



Update on Federal Policies that Impact Home and Community Based Services

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What Are the Goals for our HCBS System?

- Support people with disabilities to **have lives like people without disabilities**
- Provide opportunities for **true integration, independence, choice, and self-determination** in all aspects of life – where people live, how they spend their days, and real community membership
- Ensure **quality services** that meet people's needs and help them achieve goals they have identified through real person-centered planning

Update on Federal Policies Impacting These Goals

- Context for where we are
- Recent federal policies
 - Enforcement of the ADA and Olmstead, including around home care services
 - Home and Community Based Services Settings Rule
- Concerns on the horizon
 - Threats to Medicaid
 - Agency priorities and regulations

Context for Where We Are

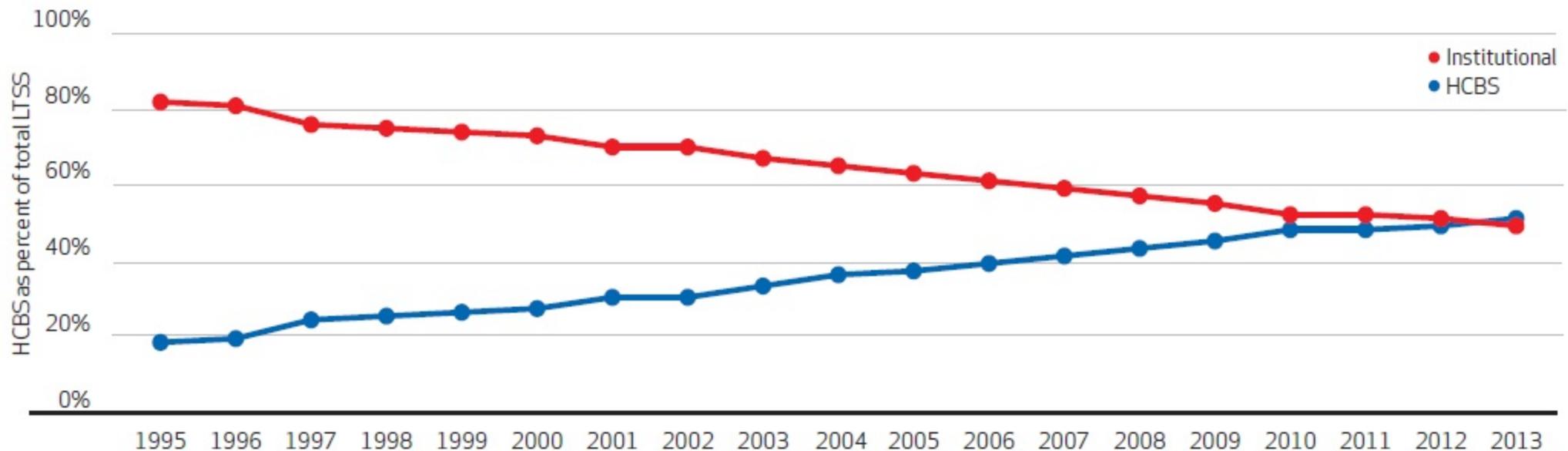
Advocacy For Community Services

- Until the 1980s, public disability funding only paid for care in institutions
- Beginning in 1982, Medicaid created an optional “waiver” program that allowed states to provide community services as an alternative to institutional care
- Now every state provides Home and Community Based Services (HCBS) through a range of funding streams, including 1915c waivers, 1915k Community First Choice, and 1915i State Plan HCBS, as well as state plan services and managed care authorities

National HCBS vs Institutional Spending

EXHIBIT 1

Medicaid Home and Community-Based Services (HCBS) Expenditures as a Percentage of Total Medicaid Long-Term Services and Supports Expenditures, FY 1995-2013



SOURCE "Medicaid Expenditures for Long-Term Services and Supports in FFY 2013," Truven Health Analytics, June 30, 2015, page 7.

Shift Towards

Community Services (cont'd)

- Dramatic shift away from institutional care towards community services
 - 53% of spending nationally on community services
 - Varies by disability (75% of IDD vs. on 41% for aging, PD & MH services)
 - State differences (a low of 27% in Miss to a high of 79% in OR)
- Most people now live in small community settings (from IDD dataset)
 - In family home (56%), own home (11%), host home (5%) or group home with less than 3 others (5%)
 - But still many in larger congregate settings: 4-6 person (12%), 7-15 person (5%) and, 16+ people (6%)

Evolving Models of Disability Services

- Early “community” models – disability specific, congregate care settings, where people with disabilities live/spend the day together in settings where services were provided
 - Ex. group homes, day habilitation & sheltered workshops
- Today’s models focus more on integration & independence
 - Flexible, mobile services available to people in their own homes and communities (separation of housing and services)
 - More models of independent/supported living
 - Supports to work in mainstream jobs alongside non-disabled peers
 - **Consumer-directed models as an alternative to agency providers**

Community Living for People with Disabilities

As a Civil Right

- Disability advocates have fought for civil rights laws to protect against discrimination and ensure their inclusion
 - Rehabilitation Act of 1974 prohibited discrimination by recipients of federal funding
 - Culminated in 1990 with the Americans with Disabilities Act “to provide a clear and comprehensive national mandate for the elimination of discrimination against individuals with disabilities.”
 - ADA found that **segregation, isolation, exclusion and institutionalization of people with disabilities is a “serious and pervasive problem”**
 - ADA’s goal is to **assure equality of opportunity, full participation, independent living, and economic self-sufficiency** for individuals with disabilities.

The ADA and *Olmstead*

Title II of the ADA

- Prohibits discrimination by public entities in services, programs and activities
- Integration regulation requires administration of services, programs and activities **in the most integrated setting** appropriate
- Most integrated setting is one that enables people with disabilities to **interact with people without disabilities to the fullest extent possible**

Olmstead v. L.C.: Unjustified segregation is discrimination

- Two women in Georgia's state hospitals claimed the state was violating the ADA by not providing them services in the community.
- In 1999, the Supreme Court held that **Title II prohibits unjustified segregation of people with disabilities**, relying on “two evident judgments” about institutional placement:
 1. “perpetuates **unwarranted assumptions** that persons so isolated are incapable or unworthy of participating in community life”
 2. “**severely diminishes the everyday life activities of individuals,**” including family, work, education and social contacts

Olmstead v. L.C. (cont'd)

- Held public entities are required to provide community-based services when:
 - Such services are appropriate;
 - Affected persons do not oppose community-based treatment; and
 - Community-based treatment can be reasonably accommodated, taking into account the resources available to the entity and the needs of others receiving disability services

When is the ADA's Integration Mandate Implicated?

- Not limited to state-run facilities/programs
- Applies when government programs result in unjustified segregation by:
 - Operating facilities/programs that segregate people with disabilities
 - Financing the segregation of people with disabilities in private placements
 - Promoting segregation through planning, service design, funding choices, or practices.

Who Does the Integration Mandate Cover?

- ADA and *Olmstead* are not limited to individuals in institutions or other segregated settings
- They also extend to people **at serious risk of institutionalization or segregation**
 - Example: people with urgent needs on waitlists for services or people subject to cuts in community services; students with disabilities who are directly placed by schools into sheltered workshops or segregated day programs.

What is a Segregated Setting?

- Have **institutional qualities**, including:
 - Congregate settings with primarily or exclusively people with disabilities; or
 - Regimentation in daily activities, lack of privacy/autonomy, limits on ability to freely engage in community activities; or
 - Settings that provide for daytime activities primarily with other people with disabilities
- Examples: DD facilities, psychiatric hospitals, nursing homes, adult care homes, sheltered workshops, segregated day programs

What is an Integrated Setting?

- Integrated settings provide people with disabilities the **opportunity to live, work and receive services in the greater community**
 - Located in mainstream society
 - Offer access to community activities when and with whom the person chooses
 - Choice in daily life activities
 - Ability to interact with people without disabilities to the fullest extent possible
 - Examples: scattered site supportive housing, supported employment in a mainstream job

Need for *Olmstead* Enforcement

- Despite progress, too many people with disabilities still remain unnecessarily in institutions or other segregated settings
 - Ex. DD facilities, psychiatric hospitals, nursing homes, board and care homes, sheltered workshops, and other segregated day settings
- Many others at serious risk of entering institutions or segregated settings
 - Ex. people on waitlists, using emergency rooms or interacting with police during a mental health crises, homeless individuals with disabilities, or students in the school-to-sheltered workshop
- Enforcement activities can be by either DOJ or private plaintiffs (like protection & advocacy organizations)

Olmstead as a “Tool” to Address These Problems

- Using *Olmstead* to create **statewide, systemic reform activities**:
 - Increasing the capacity of community services that are critical for successful community tenure
 - Expanding the supply of affordable, permanent community housing
 - Expanding opportunities for employment for people with disabilities

Olmstead and Home Care: “At risk” Cases

- Litigation has focused on people receiving home care services who are facing cuts and as a result are **at serious risk of institutionalization**
 - During the recent economic downturn, many states tried to cut optional Medicaid services, particularly personal care services
 - Numerous legal challenges to these proposed cuts, claiming that the “across-the-board” cuts would place people at risk of institutionalization in violation of the ADA and *Olmstead* (challenges in Washington, California, and Louisiana)

“At risk” *Olmstead* Cases

- These cases created legal precedent that:
 - People need only show “serious” not “imminent” risk of institutionalization to have a claim; decline in health that could lead to eventual institutionalization
 - Across the board cuts can violate *Olmstead*
 - States must have in place an individualized process for individuals who are at serious risk of institutionalization to seek an exception from the cut or alternative services

Olmstead and the Home Care Rule

- If a state enacts a restrictive policy (like a 40 hour worker cap), the state must create a process that allows consumers who would be placed at risk of institutionalization by new policies to be excepted or given alternative services.
- DOJ and HHS' Office of Civil Rights "Dear Colleague" Letter from December 2014 says the ADA and *Olmstead* generally prohibit across-the-board restrictions and caps and that states must have exceptions process
 - People "at risk" include those who may lose services because they cannot find additional workers (eg, they live in areas with worker shortages) or who might be harmed by having multiple workers due to specialized needs.

Key Components of Exceptions Processes

- **Robust exceptions criteria**

- Long-term criteria

- Lack of providers/unable to find an additional provider
- Individual's unique medical or behavioral needs makes them unable to handle multiple providers

- Emergency criteria

- Provider quits, is terminated or no longer meets certification requirements
- Additional provider is sick or unavailable (like a weather emergency)
- Emergent medical needs

Key Components of Exceptions Processes (cont'd)

- **Exceptions process**
 - Clear and advanced notice to consumers of the exceptions process and criteria
 - Both consumer and case managers can request exceptions
 - Appeals process
 - Collection of data to ensure that the exceptions process is effective and not leading to increased institutionalization or poor health outcomes

State Implementation of Exceptions Processes

- Some states have developed good exceptions processes:
 - OR: Exceptions to cap (50 hours for existing workers, 40 for new workers) for lack of providers, provider unable to work, out-of-town situations, relief or substitute care, emergent need, and unique/complex needs
 - WA: Exceptions to 60 hour cap for limited providers, complex medical or behavioral needs, language needs, and emergency situations that pose a health or safety risk
 - MA: Exceptions to 50 hour cap (up to 66 hours) for short-term (travel, loss of worker) or long-term exceptions for complex medical needs, respite care, or live-in worker

State Implementation of Exceptions Processes

- Other states have no exceptions processes or very narrow processes that may violate *Olmstead*
 - Maine: *Olmstead* lawsuit filed because no exceptions process
 - IL: advocates fought against 40 hour cap with very narrow exceptions policy that only allowed for temporary exceptions; state moved cap to 45 hours and advocates still fighting re narrow exceptions
 - OH: advocates fighting against 40 hour cap with very narrow exceptions; policy recently rescinded and the state is developing a new policy

CMS' HCBS SETTINGS RULE

Context for the HCBS Settings Rule

- Concerns about segregation and isolation in “community” settings
- Changing best practices in services
- *ADA* and *Olmstead* enforcement challenging settings that segregated people with disabilities yet were funded by HCBS
- Extensive public input
 - Went through multiple rounds of proposed rulemaking, with thousands of public comments
 - Rule morphed from being solely based on size or geographic location to one about individual experiences and community integration in both residential and non-residential services

Opportunities Created by the HCBS Settings Rule

- The HCBS settings rule provides an unprecedented opportunity to:
 - Expand capacity of more integrated and individualized services
 - Move state systems away from outdated, segregated service models
 - Help state comply with their obligations under *Olmstead*

Goal and Scope of HCBS Rule

- To “ensure that individuals receiving services through HCBS programs have **full access to the benefits of community living**”
- To “further expand the opportunities for meaningful community integration in support of the **goals of the ADA and the Supreme Court decision in *Olmstead***”
- Applies to all HCBS authorities

Characteristics of Home and Community Based Settings

An outcome oriented definition that focuses on the nature and quality of individuals' experiences, including that the setting:

1. Is **integrated in and supports access to the greater community**;
2. Provides **opportunities to seek employment and work in competitive integrated settings**, engage in community life, and control personal resources
3. Is selected by the individual from among setting options, **including non-disability specific settings**

HCBS Setting Characteristics (cont'd)

4. Ensures the individual receives services in the community to the **same degree of access** as individuals not receiving Medicaid HCBS
5. Ensures an individual's rights of **privacy, dignity, respect, and freedom from coercion and restraint**
6. Optimizes **individual initiative, autonomy, and independence** in making life choices
7. Facilitates **individual choice** regarding services and supports, and who provides them

Additional requirements for provider-owned residential settings

States Must Assess and Categorize All Settings

- 1) Meets all requirements of the rules (or can with modifications)
- 2) Can never meet requirements of the rules because it is an institution (nursing home, ICF, hospital or IMD)
- 3) Is presumed institutional
 - Setting is unallowable unless a state can prove through a “heightened scrutiny” process that the setting overcomes the institutional presumption and meets the rules’ requirements

Presumptively Institutional Settings

- Settings in facilities providing inpatient institutional services
- Settings on the grounds of, or adjacent to, a public institution
- Settings that **have the effect of isolating HCBS recipients from the broader community**. Characteristics may include:
 - Designed specifically for PWD or with specific disabilities
 - Comprised primarily of PWD and staff providing services
 - PWD are provided multiple types of services onsite
 - PWD have limited interaction with the broader community
 - Use restrictive interventions

Statewide Transition Plans

- States must develop a plan to transition their systems into compliance by March 2019, although recent letter from Secretary Price says there will be an extension of the timeline
- 2 step process: (1) initial approval for assessment of policies; (2) final approval for assessment of individual settings
- Public input is required on the plans and any updates
 - This is an important opportunity for stakeholder advocacy!

Status of State Plan Approvals

- 27 states have received initial approval for their systemic assessment, many included letters describing additional steps needed to be taken for final approval
 - As of April 7, this includes 27 states with initial approval: AL, AK, AR, CT, DE, HI, ID, IN, IA, KY, LA, MI, MO, NE, NM, ND, OH, OK, OR, PA, RI, SC, TN, UT, VA, WA, WV
- TN is the only state to have gotten final approval. Highlights:
 - Assessment and validation of all settings
 - Ongoing stakeholder input and engagement
 - Internal HS review before determining whether to submit to CMS
 - Using tiered standards to transform to community-based day services

Themes from CMS Approvals

- Public Comment
 - STPs must include summary of & response to comments
 - Public comment required for completed assessment and HS evidence
- Systemic settings assessments
 - STP must crosswalk state standards to HCBS requirements and note if in compliance, conflict, or silent; must include remediation plan
- Individual setting assessments
 - All settings must be adequately assessed; provider self-assessments must be validated; participant surveys must be linked to specific settings; must have criteria for on-site visits
 - Reverse integration is not a strategy to comply with the community integration requirements

Themes from CMS Responses (cont'd)

- Reimbursement rates and service definitions
 - Must ensure that **service definitions and provider reimbursement rates ensure capacity of, and incentivize, integrated settings** (esp. non-disability specific settings)
- Ongoing monitoring
 - Must describe how licensure or other QM programs will include ongoing monitoring of compliance

Positive State Examples

- Some states are moving towards more individualized and integrated services through the HCBS transition process:
 - Moving from facility-based to all community-based day services
 - Transforming models for facility-based day habilitation
 - Phasing out sheltered workshops
 - Setting size limits on residential settings
 - Requiring housing subsidies to be used in scattered site apartments
 - Expanding the capacity of competitive, integrated employment
 - Funding help bring providers into compliance through model changes
 - Aligning with *Olmstead* activities

Concerns on the Horizon: Threats to Medicaid & Agency Agendas

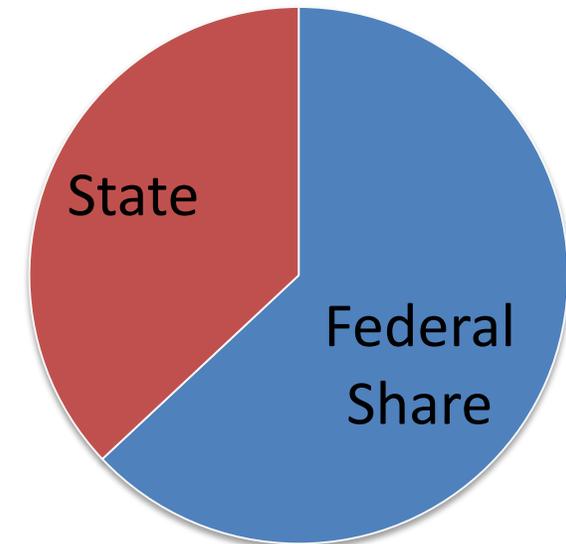
American Health Care Act & Medicaid

- Congress has been working on legislation to repeal and replace the Affordable Care Act, called the American Healthcare Act
- Because Congress is using a vehicle called “budget reconciliation,” it must reduce the deficit
- Huge cuts to Medicaid were included as the primary “pay for” to repeal the revenue-side provisions of the ACA
- The last version of the AHCA proposed **per capita caps** for Medicaid & an option to block grant Medicaid for some populations (not people with disabilities)

Medicaid's Current Structure

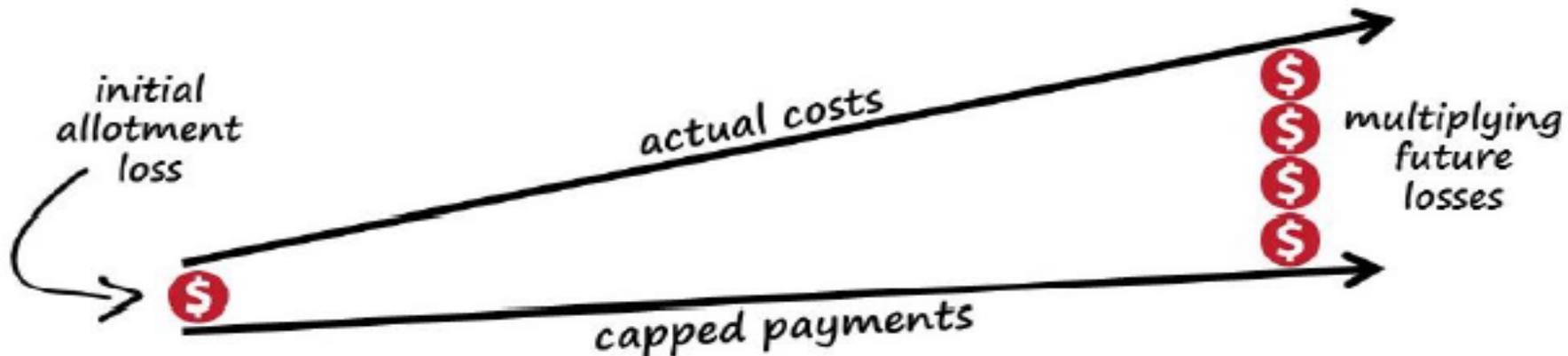
- Federal government and states share actual costs of coverage
- Feds pay on average 63%
- Different matching rates by state (50 to 75%)
- Some services or populations incentivized with higher match
 - Ex: Community First Choice Option that some states are using in their IDD systems gives an extra 6% match; Money Follows the Person 100% of costs covered for 1st year someone moves from an institution to the community

Actual Costs



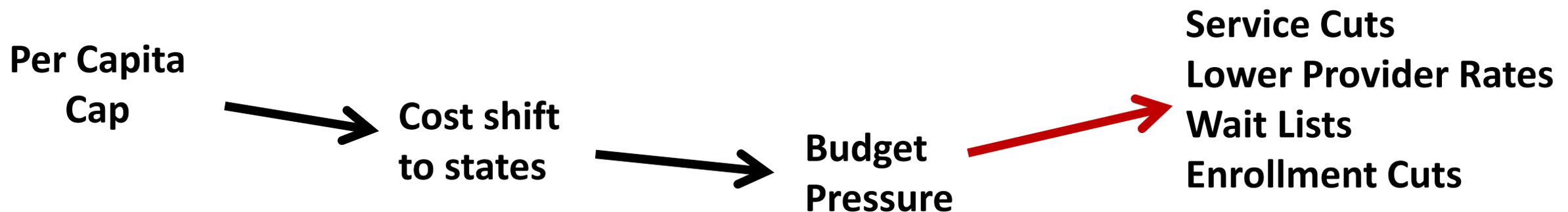
Funding Caps: Block Grant

- Provide states with a **set amount of federal money** instead of the federal government paying a share of all a state's actual costs
- **Massive cost shift to the states**
- Eliminates current Medicaid protections & likely lead to eligibility and service cuts and waitlists
- Last version of AHCA would have allowed for some populations



Funding Caps: Per Capita Caps (PCCs)

- Federal gov't pays a **set amount per Medicaid enrollee** instead of paying for state's actual service costs Same basic problem with starting rate and with annual growth
- Unlike block grant, it accounts for changes in enrollment
- Does not account for new technologies, aging population, changing health needs, etc.



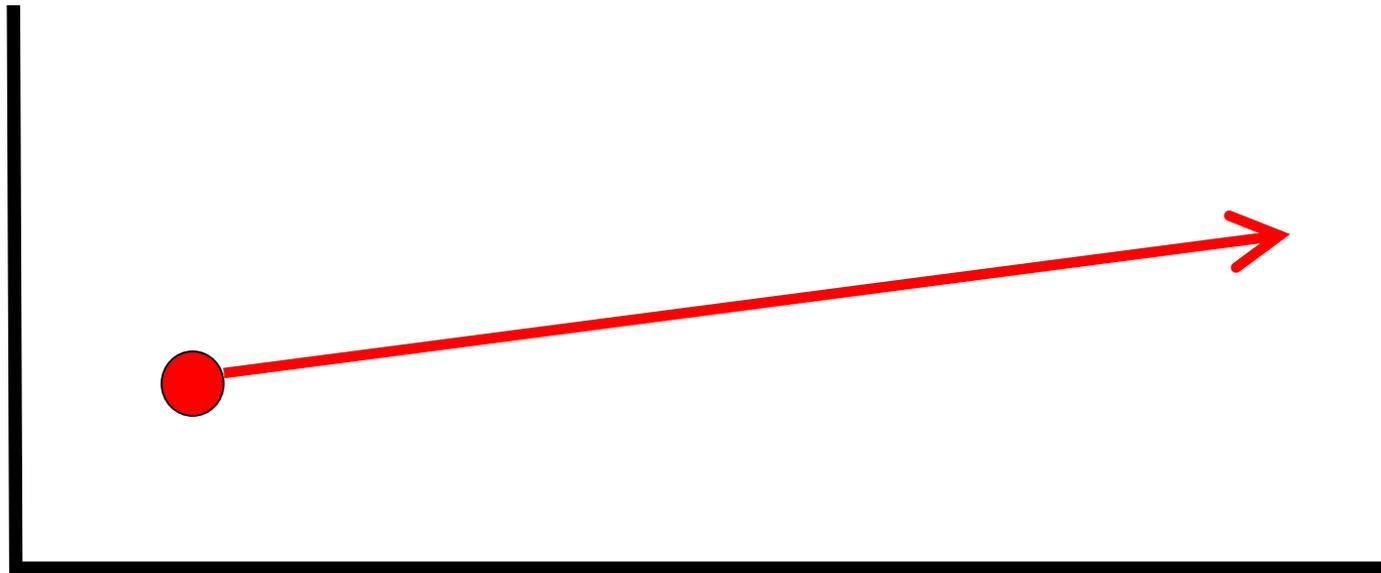
Current financing v. block grants & per capita caps (in theory)*

If your state wants to . . .	Do you get more federal \$?		
	Current Structure	Block Grant	Per Capita Cap
add more enrollees	✓	✗	✓
add more services	✓	✗	✗
cover new Rx	✓	✗	✗
increase provider reimbursement	✓	✗	✗

*This is theoretical since any proposal can alter a state's ability to add more enrollees or other features of the Medicaid program.

Designing a PCC

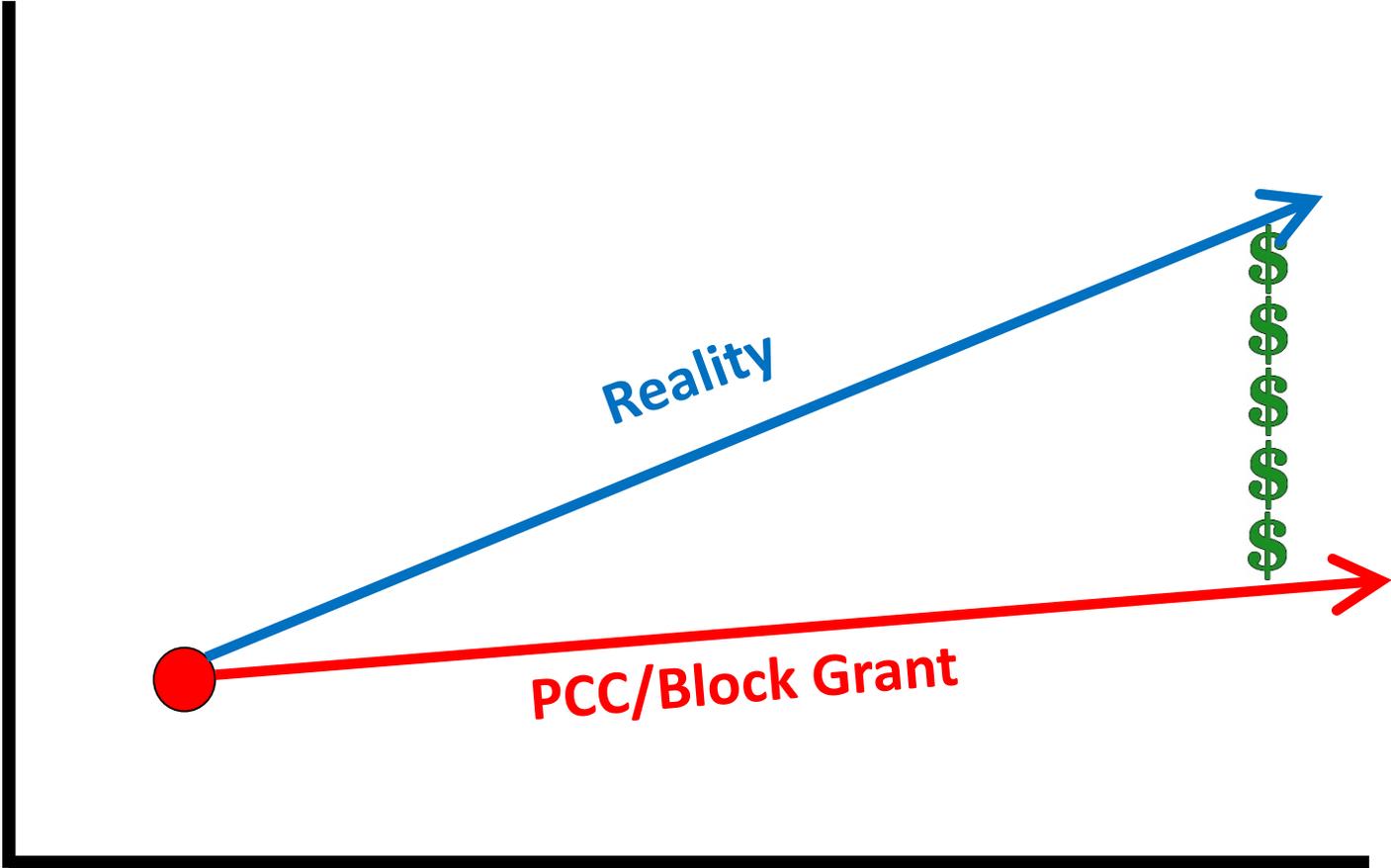
- First, a base year spending level is set
- Second, an index is used to set the yearly growth rate for the base spending level



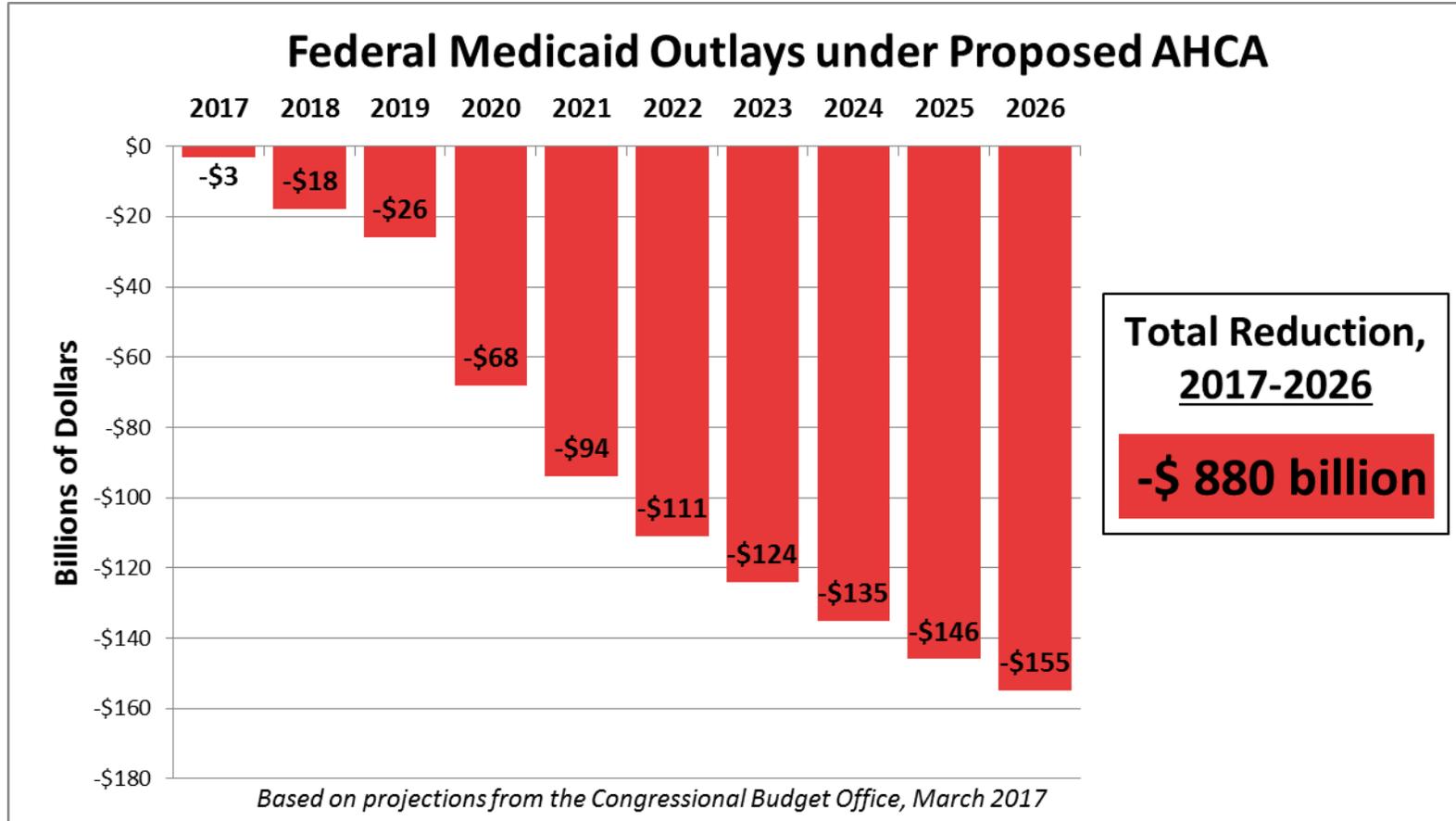
Per capita caps: Growth Index

- AHCA, like prior proposals, use a growth index based on objective factors (such as CPI) **that increase much more slowly than Medicaid spending**
- Last version of the AHCA proposed using a medical CPI plus 1%
 - Earlier leaked House draft had a worse “chained CPI”
 - But medical CPI not include LTSS in the calculation
- Ultimately they make the federal funding gap *grow* every year
- This means that states budget shortfalls in their Medicaid programs increase each year.

From bad to worse



Congressional Budget Office Estimate: \$880 billion cut in federal Medicaid spending



Impact of Budget Shortfalls on People with Disabilities

- As state Medicaid budget shortfalls grow, states may:
 - **Cut services** (particularly “optional” services like waivers)
 - **Totally eliminate optional services** (again like waivers)
 - **Increase waitlists for services** (Many states already have thousands of people on waitlists for HCBS)
 - **Decrease provider rates**
- States that spend less per capita on Medicaid will be particularly harmed
 - PCCs based on states’ 2016 spending

Potential Rollback of Medicaid Through Agency Action

- Last month, HHS Secretary Price and CMS Administrator Verma issued letters to Governors re “Medicaid flexibility”
 - They invited states to submit 1115 waiver proposals
 - Letter made clear that even if Congress does not pass the AHCA, they will attempt to allow states to make as many changes as they want to their Medicaid programs
 - Since the letter, states are now submitting proposals for Medicaid work requirements, drug testing, and block grants
 - BUT HHS’s waiver authority is limited and must further the goals of the Medicaid statute

Uncertainties: Federal Agency Priorities and Regulations

- Will federal agencies continue to play an active role in enforcement of disability laws, like the ADA?
 - Even if not, private plaintiffs can still bring private lawsuits
 - And legal precedents created in courts continues
- President Trump has issued an executive order regarding federal regulations. What will that mean?
 - Vast majority of regulations can only be repealed through formal rulemaking process (including HCBS settings rule & home care rule)
 - A few recent regulations (done in last 60 legislative days) could be repealed by Congress through the Congressional Review Act

Take Aways

- We have made steady progress towards integration and inclusion over the last several decades, across Democratic and Republican administrations.
- Recent laws and policies have added momentum and creates opportunities for state-level changes.
- But there are threats on the horizon, including potential significant cuts and restructuring of Medicaid.
- **Advocate, advocate, advocate!!!** Stakeholders must have a voice and can influence the direction of federal policies and how they are implemented at a state level.

Resources

- Olmstead resources:
 - www.ada.gov/Olmstead (Department of Justice)
- HCBS Settings Rule resources:
 - www.hcbsadvocacy.org (sponsored by national disability orgs)
 - www.medicaid.gov/hcbs (CMS)
- Medicaid resources:
 - www.protectourmedicaid.org

QUESTIONS?