



Disability Policy – Current Issues 115th Session of Congress: Second Year, 2018 (& 2019)

Consumer Advisory Council

Uconn UCED

Farmington, Connecticut

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HIGH IMPACT

Mission-based Consulting & Training www.missionbased.com

The Current Agenda in Washington, DC

- Reduce the size of the federal deficit 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.....

LRE National Data, Fall 2016 (for Fall 2014)

Students with Intellectual Disability

Ages 6-21 years

▪ > 80% of day included	16.9%
▪ 40-79% of day included	26.3%
▪ < 40% of day included	49.2%
▪ Separate school or Residential facility	7.6%

Youth Employment Data, August 2015

Bureau of Labor Statistics

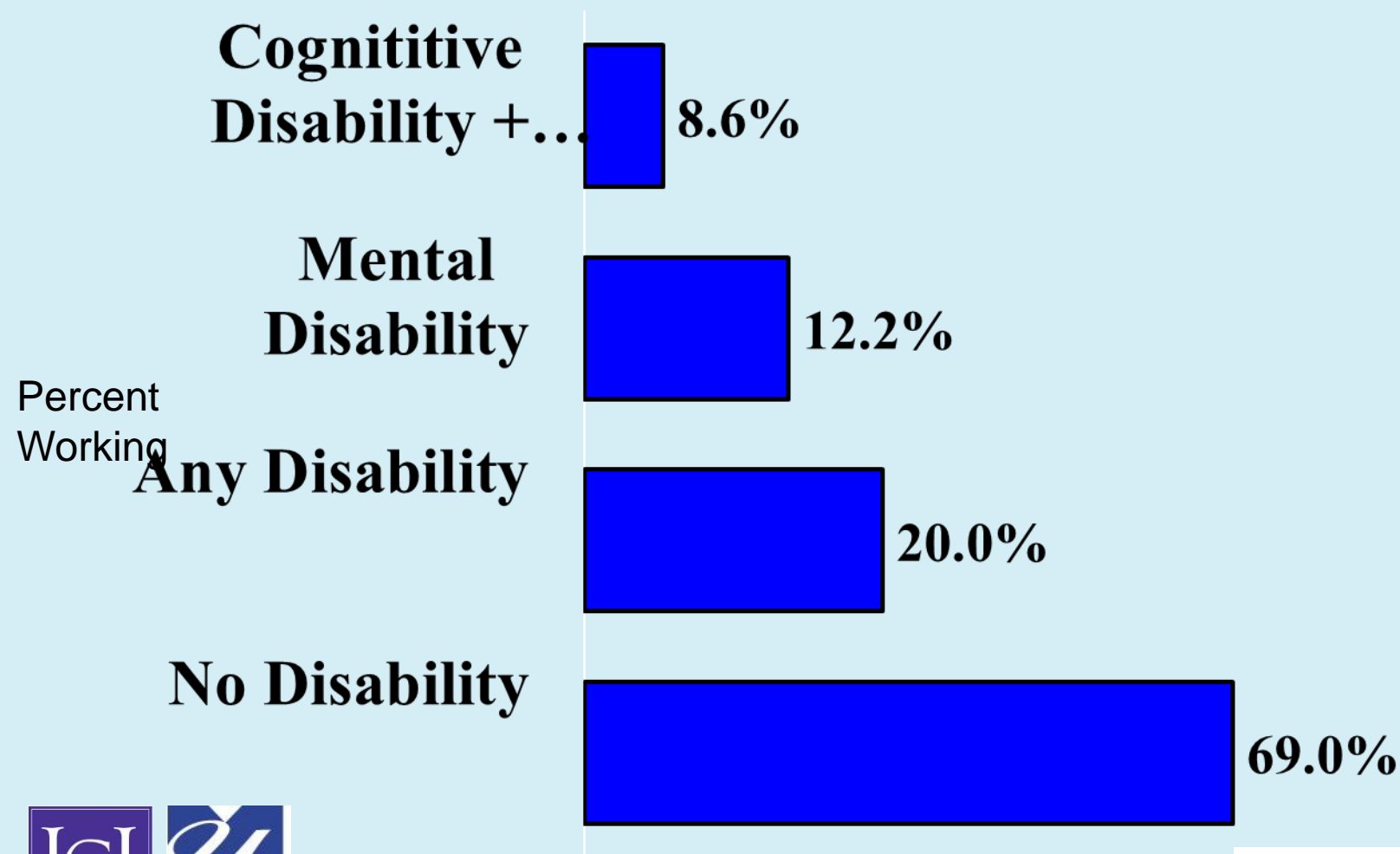
Youth Without Disabilities

- **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

Employment participation June 2018



American Community Survey



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: 19/20 ZERO earnings**
- The average earned income is \$300/year (for individuals who are blind, \$460/year)
- Less than 1% leave the rolls per year and only ½ of those for employment

SOCIAL SECURITY DATA AND TRENDS

- **SSDI and Medicare beneficiaries:**
 - 7.3 million in 2008
 - 8.8 million in 2013 (+ 1 million DAC)
 - 11.7 million projected in 2020

- **SSI and Medicaid beneficiaries**
 - 6.1 million in 2008; 8 million in 2013
 - 10.0 million projected in 2020

- Total cost in 2008: \$428 billion
- **Projected in 2018: \$1.0 trillion**

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 government, FY'16: **\$331 Billion...**

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.
- **Employment makes a huge difference**

Poverty *By The Numbers*

SUBPOPULATION	2009 Poverty Rate	2016 Poverty Rate
Children	20.7%	21.1%
African-American	25.8%	22.0%
Hispanic	25.3%	19.0%
Disability	25.0%	26.8%
Total U.S. Population	14.3%	12.7%

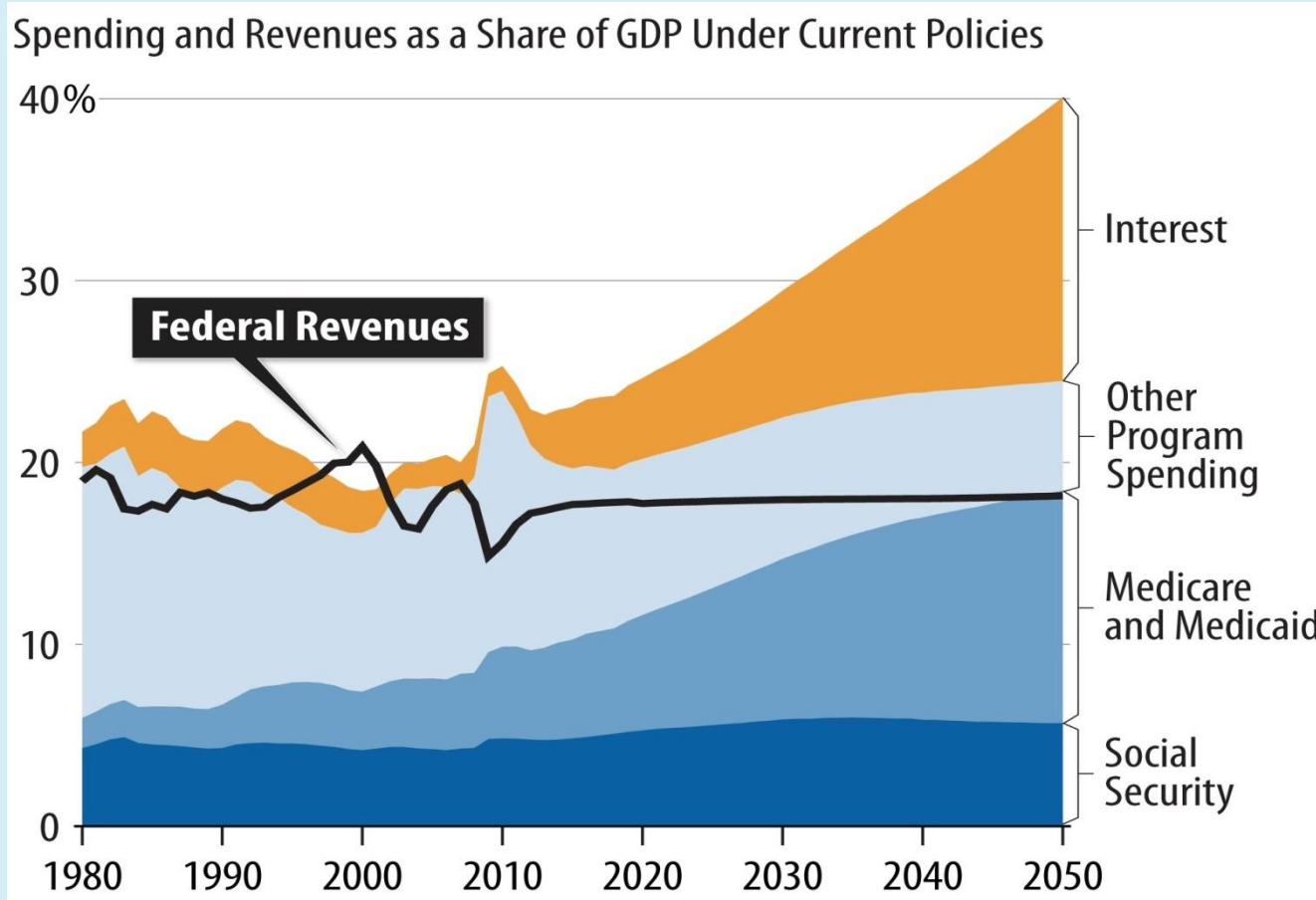
U.S. Census Bureau (September 2017)

40.6 million Americans (of 319.9 M) were living in poverty in 2016.

Persons with Disabilities experienced the highest rates of poverty of any other subcategory of Americans for the 15th 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



Source: CBPP projections based on CBO 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”**

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**

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.

Bipartisan Budget Act (Resolution)

- Enacted February, 9, 2018; 71-28 Senate; 240-186 House, 73 D's yes & 67 R's no
- **Continued government until March 23rd; need to develop Appropriations Bills**
- Lifts debt ceiling until March 2019;
- Adds over \$300 Billion over two years with \$165 B in Defense and \$131 B in NDD
- + \$90 B for Disaster Relief; + 6 B for Opioid Epidemic; +20 B for Infrastructure; +2 B for NIH; all over 2 years
- Continue \$ for Community Health Centers
- Continue CHIP for 4 more years (10 total)

Federal Budget

- \$3.65 Trillion for FY '17 with a \$0.44 Trillion deficit.....
- **\$4.094 Trillion for FY'18 with another \$0.44 Trillion (\$440 Billion) deficit**
- **(national debt now over \$21 Trillion)**
 - 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

- **Defeat** any free standing bill that cuts SSI, **Medicaid**, Medicare, SNAP, HUD
- **Defeat any ADA attack**
- **Defeat any Balanced Budget Amendment**
- **Support** passage of the Disability Integration Act (DIA); S 910 (23 D&1 Ind.); HR 2472 (103D & 15R Cosponsors)
- **Support passage: the Empower Care Act**
- **Defeat any attempts to weaken HCBS “settings” rule or WIOA definition of Competitive Integrated Employment**

Defeat Nomination of Judge Brett M.

Kavanaugh for U.S. Supreme Court Justice

- Concerns over his treatment of pre-existing conditions and issues of health care access for individuals with disabilities and chronic health conditions
- Concerns over his treatment of the decision making capacity of individuals with intellectual disabilities; testimony of Liz Weintraub, self advocate with AUCD.
- **5 Senators targeted: Collins (ME); Murkowski (AK); Manchin W.V.); Heitkamp (N.D.); and Donnelly (IN.)**

President Trump's FY'19 Budget

- “The President’s **‘An American Budget’** is an Unamerican Attack on People with Disabilities”. (CCD Alert)
- **Medicaid:** drastically cut through per capita caps and block grants; also dramatically repeals many sections of the ACA, including the Essential Health Benefits and affordable plans for individuals with pre-existing conditions
- **Social Security and SSI:** would be cut by roughly \$70 billion over 10 years

An American Budget -2-

- **Developmental Disabilities (DD) Act Programs:** double digit cuts; State Councils by 23%; University Centers for Excellence by 13%; and Projects of National Significance by 90%.
- **Supplemental Nutrition Assistance (SNAP) or Food Stamps:** cut by \$213 billion, a reduction of 30% over 10 years
- **Housing:** Affordable Housing programs at HUD would lose \$6.8 billion, including major cuts in housing choice vouchers, and public housing programs like 811, etc.

An American Budget – 3

- **Social Services Block Grant:** Eliminates all funding for Title XX
- **Medicaid Work Requirements:** Proposes the addition of work requirements to all “able bodied” Medicaid beneficiaries
- **Education:** Proposed a \$1.1 billion down payment towards a \$20 billion federal investment in school “choice vouchers” for private schools (for which one gives up all rights and protections under the IDEA)

Status of FY'19 Appropriations

- Federal Fiscal Year 2018 ends Sept. 30th;
- House and Senate conferees have agreed on budget for FY'19
- Details not public yet; concerns over many line items
- President Trump has been strongly encouraged by Senator McConnell and Speaker Ryan to NOT veto and to NOT shut down the government over costs and that “the wall” is not fully included
- Must not allow a shutdown

Disability Integration Act; S910, HR2472 (**CT. Blumenthal & Himes**)

- 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 and supports;
- **Assures that states and other LTSS insurance providers deliver services in a manner that allows PWD to live in the most integrated setting, have maximum control over their services and supports, and lead an independent life;**

The Disability Integration Act – 2

- Articulates the right to live in the community without creating unnecessary or wasteful Government programs; States have broad latitude to determine how they will 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 mechanisms.**

EMPOWER Care, S.2227; HR5306

- To Continue Money Follows the Person Projects; **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**\$
- **Texas Data** (Mathematica report, 9/24/17, from beginning until 12/31/16)
- Total transitioned: 11,433; Older Adults, 4,362; People with Physical Disabilities, 4,406; **People with Intellectual D, 2,665,** People with Mental Health Issues..0000

Empower Act, S. 2227; HR 5306

- Senate Co-Sponsors: Portman, (R), Ohio and Cantwell (D), Washington State
- Introduced December 13, 2017; 4 cosponsors; CONN.....000
- House Co-Sponsors: Guthrie (R), Kentucky, and Dingell, (D), Michigan
- 53 cosponsors (37 D, 16 R); CONN., Joe Courtney (9/7/2018)

Over 75,000 individuals have moved out of institutions in 43 states and D.C.

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

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

(2) rehabilitation and other services to help such families and individuals attain or retain capability for independence or self-care, there is hereby authorized to be appropriated for each fiscal year a sum sufficient to carry out the purposes of this title. The sums made available under this section shall be used for making payments to States which have submitted, and had approved by the Secretary, State plans for medical assistance.

Medicaid Structure for States

- Eligibility: Mandatory and **Optional**
- Services: Mandatory and **Optional**
- Services: **Amount, Duration and Scope sufficient to meet the purpose (states can and do set limits; a lot of flexibility)**
- Statewideness, Comparability and Freedom of Choice (unless waivers obtained)
- **Reimbursement methodology: Rates**
- Provider standards: Compliance with federal regulations and whatever state wants to add
- Quality Assurance:
- **Entitlement to federal matching funds: no cap**
\$

Eligibility for Medicaid

■ **Mandatory:**

- Low income families and children under 18 in families up to 138% poverty
- Pregnant women up to 138% FPL
- SSI recipients, children, adults and seniors; also low income and assets

■ **Optional:**

- “Medically Needy” due to high med. cost
- Katie Beckett families: TEFRA 134
- Variety of work incentives for PWD
- ACA Expansion to 138% FPL for parents and childless adults

Mandatory State Plan Services:

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

42CFRss440...

Mandatory State Plan Services-2

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

Early Periodic Screening, Diagnosis & Treatment-EPSTD

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

Optional State Plan Services

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

Optional State Plan Services-2

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

Optional State Plan Services 3

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

Optional State Plan Services 4

- Emergency Hospital Services
- Respiratory Care for Ventilator-Dependent Individuals
- Home & Community-Based Services (HCBS); waivers or state plans
- Community First Choice
- Medical Health Homes

SERVICES AUTHORIZED UNDER HCBS:

- Case Management
- Homemaker
- Home Health Aide
- **Personal Care**
- Adult Day Health
- Habilitation, including supported employment
- NO funds for room and board
- Environment Accessibility & Adaptability Equipment
- Respite Care
- Day Treatment or Other Partial Hospitalization
- Psychosocial Rehabilitation Services
- Clinic Services
- Enhanced Therapies...
- **Transportation-Non Med.**
- Personal Emergency Response Systems
- Assisted Living
- Other.....

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

- Applies to 1915 (c) HCBS waivers; 1915 (l) SPA for HCBS; and, 1915 (k) & 1115
- Extensive criteria for the development of a “person centered plan”
- “Informed choice”
- 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.**

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

...except when the State demonstrates that the only willing and qualified entity to provide case management and/or develop person-centered service plans in a geographic area also provides HCBS.”

- **Home & Community-Based Settings** – “**must have** all of the following qualities, and such other qualities that the Secretary determines to be appropriate, **based on the needs of the individual as indicated in their person-centered service plan:.....**”

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

CMS Final Rules on HCBS

continued

#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.”

Update: Medicaid 2016

- The largest insurer in the country today
- **74 million individuals are covered**
 - **Pays for 50% of all births in the United States**
 - **Pays for about 50% of nursing home care and covers about 60% of nursing home residents**
 - **Largest source of federal grants to the states**
- Up from 4 million individuals when began in 1965 with a total cost of \$900 million, a result of
 - High poverty rates
 - Erosion in employer based group plans for lower wage workers
 - Aging population
 - **Longer life spans for persons with disabilities**
- Projected to serve 77.5 million individuals in 2024 at a total cost of \$920.5 billion, with federal share of 61%

Federal Medical Assistance Percentage (FMAP): Federal Matching Funds to States for Medicaid Services

- Each year the federal government calculates the FMAP for each state based upon population, per-capita income and other factors; **it is an entitlement with no cap on dollars**
- No state gets less than 50%; Mississippi receives 75.65% in 2018
- This opportunity will end if Congress block grants Medicaid to the states.

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- Over 74 million beneficiaries:
 - 45 % children ; 19% of expenditures
 - 36% adults; 34% of expenditures
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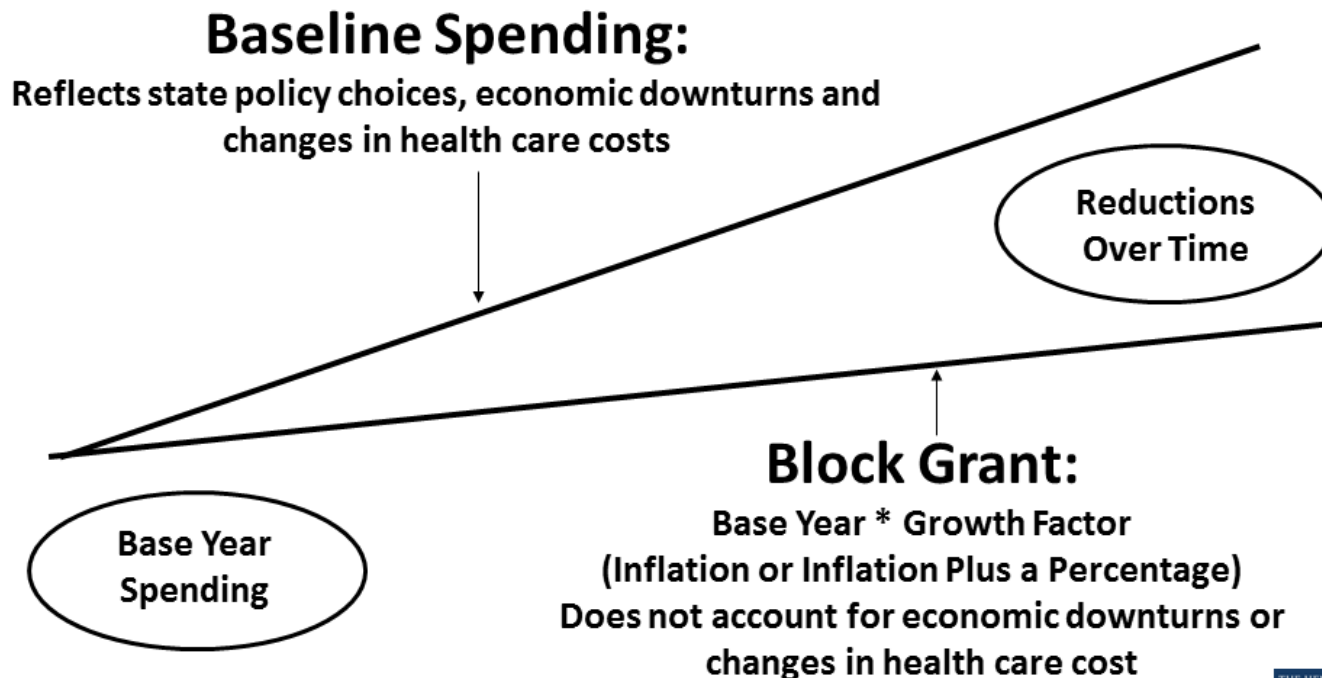
PWD & Medicaid Block Grants

- A fixed amount of money given to a state with “more flexibility” and less “entitlements”
- **No additional federal funding regardless of need, economic shifts, demographic changes, etc.**
- Alleges to give states more “flexibility” and it does not do that
- Burden would rest on the state and/or counties on how to address budget shortfalls.
 - Increase their funding
 - Cut services or hours of services
 - Reduce payment rates
 - Tighten eligibility rules
 - Any combination of the above
 - **PWD and seniors most likely to be impacted harder because of current use and expenses**

Block Grants

Figure 2

Under a block grant, reductions in federal spending are obtained by setting caps below expected spending.



Medicaid & Per Capita Caps

- Establishes limits on per capita spending, but how will that be done? **Sets a dollar cap per beneficiary**
 - One statewide average
 - **By population groups**
 - Acute care separate from LTSS and Institutional care
 - Exemption of some groups
 - Exemption of some services such as prescription drugs
 - What is the **formula for annual growth???** **Can be changed**
 - How will the caps grow with changing demographics of aging and poverty??
- Federal rules, as in Block Grants, would be altered to allow the states “flexibility” to **reduce costs by changing:**
 - Eligibility; work requirements; premiums; co-pays
 - Services available and limits or caps on benefits
 - Payment rates to providers that already are very low
 - **CMS already doing today with 1115 waivers; IN., KY.**
 - 1115 waiver requests also pending in many other states

Medicaid Per capita caps

“Medicaid Per Capita Cap Has Same Damaging Effects as Block Grant” – Center for Budget & Policy Priorities

- Provides fixed funding per person, regardless of needs
- Essentially caps federal funding, using 2016 as a base year. Over the next 10 years federal support is projected to be cut by \$880 Billion; **states and/or counties will have to come up with the replacement revenue or make major cuts.**
- **Cuts federal/state investments in innovative plans such as coordinating care for people with chronic conditions, or programs for HCBS long-term services & supports while nursing homes and ICFs are “entitled”**

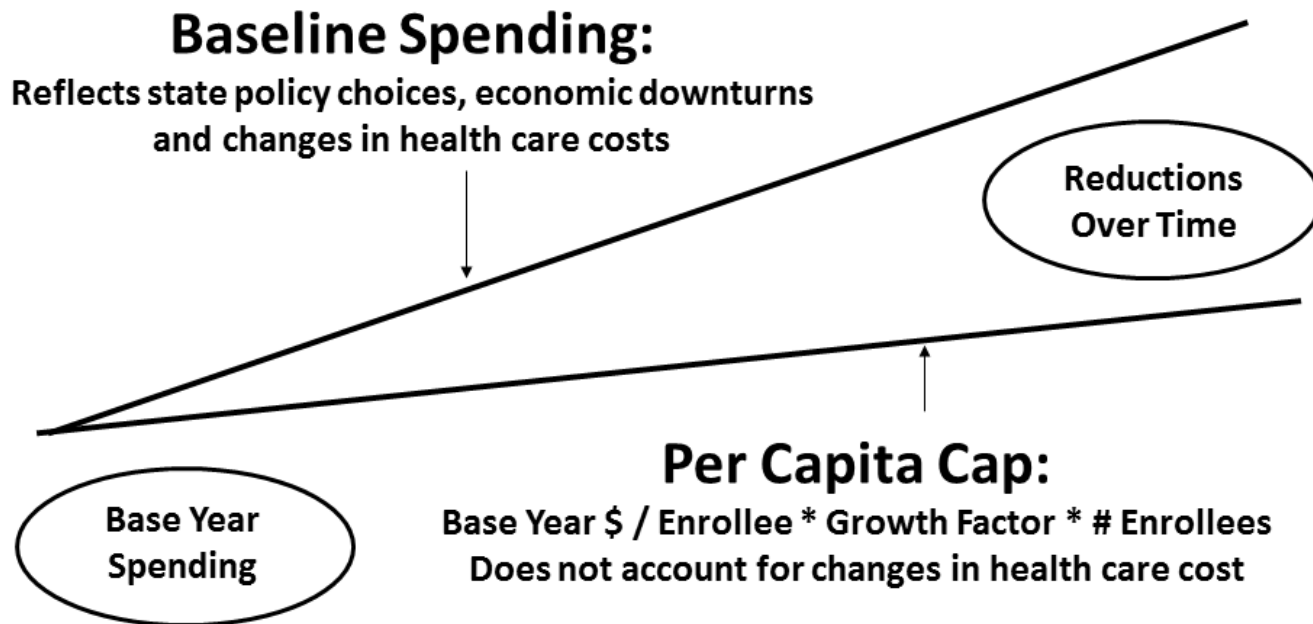
Medicaid Per capita caps

- **Cuts would grow each year.** As health care costs rise, or if there is a public health crisis, states must absorb costs.
- **States will likely impose Medicaid cuts in eligibility benefits & provider payments.**
- Medicaid is states' biggest source of federal funding, **so cuts under per capita caps will squeeze state budgets overall.**
- **Will states raise taxes or cut other services?**
- Will not control health care costs.
- Hits seniors and people with disabilities the hardest, because the majority of Medicaid spending covers their health care & LTSS.

Per Capita Caps

Figure 3

Under a per capita cap, reductions in federal spending are obtained by setting caps below expected spending.



Protecting Medicaid: Our Message

- Medicaid helps a wide cross-section of Americans
 - Largest payer of long-term supports and services
 - **Supports seniors and people with disabilities to have valued roles and to live, learn, work and play in the community**
 - Helps kids and working families stay healthy
- Medicaid works. It's efficient and has improved people's health and their lives.
- Cutting Medicaid at the federal level hurts states
- Cutting Medicaid doesn't make health care needs go away – it just passes on the costs
- The Budget cannot be balanced on the backs of PWD
- **Do NOT use the terms “Entitlement” or “Welfare” as these have negative meaning to many Americans**

Protecting Medicaid – Our Message - 2

- **Medicaid is the Foundation of Stability for Persons with Disabilities to live, learn, work and be contributing members of the community**
- There is no private insurance product to cover life long supports for people with significant disabilities
- **No one individual or family can bear the costs of supports for a life time**
- Until Medicaid HCBS, institutions were the only alternative for many PWD

Creating Your Personal Message about Medical Assistance

- Individuals with disabilities of all ages & families have to be mobilized
 - Need to understand that everyone is impacted
 - Need to think about **what role Medicaid has played and is playing in early intervention, preschool and K-12 IEPs**
 - Need to think **about what role Medicaid has played and is playing in your access to affordable health and mental health care**
 - Need to think about **what role Medicaid HCBS waivers or state plan services, Money Follows the Person and Medicaid Personal Care Services have played and are playing in your life as an integrated member of your community**
 - Need to think about **what the loss of any of these protections and services will mean to your current quality of life and what that means for your future**

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.

Some Valued Social Roles

- Family Member
- Friend
- Neighbor
- Citizen
- Athlete
- Partner
- Home owner
- Worker
- Learner/Student
- Artist

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Contacting Members of Congress

- Capitol Switchboard: 202-224-3121
- Contactingcongress.org
- Call District/Local Offices; Schedule meetings when at Home
- Attend Town Hall Meetings
- **VOTE.....**
- Use Social Media; Write Op-eds.

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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President

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