



# Your Advocacy Matters

Allison Wohl

Executive Director, APSE National

March 29 , 2017



***“Somebody has to do something, and it's just incredibly pathetic that it has to be us.”***

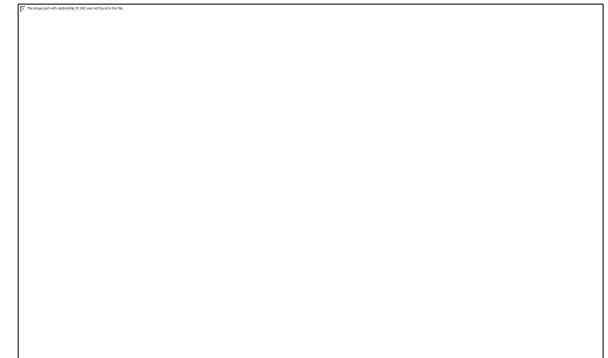
***-Jerry Garcia***







# Grassroots Advocacy Matters More Than Ever Right Now





# How Legislative Advocacy Works

- Bill introduced in the House and sometimes the Senate (Companion bill)
- [“I’m just a bill on Capitol Hill”](#)
- Bill is marked-up in committee(s) of jurisdiction (amendments considered)
- Bill is analyzed and key points summarized
- Advocacy materials developed
- Develop advocacy strategy
- Make appointments with key House and Senate staff
- Brief staff on issues and make your “ASK”
- Follow-Up and keep in touch

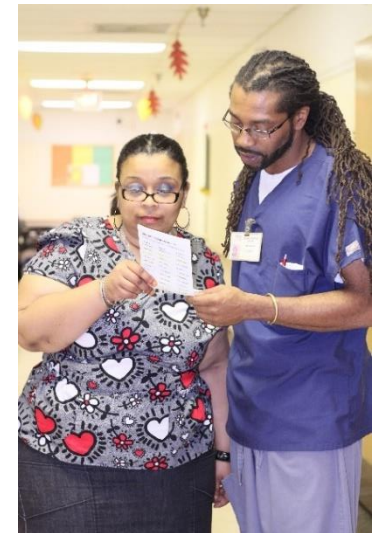




# Agency Regulation



- Before a regulation is considered, the agency puts out a Notice of Proposed Rulemaking
- After the draft NPRM is published, the agency must engage in a public comment period
- This is a chance to attend public meetings and submit your comments (usually online)
- Agency compiles all comments and publishes final rule
- Agency may publish sub-regulatory guidance, usually at the request of states or outside groups.





# How You Can Play a Role



- Attend Town Halls
    - [Tom Cotton Town Hall on AHCA](#)
  - Submit an op-ed to your local paper, detailing your personal story and how proposed legislation would impact you or someone close to you
  - Approach your legislator (state or federal) at local events and tell them your story; if possible, get a picture with him or her
  - Request meetings with your state governor's office
  - Build coalition with groups with similarly aligned issues and/or values:
    - Aging
    - Poverty
    - Healthcare providers
- Social Media: put a human face on your issue
- [CAP video \(over 1m views\)](#)



# What Legislators Want



- IT'S ALL ABOUT REELECTION, REELECTION, REELECTION
- To influence your own Member of Congress (MoC), you have to understand one thing: every House member runs for office every two years and every Senator runs for election every six years. Functionally speaking, MoCs are always either running for office or getting ready for their next election—a fact that shapes everything they do.
- To be clear, this does not mean that your MoC is cynical and unprincipled. The vast majority of people in Congress believe in their ideals and care deeply about representing their constituents and having a positive impact. But they also know that if they want to make change, they need to stay in office.
- This constant reelection pressure means that MoCs are enormously sensitive to their image in the district or state, and they will work very hard to avoid signs of public dissent or disapproval. What every MoC wants—regardless of party—is for his or her constituents to agree with the following narrative:
- ***"My MoC cares about me, shares my values, and is working hard for me."***

***\*From "Indivisible"***



# Salsa: APSE's Action Alert System



28 APSE - Calendar - Week x (1) Facebook x Washington Post: Nation x ACTION ALERT: TODAY x https://apse.salsalabs.org x Targeted Letters - Allison x Person 1

Secure | https://apse.salsalabs.org/actionalertactnowtoprotectmedicaid/index.html?eType=EmailBlastContent&id=c2b13496-adc3-4180-a043-0a8720a7b2a8

Apps Prodigy Math Game Chrome Music Lab Powtoon Google https://www.dropbox American Funds Group American Funds Group Unable to download 2017 IRA Enrollment

Supporters that medicaid reform threatening medicaid programs a clear threat to home and community-based services for vulnerable populations and the premier that care them and the families that support them. Please contact your Members of Congress and ask them to vote "NO" on this bill.

## ACT NOW TO PROTECT MEDICAID

This letter will be delivered to 3 people:

 <p>Sen. Randal Howard Paul Federal Senate Republican Party Kentucky US Senate Phone: (202) 224-4343 Fax: (202) 228-6917</p>	 <p>Sen. Addison Mitchell McConnell Federal Senate Republican Party Kentucky US Senate Phone: (202) 224-2541 Fax: (202) 224-2499</p>	 <p>Rep. James R. Comer Jr. Federal House Republican Party Kentucky District 1 Phone: (202) 225-3115 Fax: (202) 225-3547</p>
---	---	---

### Vote "NO" on the American Health Care Act (ACHA)

I am your constituent and a person with a disability/ family member of someone with a disability/ professional in the disability field. I am writing to ask you to vote NO on the American Health Care Act (ACHA). The ACA and Medicaid help me/my family member/ the people my agency serves to have health care and community-based services.

This bill will make it more difficult for individuals with disabilities to exercise their right to live in the community because the AHCA is a giant budget cut to Medicaid. A per capita cap would make it far more difficult my state to meet the need for HCBS by cutting federal Medicaid funding by growing amounts over time. A per capita cap would reverse states' progress in enabling people to remain in their homes and communities instead of having a nursing home as their only choice.

Remaining: 176

2:04 PM 3/28/2017





# Issues that APSE is Facing



# Medicaid



- **American Health Care Act (AHCA)**
  - Attempt to repeal and replace the ACA
  - APSE Medicaid Action Center
  - Per capita caps for Medicaid would slash the federal contribution to Medicaid by \$880B over 10 years
  - All Medicaid Home and Community-Based Services (HCBS) are optional services
  - These types of cuts would eliminate services and/or tighten eligibility restrictions
  - Elimination of Medicaid as an entitlement
  - Roll back Medicaid expansion

# of people with disabilities in KY	# of PWD who have insurance through Medicaid	Coverage at Risk
771,272	325,006	42%



# Medicaid



## Why would Congress do this?

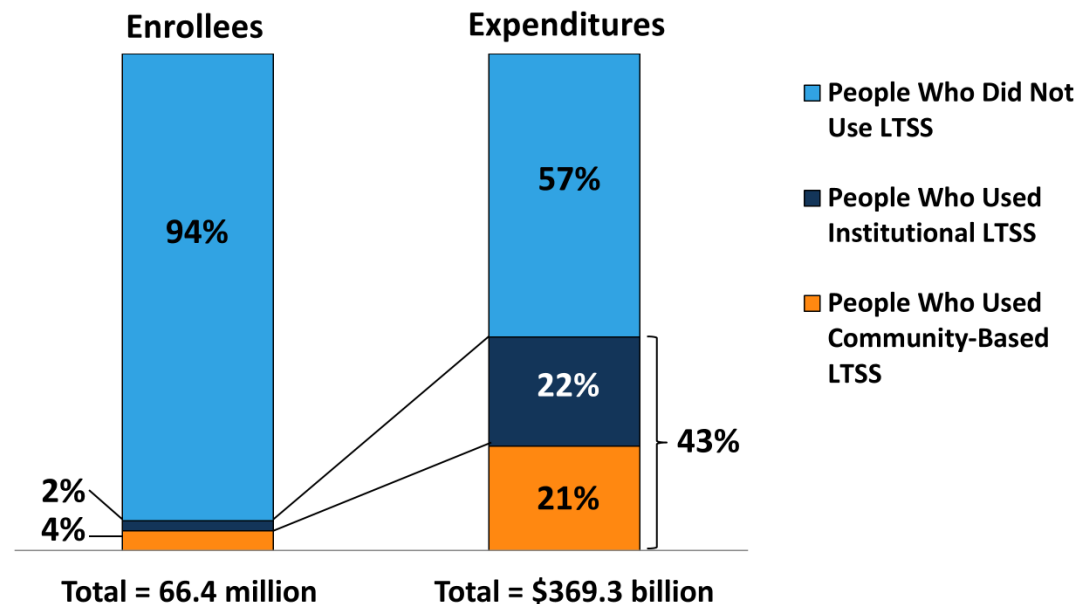
Congress wants to give tax breaks and it needs to Medicaid revenue to do make that happen

We will see this same fight again soon with Tax Reform comes up

## Other Ways to Weaken Medicaid:

Secretary Price issued a letter to states expressing his desire to “free states from regulatory burdens” through waivers

## Medicaid Long-Term Services and Supports (LTSS) Users Accounted for Nearly Half of Medicaid Spending, FY 2010



NOTE: Individuals who used both institutional and community-based services in the same year are classified as using institutional services in this figure.

SOURCE: KCMU and Urban Institute estimates based on data from FY 2010 Medicaid Statistical Information System (MSIS) and Centers for Medicare & Medicaid Services (CMS)-64 reports. Because the 2010 data were unavailable, 2009 data were used for CO, ID, MO, NC, and WV, and then adjusted to 2010 CMS-64 spending levels.



***A small number of enrollees account of a significant amount of expenditure***



# Medicaid

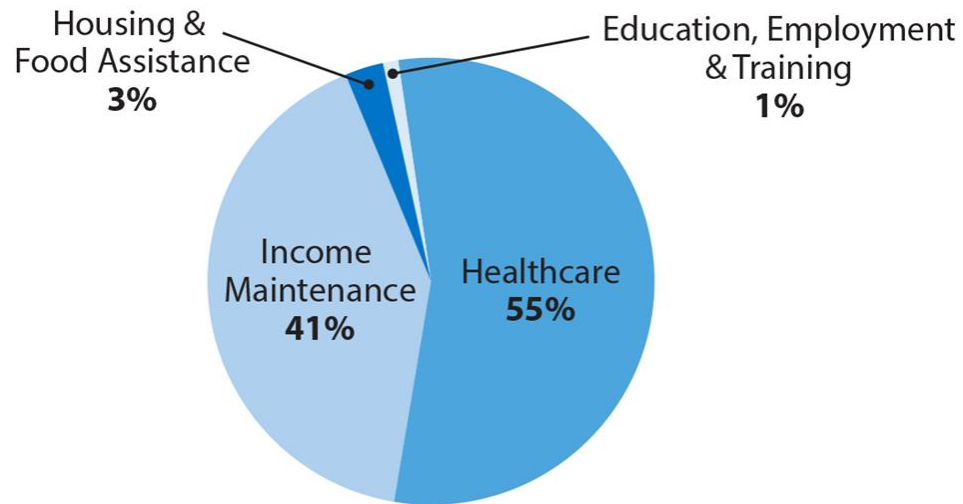


Figure 1. Percentage of Estimated Federal and State Expenditures for Working-Age People with Disabilities by Major Expenditure Category, Fiscal Year 2008<sup>1</sup>

<sup>1</sup> Adapted from Livermore, Stapleton and O'Toole (2011, Health Affairs)



# HCBS Settings Rule

- Hard to see HHS enforcing this rule in the short-term, especially given the fact that there are so few political appointees at federal agencies
- Unlikely go be rescinded—this would require going through the public comment process again after taking 5 years to develop the rule
- Potential law suit challenging the rule using the disparate impact argument → relating to the rule pertaining to residential settings
- Still in effect although some state plans will likely not be approved



# Challenges to WIOA



- State WIOA challenges in the form of attempts to “celebrate sheltered workshops”
  - Missouri
  - Washington
  - Wisconsin
- Attempts to eliminate the Discovery requirement in WIOA
- Attempts to get “work unit” removed from the regulations
- Rumors of attempts to file a law suit challenging Section 511 requirements



# Challenges to the ADA



- The ADA “integration mandate” (Title II) remains the most powerful legal mechanism for advocates
  - Basis for 1999 Olmstead decision
- H.R. 620: The ADA Education and Reform Act of 2017

*The bill prohibits civil actions based on the failure to remove an architectural barrier to access into an existing public accommodation unless: (1) the aggrieved person has provided to the owners or operators a written notice specific enough to identify the barrier, and (2) the owners or operators fail to provide the person with a written description outlining improvements that will be made to improve the barrier or they fail to remove the barrier or make substantial progress after providing such a description. The aggrieved person's notice must specify: (1) the address of the property, (2) the specific ADA sections alleged to have been violated, (3) whether a request for assistance in removing an architectural barrier was made, and (4) whether the barrier was permanent or temporary.*
- H.R. 985: Fairness in Class Action Litigation Act of 2017
  - The FCALA seeks to reign in class actions by making several major changes to how such lawsuits proceed



# Challenges to Special Education Policy



- **Congressional Review Act (CRA)**

- Allows Congress to rescind regulations that were finalized within 60 legislative days of the new administration when a party controls the executive and legislative branches
- Every Student Succeeds Act (ESSA)
  - Hold states accountable to the academic growth of students with disabilities (as well as English Language Learners and low-income students)

- **Political Appointments**

- Still no one appointed beneath the cabinet secretary level, which means that regulations may not be enforced (this includes IDEA)

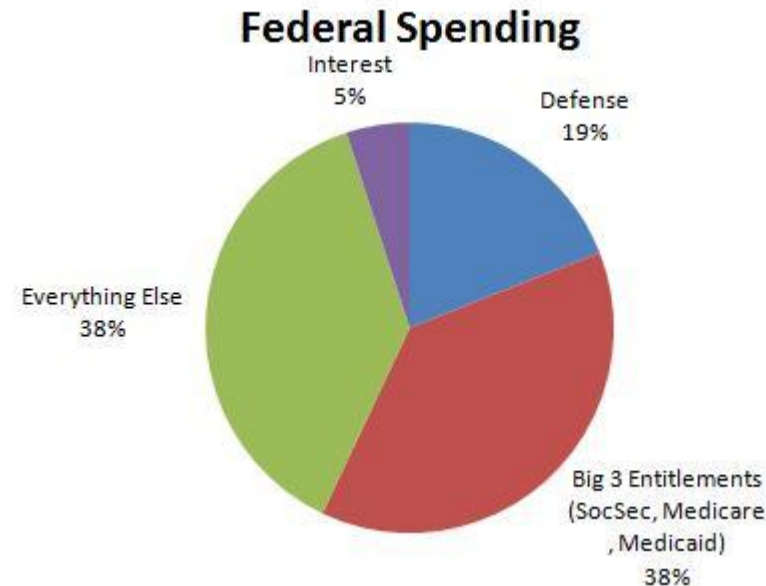
- Potential to take up IDEA reauthorization in this Congress.



# The President's Budget

Proposed massive cuts to Domestic Discretionary Programs in President's FY 2018 budget:

- DOL Office of Disability Employment Policy (ODEP)
- ED Office of Special Education and Rehabilitative Services (OSERS)
  - This includes RSA
- HHS Administration for Community Living
  - This includes DD Act programs, such as Protection & Advocacy, AUCD, and the DD Councils







# What Can YOU Do?



# What can you do?

Get involved in your state Employment First Coalition



www.apse.org/about/chapter-directory/

Use the information below to find your state's APSE chapter. If your state does not have a chapter please [contact our chapter liaison](#).

**Key**

■ States with chapters ■ States without chapters

The map shows the following states with chapters (blue): VA, OR, CA, NV, UT, CO, AZ, NM, TX, LA, MS, AL, GA, FL, NC, SC, VA, WV, OH, MI, IN, IL, MO, KS, NE, SD, MN, WI, PA, NY, ME, NH, VT, MA, RI, CT, NJ, DE, MD, DC. The following states are shown without chapters (grey): MT, ID, WY, AZ, NM, OK, AR, TN, KY, WV, VA, NC, SC, GA, FL, AL, MS, MO, IL, IN, OH, MI, WI, MN, SD, NE, KS, CO, UT, NV, OR, WA, ID, MT.

**Join Our Email List**  
Sign up for conference info, chapter events and webinar updates.  
  
[Sign up](#)

**Join APSE**  
[Learn About Membership](#)

**About APSE**

- [Mission/Vision](#)
- [APSE History](#)
- [What Does APSE Mean to You?](#)
- [APSE National Board of Directors](#)
- [APSE Foundation Board of Directors](#)

4:06 PM 5/20/2015



# What can you do?

## Take Your Legislator to Work Day

- This is a campaign to raise awareness that every adult with a disability can participate in gainful employment and have a meaningful job in the community.
- They are usually held every October as part of National Disability Employment Awareness Month





# What can you do?

## Strategies for Governor Meetings

- Don't just ask for general support of employment of people with disabilities
- Be clear and specific about what action you are asking for
- Policy advocacy is not a one-time thing – it's about building relationships over time





# What can you do?

## Raising Expectations



- Expectation of employment starting at a young age
- Get involved and connected with elementary & middle school special education programs-share information about employment-ask them how you can be a resource
- Family & Caregiver Involvement
- Person-Centered Planning
- Define Employment
- Be actively involved in IEP meetings





# What can you do?

## Sharing information

- Success stories:
  - Integrated/competitive employment
  - Employers who hiring diverse workforces
  - Work Incentive success stories
  - Direct service staff
- Sharing on/with:
  - Social Media
  - Newsletters
  - Events
  - Community Conversations





# What can you do?

## Social Media

- Use for:
  - Sharing information
  - Publicizing your campaign
  - Expanding your constituency
  - Taking action
- Examples:
  - Twitter
  - Facebook





# Moving from “What Can You Do? “ to “What Will You Do?”

- Educate others in the beliefs that:
  - All individuals can and should be contributing members in their communities
  - Everyone deserves the opportunity to find and develop their passions and interests
  - Local economies benefit from individuals who purchase goods and services...And pay taxes
  - Individuals with disabilities, families, employers, employment agencies, schools and entire communities CAN come together to include individuals with disabilities in all aspects of life.





# What Will You Do?



Find out what Employment First look like in your state right now

	Kentucky 2015		Nation 2015	
	Number	%	Number	%
Total in Day & Employment Services	6,581		610,188	
Total in Integrated Employment Services	636	10%	113,223	19%
Total Funding for Day & Employment Services	\$76,445,561.00			
Total Funding for Integrated Employment Services	\$3,128,067.00 4%			

[\\*ICI State Data Report](#)



# What Will You Do?

- What needs to happen to move Employment First Forward in your state?
- What will you do to advance Employment First in your community/your state within the next 6 months? 12 months?
- Let us know how we can help.







# QUESTIONS?

Allison Wohl

Executive Director, APSE National

[allison@apse.org](mailto:allison@apse.org)