

How ACA Repeal and Medicaid Reform Will Impact People with Disabilities And What You Can Do!

Moderator: Rahnee Patrick

Director of Independent Living, Access Living

National Disability Leadership Alliance (NDLA)

NDLA Organizers Forum

ADA Legacy Project – DisBeat

Access Living (Chicago)

Great Lakes ADA Center (Chicago)

Welcome!!!

- Thank you for joining this webinar
- Today, our goal is to increase the power of disability organizing to fight back on attacks on healthcare!

Housekeeping

- To access CART, please click on the “CC” button in the upper left hand corner
- You can submit questions at any time. Use the chat box in the lower left corner to submit questions to the organizers. Questions will be compiled. We will answer as many as we can.

National Perspective Presenters

- Lindsay Baran, Policy Analyst for the National Council on Independent Living
- Alison Barkoff, Director of Advocacy for the Center on Public Representation
- Allan Bergman, President & CEO, HIGH IMPACT Mission-Based Consulting

ACA Repeal: What Is It and What Does It Mean for People with Disabilities?

Lindsay Baran

National Council on Independent Living

Lindsay@ncil.org



How will ACA repeal impact people with disabilities?

- The ACA has helped people with disabilities in many ways:
 - Insurance companies cannot discriminate against people with pre-existing conditions.
 - Insurance companies cannot impose lifetime or annual limits.
 - Money Follows the Person (MFP) was extended.
 - The Community First Choice Option (CFCO) was established.
 - The ACA authorized accessibility standards for Diagnostic Medical Equipment.
 - Also: Medicaid expansion, young adults can stay on parents' insurance plan until age 26, subsidies, minimum benefits.

How will Congress repeal the ACA?

- Republican lawmakers are using the budget reconciliation process to repeal pieces of the ACA.
 - Goal of reconciliation process is cost savings.
- Senate and House have now both passed the Budget Resolution.
 - This kick starts the budget reconciliation process.
- This process only deals with provisions of the ACA that deal with budget.

What comes next in the “repeal” process?

- There are still many steps left in the repeal process:
 - In the budget resolution process, specific instructions are sent to specific House and Senate Committees:
 - Senate: Finance; Health, Education, Labor & Pensions (HELP)
 - House: Ways & Means; Energy & Commerce
 - Committee votes
 - Full House and Senate Votes
 - Not subject to filibuster in the Senate
 - Conference
 - President signature

What is the “replace” process?

- Replace process:
 - Repeal and delay?
 - **Repeal and replace?**
- Now leaning toward repeal and replace happening at the same time, with talk of some pieces being repealed and replaced in the same bill.

What changes can we expect?

- Pre-existing conditions
- Lifetime and/or annual limits
- MFP and CFCO
- Accessibility standards for Diagnostic Medical Equipment
- Medicaid

How can we fight this?

- Make sure the disability arguments are getting out there!
- Start (or continue) advocacy efforts to fight the repeal of the ACA and the disability-specific provisions.
 - Link up with advocacy efforts in your state
 - Link up with national advocacy efforts
 - Talk to your governors and your members of Congress
 - Write an op-ed
 - Respond to action alerts
 - Get your story out



Threats to Medicaid: How People with Disabilities Could Be Impacted and What You Can Do

Alison Barkoff
Director of Advocacy
Center for Public Representation
abarkoff@cpr-ma.org

National Disability Leadership Alliance
Webinar
January 17, 2017

What Is Medicaid?

- The **primary health insurance program for people with disabilities**, older Americans, and low-income populations.
 - Covers more than 10 million non-elderly people with disabilities.
- Provides a wide range of **services that people with disabilities need to live and thrive in the community**
 - Personal care/attendant services, rehabilitative and habilitative services, employment supports, residential supports, medical and nursing services, durable medication equipment, assistive tech., etc.
- **Federal and state government share the cost of all services**
 - Federal share ranges from 50 to 75% depending on the state (in some states counties pay some or all of the “state” share)

Why Are There Concerns Re Medicaid Now?

- Goal of ACA repeal is huge cuts in federal spending, likely leaving inadequate money for a replacement.
 - **Medicaid program a likely source to “pay for” the ACA replacement**
 - Expansion states will likely look to their general Medicaid program to cover the expansion group (which has been covered by federal \$) b/c they won't want to leave these voters w/o any coverage
- Republican Congressional Leaders and Pres.-elect Trump have said they will be doing a large tax cut package later this year
 - **Cuts/changes to Medicaid likely to be part of any tax cut package**
- Republican Congressional Leaders and President-elect Trump's nominee for Secretary of Health and Human Services previously proposed Medicaid cuts & structural changes

What Are the Potential Changes to Medicaid?

- **Block grant**
 - Would provide states with a **set amount of federal money** instead of the federal government paying a share of all a state's actual costs
 - Amount depends on past spending and a formula for the future to decrease federal costs. **Could lead to a nearly 40% cut in federal funding of Medicaid over the next 10 years** (decrease in growth).
 - **States would responsible for any costs beyond the allotment**, likely leading to reduced eligibility, service cuts, wait lists, reduced reimbursement rates, etc.
 - Few/no requirements → eviscerating current Medicaid protections
 - Past proposals by House Speaker Ryan & HHS nominee Price to block grant

What Are the Potential Changes to Medicaid? (continued)

- **Per capita caps (PCCs)**
 - Federal government pays a **set amount per Medicaid enrollee** instead of paying for state's actual costs for providing services.
 - Like block grants, PCCs based on formula aimed at **cutting federal Medicaid spending by up to 40% over next 10 years**
 - Unlike block grants, will likely not lead to reducing eligibility. But will still likely lead to service cuts, wait lists, decreased provider rates, etc.

Bottom line: both Medicaid block grants and PCCs would lead to huge decreases in federal money to states, causing states to cut services, rates, and create wait lists

Is Block Granting or PCCs Needed To Give States Flexibility?

- Some people pushing for block grants and PCCs argue they will give states “flexibility” to design their programs.
- **But Medicaid already has a lot of options that give states flexibility in designing their programs, including:**
 - A range of optional services, including Home and Community Based Service (HCBS) options like 1915(c) waivers (states choose the service package and can limit # of participants), 1915(i) state plan services (states choose the service packages and designate target populations), 1915(k) Community First Choice (states get a 6% enhanced federal match)
 - Managed care authorities and 1115 demonstrations

What Can I Do to Fight to Protect Medicaid?

- **Strongly advocate NOW** against the repeal of the ACA, especially without an adequate (& funded) replacement
 - REMEMBER: Repeal of ACA sets in motion the attacks on Medicaid
- **Educate your representatives in Congress** about the importance of Medicaid for people with disabilities, its current flexibilities, and advocate against major changes
- **Educate your governor & state legislature** about how block grants or PCCs would hurt state budgets & shift costs to states
- **TELL YOUR STORY!** National advocates are collecting stories for advocacy, the media, etc. Write an op-ed.

How Do We Work Together?

- **Build state level advocacy coalitions**
 - Cross-disability and aging advocates should work together closely
- **Connect with national efforts**
 - There are key states for grassroots advocacy based on Congressional representatives on committees of jurisdiction, states who have done the Medicaid expansion or Community First Choice, and Congressmen or governors who have taken helpful positions, etc.
 - Work with national advocates in telling your story
- If you are interested in taking a state-level leadership role, let Amber Smock at Access Living know your name, organization, state, and contact information

Resources to Keep Informed and Help You Advocate

- Protect Our Care Coalition:
<http://familiesusa.org/initiatives/protect-our-care>
- The Arc: <http://www.thearc.org/what-we-do/public-policy>
(Lifeline Toolkit)
- National Health Law Program: <http://www.healthlaw.org/>
- Center on Budget and Policy Priorities: <http://www.cbpp.org/>
- Consortium for Citizens with Disabilities (CCD) through national organizations (e.g., NCIL, ASAN, the Arc, etc.)

Key States and Members of Congress Impacting ACA and Medicaid

January 17, 2017

Allan I. Bergman

President & CEO

HIGH IMPACT Mission-based Consulting

aibergman@Comcast.net

Theme for the Legislative Advocacy Process

“Opportunity is missed by most people because it is dressed in overalls and looks like work.”

Thomas Edison

MEDICAID EXPANSION: 31 States & D.C.

** is (R) Gov,; Gov. Stated concerns

Red is (R) Senator, Key Committee

- **Alaska** – Indep.
- Arizona **
- Arkansas **
- California
- Colorado
- Connecticut
- Delaware
- D.C.
- Hawaii
- Illinois **
- **Indiana** **
- **Iowa** **
- **Kentucky** **
- **Louisiana**
- Maryland **
- Mass. **

MEDICAID EXPANSION STATES, 2

- Michigan **
- Minnesota
- Montana
- Nevada **
- N. Hampshire **
- New Jersey **
- New Mexico **
- New York
- North Dakota **
- Ohio **
- Oregon
- Pennsylvania
- Rhode Island
- Vermont **
- Washington
- West Virginia

COMMUNITY FIRST CHOICE STATES

with 6% additional FMAP \$\$

** is Republican Governor

Red is R Senator on Key Committee

- California
- Connecticut
- Maryland **
- Montana
- New York
- Oregon
- **Texas** **
- Washington

SENATE FINANCE COMMITTEE: (R)

Red is State with Expansion or CFC

- Orin Hatch, Chair UT.
- **Chuck Grassley, IA**
- Mike Crapo, ID.
- Pat Roberts, KS.
- Michael Enzi, WY.
- **John Cornyn, TX.**
- John Thune, S. D.
- Richard Burr, N.C.
- Johnny Isakson, GA.
- **Rob Portman, OH.**
- **Patrick Toomey, PA.**
- **Dean Heller, NV.**
- Jim Scott, S.C.
- **Bill Cassidy, LA.**

Senate Finance Committee (D)

** is state with Expansion and/or Community First Choice

- Ron Wyden, Ranking Member, OR. **
- Debbie Stabenow, MI **
- Maria Cantwell, WA**
- Bill Nelson, FL.
- Robert Mendez, N.J. **
- Thomas R. Carper, DE. **
- Benjamin C. Cardin, MD. **
- Michael F. Bennet, CO. **
- Sherrod Brown, OH** .
- Robert P. Casey, Jr., PA. **
- Mark R. Warner, VA** .
- Claire McCaskill, MO.

Senate HELP Committee (R)

** is state with Expansion

- Lamar Alexander, TN., Chair
- Johnny Isakson, GA.
- Bill Cassidy, M.D., LA. **
- Pat Roberts, KS.
- Michael Enzi, WY.
- Rand Paul, KY. **
- Todd Young, IN. **
- Lisa Murkowski, AK. **
- Richard Burr, N.C.
- Susan Collins, ME.
- Orin Hatch, UT.
- Tim Scott, S.C.

Senate HELP Committee, (D)

**** is state with Expansion**

***** is state with Expansion & CFC**

- Patty Murray, WA.,
Ranking Member ***
- Al Franken, MN.**
- Tammy Baldwin, WI.
- Tim Kaine, VA.
- Bernie Sanders, VT.**
- Michael Bennet,
CO.**
- Christopher S.
Murphy, CT. ***
- Maggie Hassan,
N.H.**
- Robert P. Casey, Jr.,
Pa. **
- Sheldon Whitehouse,
R.I. **
- Elizabeth Warren,
MA. **

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.

Brief Questions (10 minutes)

- We can answer a few questions before moving on to the next section.

State Level Advocacy

- How are advocates in the states “pushing up” on this federal fight in Congress?
- Let’s take a look at:
 - Florida
 - Massachusetts
 - Texas
 - Illinois

Illinois

Maxx Boykin

Community Advocacy and Social Justice Manager

AIDS Foundation of Chicago

And

Field Committee Chair

Protect Our Care Illinois Coalition

FLORIDA

- Presenter: Karen Clay, FAAST
- mikesmom31@mac.com

Florida's Assistive Technology Program



How did FFAST get involved in Medicaid Block Grants?

- FS 413.407 mandates FFAST to review federal and state legislation and agency policies and practices and to identify facilitators of and barriers to **access** and utilization of **assistive technology** services, devices, and **funding sources**.

Florida Medicaid is the primary funding source of funding for the following items:

1. Manual wheelchairs,
2. Power wheelchairs,
3. Specialized seating systems,
4. Scooters, and
5. Speech generating devices.

All of these items are considered assistive technology.

Any change to the Florida Medicaid system would impact Floridians with disabilities access to assistive technology.

The Florida Timeline

- November 8: Election Day
- November 10: FFAST identifies Medicaid Block Grant could be a threat to assistive technology funding.
- November 13 through 23: FFAST and the Family Café begin the process of developing a grassroots movement to advocate on disability issues.
- This movement is called COMPADRES.
- Coalition of Organization for Meaningful Public Affairs, Disability Rights, and Empowering Services.
- November 18: After meeting with President-elect Trump, Florida Governor Rick Scott is quoted saying he wants Florida to lead the nation implementing Medicaid Block Grants.
- December 5: COMPADRES first meeting. 18 people attend representing 13 organizations.
- 16 organizations are listed as founding members of COMPADRES including FFAST, the Family Café, the development disability council, the independent living council and association, and the state's protection and advocacy agency.

The Florida Timeline, continued

- December 15: Medicaid Block Grants are placed on the agenda for Florida Senate Appropriations Committee.
- December 20: Florida Senate President Joe Negron mentions he wants the Florida Senate to begin “building the framework for a block grant program...”
- December 21: FFAST files two public records requests. One is to the state agency that oversees Medicaid. The second is to the Governor’s Office.
- January 5: FFAST sends out an Action Alert to call Governor Rick Scott to say no to Block Grants.
- January 6: Governor Scott sends Florida’s response to the US House of Representatives.
- January 9: Second COMPADRES meeting. A subcommittee is formed to follow Florida’s Medicaid Block Grant efforts.
- January 12: Medicaid Block Grants is presented for the first time in the Florida Senate’s Appropriations Committee.
- FFAST provides public comment.

Florida's Next Steps

- Press ahead with the public records requests. FFAST still has not received any formal responses.
- First COMPADRES Medicaid Block Grant subcommittee meeting scheduled the week of January 16.
- Schedule a meeting with Medicaid staff to press for the inclusion of stakeholder groups during the planning process.
- Schedule meetings with key state and federal legislators to educate them on the issues surrounding Medicaid Block Grants.
- Keep an eye on any legislation filed in Washington and Tallahassee.

Massachusetts

- Charlie Carr
- Legislative Liaison, Disability Policy Consortium Massachusetts
- CharlesCarr@DCPMA.org

What's Happening in Massachusetts

**ACA repeal is real but we've narrowed in on
Medicaid and how Block Grants and Per Capita
Caps could blow up our fragile HCBS network.**

In the Weeds

- Massachusetts spends about \$3 billion a year for non-institutional LTSS.
- We have about 9 HCBS waivers that provide community living options for people with physical, psychiatric, developmental disabilities and elders.
- We also have a very successful MFP demonstration that has transitioned over 2000 people out of nursing homes in the last 4 years but, unfortunately, is about to sunset.
- Personal Care Assistance is a state plan service; it has a budget of approximately \$750 million and serves 26,000 people.

Prioritization of Advocacy

- Fighting against repeal of the ACA is critically important and has a much larger advocacy footprint than disability organizations. We chose to coalesce and work with them in an intersectional way but to drill down to LTSS/HCBS programs that support our people who live in the community outside of institutional settings.
- Our messaging focuses on disabled people and our civil right to live outside of institutions.
- It only makes sense that we fight for keeping the Medicaid program intact and not damaging vital programs through Block Granting and Per Capital Caps.

What have we done so far?

- **We urged our governor to support the ACA and Medicaid**
 - Our governor is a “moderate conservative” Republican and immediately after the Senate cleared the way for repeal of the ACA, he came out in support of keeping critical pieces of the ACA intact and also not to Block Grant or impose Per Capita Caps and said how it would create huge budget holes and pit groups of Medicaid recipients against each other.

What have we done so far? (con't)

- **We have urged people to contact friends and family members in "Red States" to contact their senators**
 - Massachusetts has 2 Democratic Senators who are opposed to repealing the ACA and Medicaid Block Granting.
 - We certainly reached out to them but also encouraged advocates in Red States to contact their Senators and push for no repealing of the ACA or Medicaid Block Grants.

What have we done so far? (con't)

- **We're meeting to zero in on disability concerns - HCBS!**
 - Because all of this came so quickly, we didn't have the chance to organize on the ground with larger groups of disabled people so we've set up a statewide My Medicaid Matters forum on February 1 sponsored by Disability Advocates Advancing our Healthcare Rights (DAAHR), a consumer led cross disability advocacy group. Participation will help us to refine our agenda so that it truly reflects the needs of our broad community.
 - It's our hope that a strong plan will serve as a base for other meetings of disability organizations and that our messaging is powerful and consistent.

What have we done so far? (con't)

- **We're connecting with other advocates (Health Care for All, SEIU, Mass Homecare (elder organizations) and ADDP (ID/DD organizations) and Recovery Learning Communities (psychiatric survivor community) and growing.**
 - Because of the sheer enormity and complexity of the ACA and the Medicaid program, we truly believe that all of our work must be intersectional and our collective power is our best hope to keep our program safe from the onslaught of attacks that lie ahead.

Onward!

- Many thanks to those who organized this webinar and we hope that we can come together again to measure our progress and continue sharing our ideas.

Charlie Carr

CharlesCarr@DCPMA.org

Legislative Liaison

Disability Policy Consortium

Massachusetts

Texas

- Bob Kafka
- ADAPT of Texas (Austin)
- Bob.adapt@sbcglobal.net

Fast Action From ADAPT!

- You can go to www.adapt.org. There is an easy ACA action alert link you can share on social media and email. Letters go to your members of Congress!

Brief Questions (10 minutes)

- We can take a few questions before moving on to the next section.

Storytelling!

- **Presenter: Stephanie Hydal:** Program Manager at Westside Center for Independent Living (WCIL), Independent Audio Producer and DisBeat
- **Presenter: Dominick Evans:** Filmmaker, Speaker, Media and Entertainment Advocate at CDR, #FilmDis and DisBeat Media Chair

The disability view on news.



Dis
Beat

Dominick Evans



Photo
of
Domini
ck
Evans

- Filmmaker, Speaker,
- Media and Entertainment Advocate at CDR
(Center for Disability Rights)
- #FilmDis founder,
- DisBeat Media Chair

Stephanie Hydal

- Program Manager at WCIL
(Westside Center for
Independent Living)
- Independent Audio
Producer
- DisBeat



Making Strong Health Care Stories

Context for health care storytelling.

- The U.S. health care system is frustrating:
 - Not everyone has health care coverage.
 - During annual insurance enrollment, you need to make choices weighing coverage against expense.
 - Every state has a different health system; some are better or more expensive than others.
 - It is fight to advocate and secure community-based long-term services and supports (LTSS)

Two challenges facing media advocacy storytelling:

- For those not dealing with health care in the immediate “now,” issues about coverage feels vague, looming, and abstract.
- Feelings towards medical system: ‘it’s just politics,’ powerless, overwhelming, and fear.

Barriers to media advocacy.

- I'm not interesting. (Yes you are.)
- Who is going to listen?
- How is my story ever going to make a difference?
- I don't know how to tell my story. (You probably do it every day).

You as a storyteller have a mission...

- **And it is not to simply tell what happened to you.**

Should you choose to accept.
Your mission....

1. To make those who say, “It’s not urgent, and it’s out of my hands” care about health coverage.

**2. IGNITE A SPARK FOR YOUR AUDIENCE
TO TAKE ACTIONS TO PROTECT AND
EXPAND HEALTH CARE.**

**3. PROVIDE A SPECIFIC ACTION
THEY CAN DO.**

HOW ARE YOU GOING TO DO THIS?

YOU ARE GOING TO TELL A STORY

(And you are going to make it
memorable.)

Elements to a strong advocacy story:

1. Make the Health Care battle concrete by telling specific life stories.
2. Why should other people care?
3. Call to action.

Specific

- Share your personal experiences through a specific example.
- Choose the story that highlights the most extreme situation.
- This story should show what's at stake for you as an individual. What makes this Life and Death?

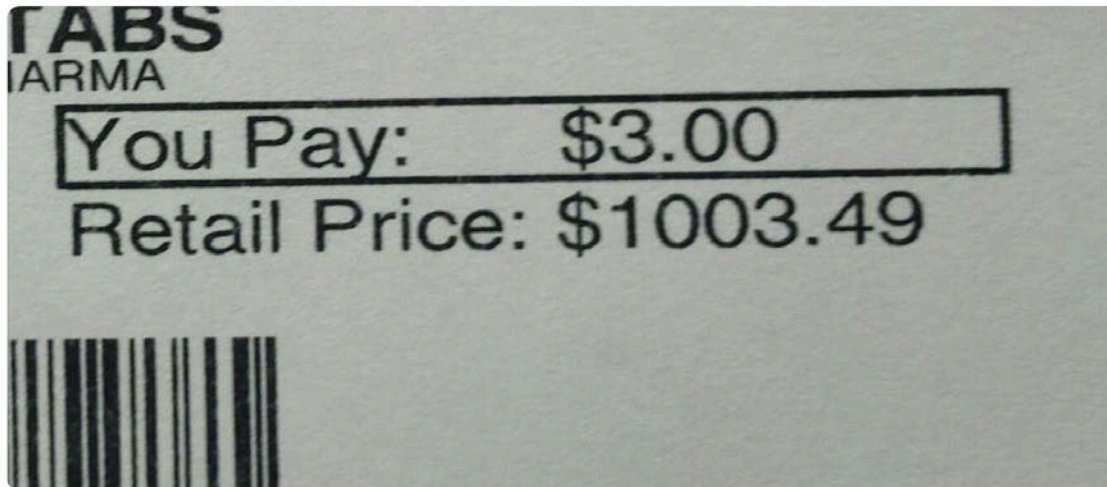


Megh Wright

@megh_wright



My dad starts chemo Monday. Here's just ONE prescription he needs. It's really very simple: without Obamacare, within 8 months he'd be dead.



12:26 PM · 14 Jan 17

Why should other people care?

- For maximum punch, widen scope of your story:
- It's likely not just your experience.
- How many others are in a similar situation?
- Are there statistics that can connect?
- How many people would be in nursing homes if it weren't for LTSS?
 - MFP, CFCO statistics.

Your story is a call to action.

- Shape it to your audience:
 - The general public
 - Policy makers
 - Journalists

What do you want your general public audience to do?

- “Before Obamacare, 1 uninsured person died every 24 minutes....
- Call, write, and visit your elected officials.”

What do you want policy-maker audience to do?

–“Over 100,000 in your district face the tough decision between food, shelter, or medicine. As my elected official, you represent my interest: Save the ACA. #ReadB4Repeal”

What do you want journalists to do?

–“Over 200,000 under 65+ live in nursing homes. We need your help to tell our stories and show how community-based LTSS are civil rights.”

How to use this story structure: Media Advocacy

- Press releases, media advisories,
- Media interview
- Op-ed, letters to the editor,
- News articles, comments
- Press conferences & forums.

How to use this story structure: Grassroots Activism.

- Social media (Twitter, Facebook, Instagram, SnapChat...)
- Podcast
- Town Hall 2 minute public testimony.
- Speeches: rallies, key-notes,
- Advocacy materials: flyers, newsletters, handouts, signs, banners

Moving forward:

- Submit your stories to:
- DisabilityHealthStories.com
- DisBeat is offering to conduct Media training workshops.

More Options For Organizing!

Contact Amber Smock at Access Living by emailing her at asmock@accessliving.org to:

- Sign up for the new Disability Healthcare Hotwire email list
- Get extra handouts and information from the presenters of this webinar
- Gain access to the archived version of this webinar, which will include the audio and CART
- In your email please note which options you want

Question Time!

- Please remember that questions should be submitted to the chat box and the organizers are compiling the questions.
- We will do our best to answer your questions!