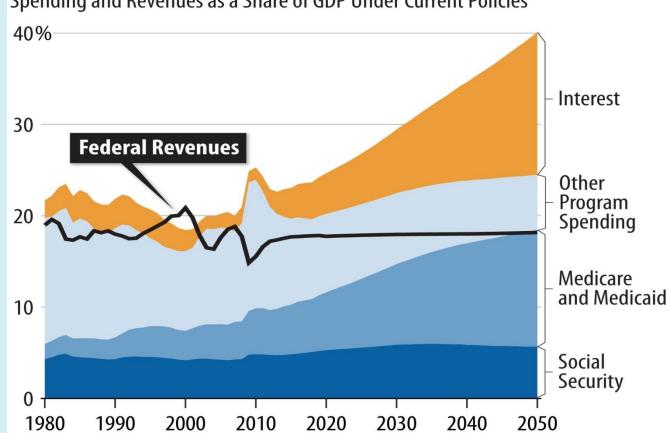
U.S. Census Bureau (September 12, 2018)

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

Persons with Disabilities experienced the highest rates of poverty of any other subcategory of Americans for the 16th year in a row.

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

Current Policies Are Not Fiscally Sustainable



Spending and Revenues as a Share of GDP Under Current Policies

Source: CBPP projections based on CBO data.

Purpose of DD Act (mission) "to assure that individuals with DD and their families participate in the design and have access to needed community services, individualized supports, and other forms of assistance that promote selfdetermination, independence, productivity, and integration and inclusion in all facets of community life, through culturally competent programs authorized..." Section 101 (b)

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."

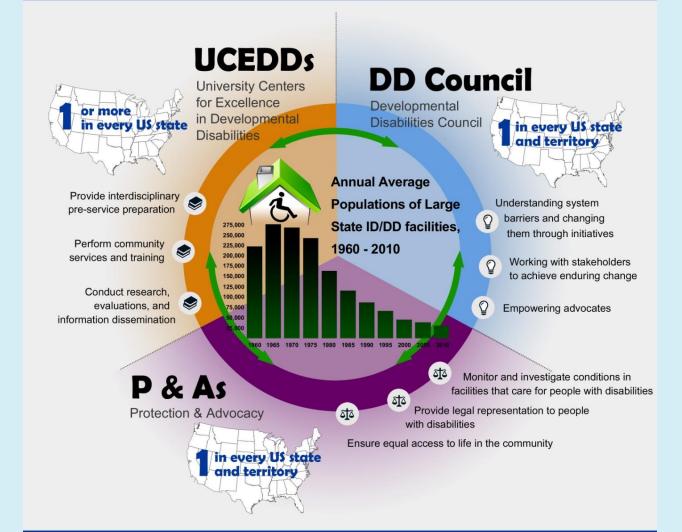
Dr. Martin Luther King, Jr.

1978 Amendments to DD Act (P.L. 95-602)

- Functional definition of developmental disabilities as having a life-long impact in <u>3 or more major areas</u>
 - Self-care
 - Communication
 - Learning
 - Mobility
 - Self-choice
 - Independent living
 - Economic self-sufficiency

The DD Act directs the DD Network Partners to collectively promote Community Integration.

This toolkit highlights the UCEDDs role and identifies the possibilities for collaboration around this activity.





ASSOCIATION OF UNIVERSITY CENTERS ON DISABILITIES Research, Education, Service Residential Services for Persons with Developmental Disabilities: Status and Trends Through 2010 by Sheryl Larson, Amanda Ryan, Patricia Salmi, Drew Smith, & Alise Wuorio Research and Training Center on Community Living Institute on Community Integration/UCEDD

SOURCES

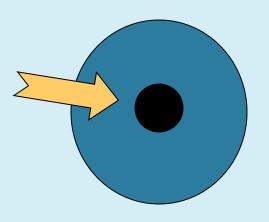


Longer Lifespans for Individuals with Disabilities Impacts Multiple Public Funding Sources:

- Life expectancy for PW/IDD has increased from average of 19 years in the 30's to 66 years in 2010 (Coppus, A.M.W., 2013)
- Individuals with Mild ID 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.

What To Do???







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

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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)

CPSD: Values & Principles for Policy Framework

- Core Values:
 - Equality
 - Choice
 - Competence
 - Community
 - Home
 - Work
 - Dignity of RiskEquity

Where is the Future?



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

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**

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!!!

"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...." "Changing introductions from deficits and what cannot do, to <u>strengths, preferences, interests, gifts &</u> <u>contributions</u>"

> ...Relationships matter; Location matters. Erik Carter, Ph.D. Vanderbilt University December 3, 2015

Endrew F. v. Douglas County School District; SCOTUS, March 21, 2017

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

Endrew v. Douglas County Schools, 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."

Workforce Innovation & Opportunity Act

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

Workforce Innovation & Opportunity Act Pre-employment transition services are

- defined as, and 15% \$ 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 office <u>must</u>engage in

pre-employment transition coordination with all local schools and workforce system

Workforce Innovation & Opportunity Act

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

- Why Target Transition, Ages 14–24? 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, Of those students, 40,000 - ID; 15,000 autism; 9,000 - multiple disabilities; and, 2.500 – TBI.
- 462,000 SSI recipients between ages of 14 & 17 in 2014

The Impact of Employment on Medicaid Utilization and Costs

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

Iowa Employment-Medicaid Data, 2 Calendar year 2011, 129,369 MEPD member months produced \$20,828,409 in total Medicaid claims savings.

Stated another way, the total claims paid by the individuals who became employed in 2011 were 21.6% less than expected based on their previous claims experience and the claims experience of SSI related Medicaid beneficiaries.

The Administration for Community Living

ACL is based on a commitment to one fundamental principle—that people with disabilities and older adults should be able to live where they choose, with the people they choose, and fully participate in their communities. Inherent in this principle is the core belief that everyone can contribute throughout their lives.

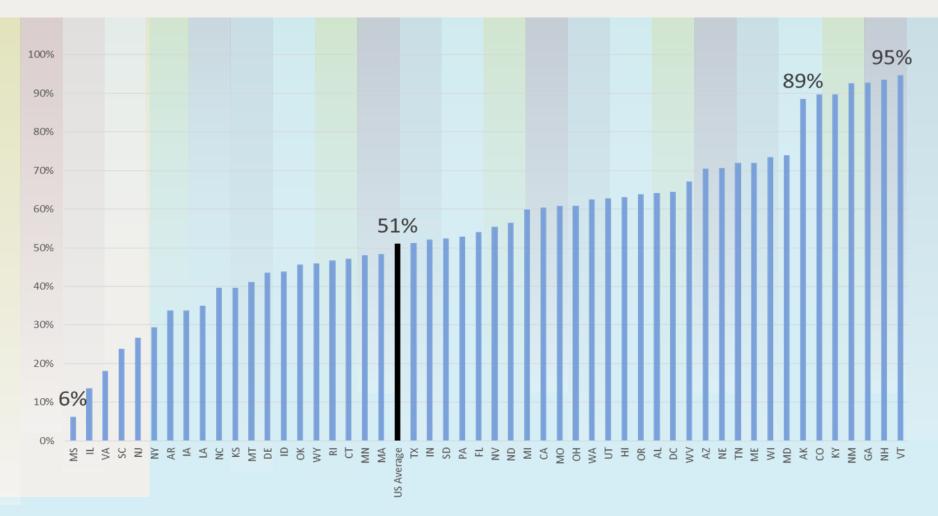
Characteristics of High-Quality Community Living: <u>50 years research</u>

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

Characteristics/Key Components (2)

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

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



% of People Residing in Settings of 3 or Fewer



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

- **75-70%**
 - Maryland
 - Wisconsin
 - Maine*
 - Tennessee* 71%
 - Nebraska
 - Arizona 70%

* No Institutions

% of People Residing in Settings of 3 or Fewer

• <u>69-60%</u>

- West Virginia*
- District of Columbia*
- Alabama*
- Oregon*
- Hawaii*
- Utah
- Washington
- Ohio
- Missouri
- California
- * No Institutions

<u>53-40%</u>

- North Dakota -56%
- South Dakota 53%
- Connecticut 48%
- Wyoming 45%
- Idaho 42%
- Montana 40%

% of People Residing in Settings of 3 or Fewer

• <u>6-35%</u>

- Mississippi***
- Illinois***
- Virginia***
- South Carolina
- New Jersey***
- New York***
- Arkansas
- Iowa
- Louisiana
- *** Among 10 states with largest state institutional populations

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

- Applies to 1915 (c) HCBS waivers; 1915 (I) SPA for HCBS; and, 1915 (k) Community First Choice SPA
- Extensive criteria for the development of a "person centered plan"
- "Informed choice"
- "Providers of HCBS for the individual, or those who have an interest in or are employed by a provider of HCBS for the individual must not provide case management or develop the PCP.....

CMS Final Rules, 1-16-2014, cont. ...except when the State demonstrates that the only willing and qualified entity to provide case management and/or develop personcentered 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. (ii) The setting is selected by the individual from among setting options including....

Qualities of an HCBS Setting

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

Qualities of HCBS Settings, 2

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

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

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

Work

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

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

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

The Power of Language 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
- Watch your language.....pity and charity
 Handicapped: Wheelchair Bound:
 - Handicapped; Wheelchair Bound;
 - Most Vulnerable;SpecialNeed;Meltdown
 - High Functioning- Low Functioning
 - Mental age of a Year old
 - Compassion

Some Valued Social Roles

- Family Member
- Friend
- Neighbor
- Citizen
- Athlete

- Partner
- Home owner
- Worker
- Learner/Student

Artist

Adapting to the "New Normal"

Metrics and Measurement; accountability

- All costs must produce clear measurable benefits; cost effectiveness
- Equity in resource allocation
- Pockets of excellence must be scalable; disparities in outcomes must translate statewide
- Sustainable value that can be quantified
 Transformational policy and infrastructure change

Vision.... "The only thing that is constant is change." **Heraclitus** 535-475 BC

Connecticut Congressional Delegation

- Senators: Richard D.Blumenthal (D) and Chris Murphy (D)
- Representatives: John Larson (D), 1; Joe Courtney (D), 2; Rosa DeLauro (D), 3; Jim Hines (D), 4; and, Jahana Hayes (D), 5.

Contacting Members of Congress Capitol Switchboard: 202-224-3121

- Contactingcongress.org
- Call District/Local Offices
- Attend Town Hall Meetings
- Schedule Meetings at Home when on Recess
- Use Social Media like Facebook ALLAN 1. BERGMAN High Impact Mission-based Consulting and Training

How you can help?

 Reach out and begin to develop (or continue to develop) relationships with Members and their staff and educate them about what issues are important for them to learn about and help address this year and into the fall Congressional elections this November

Members need to hear both the data, and the stories that demonstrate both the problem and if known, a proposed solution.

 Continue to be in touch with staff in the offices throughout the year by sharing information about what is happening in Texas.

The Current Agenda in Washington, DC

- Reduce the size of the <u>federal deficit</u> created by the Tax Reform & Jobs Act; estimated to be at least \$1.1 Trillion.....
- Attack "Welfare" & "Entitlements"
- Reduce the next ten years of the cost of Medicaid, Medicare, SSI, SNAP, Housing Subsidies, etc. to the federal government
- Congressional Budget Office estimates that the Medicaid proposals will reduce the federal expenditures for Medicaid over the next ten years by \$880 Billion.....

Federal Budget

- \$3.65 Trillion, FY '17 with a \$0.44 T. deficit
- \$4.094 Trillion for FY'18 with another
- \$0.44 Trillion (\$440 Billion) deficit
- Inational debt hit \$22 Trillion, 3/2/19
- Interest on Debt grew by \$50 B to \$310 B
 - Funds a wide variety of programs
 - Two types of Budget items Entitlement/Mandatory Discretionary
 - Unified budget of trust funds for Social Security and Medicare is confusing as regards the deficit and national debt

Key Legislative Advocacy Goals Support passage of the Disability

Integration Act (DIA); S 117; HR 555

- Support passage of the Empower Care Act was MFP); S.548; HR 1342
- Support passage of the Transformation to Competitive Employment; HR 873; S 260
- Support passage of the Autism Cares Act HR 1058; S 427
- Support passage of the Disability Employment Incentive Act; S. 255
- Support passage of the ABLE Age Adjustment Act; S. 651; HR 1814

- Key Legislative Advocacy Goals 2
 <u>Support passage of Social Security</u> 2100; S. 269; HR 860
- Promote legislation to prohibit use of seclusion & restraint in schools
- <u>Defeat</u> any free standing bill that cuts SSI, Medicaid, Medicare, SNAP, HUD
- Defeat President's FY'20 Budget
- <u>Defeat</u> any attempts to weaken HCBS "settings" rule or WIOA definition of CIE
- Defeat any attempts to weaken the definition of competitive integrated employment

Disability Integration Act; S117, HR555

- Schumer/Gardner; 25 D & 1 R cosponsors
 Blumenthal, cosponsor; Thank You
- Sensenbrener/Doggett; 201 D & 14 R;
 Courtney, Delauro, Himes; Thank you (Judiciary C)
- Creates a comprehensive solution, assuring the full integration of PWD in the community
- Clarifies that every individual who is eligible for LTSS has a federally protected right to a real choice in how they receive services & supports;
- Assures that states & other LTSS insurance providers deliver services that allows PWD to

The Disability Integration Act – 2 live in the most integrated setting, have maximum control over their services & supports, and lead an independent life;

- Articulates the right to live in the community without creating unnecessary or wasteful Government programs; States have broad latitude to determine how to secure that right;
- Establishes a comprehensive planning requirement, including enforceable targets
- Requires public entities to address the need for affordable, accessible, integrated housing that is independent of service delivery; and establishes stronger, targeted enforcement

EMPOWER Care Act, S. 548; HR 1342

- To Extend Money Follows the Person through 2024; Pres. George W. Bush, 2005; bipartisan support; ended in 9-2016
- Several reports by CMS and Mathematica conclude that individuals have a better quality of life & costs are 23% lower\$

Empower Act, S 548; HR 1342

- Senators Portman & Cantwell (Collins & Casey); 2 D and 2 R (no CT) in Finance Comm.
- Representatives Dingell & Guthrie; 34 D and 8 R; Courtney, Thank You: in Ways & Means Comm.

Thinking for the Long Term

Type of Service	Cost per Person	20 yrs. Cost	30 yrs. Cost
ICF/MR Institution	\$128 <i>,</i> 275	\$2,565,600	#3,848,250
HCBS 24hr staffed Residential	\$70,133	\$1,402,660	\$2,103,990
Shared Living (Adult Foster Care)	\$44,122	\$882,440	\$1,323,660
Supports in Own or Family Home	\$25,072	\$502,440	\$752,160

NASDDDS

National Association of State Directors of Developmental Disabilities Services

Transformation to Competitive Employment: HR 873 & S 260

- Scott & Rogers; 35 D & 6 R (No CT); in Education & Labor Comm.
- Casey & Van Hollen; 6 D; I I; (No CT)., PA, MD,CA, ME, NH, NY, WI.<u>in HELP</u>
- To strengthen and enhance the disability employment service delivery systems in states while phasing out sub-minimum wages over 6 years
- Provides major grants to states to build capacity by providing training and technical assistance to providers and..

Autism CARES Act: HR 1058; S 427 Collaboration, Accountability, Research,

- Education and Support Act
- Expires Sept. 30, 2019 if not reauthorized
- Currently: research at NIH
- Surveillance & Awareness at CDC
- Workforce Development & Research for more effective systems of care at HRSA, including the LEND (Leadership Education in Neurodevelopmental and Related Disabilities
- Reports to Congress on critical issues activities and outcomes; e.g. transition

Autism Cares Act - 2

- Rep. Chris Smith; 23R & 80D;.
- Thank You, Larson, Courtney, DeLauro, and Hayes; thank you.
 In Energy & Commerce Comm.

 Sen. Menendez; 11D & 11R; Blumenthal, Thank You.
 In HELP Comm.

ABLE Age Adjustment Act; S. 651; HR 1814

- To amend current age of eligibility for one's disability from before the age of 26 to the age of 46; to move back towards original legislation on 2014
- Sen. Casey & Moran 8 D & 4 R Thank
 You Sen. Blumenthal, in Finance Comm.
- Rep. Cardenas & McMorris-Rogers 16 D & 10 R, (NO CT.); in Ways & Means Comm.

Disability Employment Incentive Act; S 255; no House bill at this time

- To increase tax incentives for employers to employ and retain employees with disabilities from SSI or SSDI
- Raise WOTC for year one base from \$6,000 to \$12,500 for 40% tax credit
- Add a WOTC for year two for 20% of up to \$12,500 (a \$2,500 credit)
- Increase the size of small business for Disability Access Expenditures Credit from 30 to 60 FTE and maximum tax credit from \$5,000.00 to \$10,000.00

Disability Employment Incentive Act - 2

- Increase the tax credit for architectural and transportation barrier removal expenses in a single year from \$15,000.00 to \$30,000.00; also will add costs of making online business operations and telecommunications accessible
- Casey; 7 D & 0 R Thank you Senator Duckworth (NO CT.); in Finance Comm.

Prohibit Use of Seclusion & Restraints in Public Schools

- Reintroduce the Keeping All Students Safe Act, first introduced in 2011 by Senator Tom Harkin; (H.R. 7124 in 2018)
- House Education & Labor Subcommittee on Early Childhood, Elementary & Secondary Education held a hearing on February 27, 2019 "Classrooms in Crisis: Examining the Inappropriate Use of Seclusion & Restraint Practices"

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.

THE ULTIMATE TEST OF POLICY IS YOUR BUDGET

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

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

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

Connecticut Department of Developmental Services Mission Statement

"The mission of DDS is to partner with the individuals we support and their families, to support lifelong planning and to join with others to create and promote meaningful opportunities for individuals to fully participate as valued members of their communities."

October 2012

CT. DDS Vision • "All citizens supported by the DDS are valued contributors to their communities as family members, friends, neighbors, employees, volunteers, members of civic and religious associations, voters and advocates. These individuals: Live, learn, work and enjoy community life in places where they can use their

personal strengths, talents & passions

 Have safe, meaningful and empowering relationships

CT DDS Vision, cont.

- Have families who feel supported from the earliest years & throughout their lifetimes
- Have lifelong opportunities & assistance to learn things that matter to them
- Make informed choices & take responsibility for their lives & experience the dignity of risk
- Earn money to facilitate personal choice
- Know their rights/responsibilities, pursue opportunities to live the life they choose

Abraham Lincoln said:

"The people know their rights, and they are never slow to assert and maintain them when they are invaded."

"Equal Justice Under the Law"



FOR ADDITIONAL INFORMATION

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