What to Expect in Health Care Policy

Disability Policy Seminar, April 24, 2018
Bethany Lilly
Deputy Director of Policy and Legal Advocacy
bethanyl@bazelon.org

www.bazelon.org

https://www.facebook.com/bazeloncenter/

@BazelonCenter
Bazelon Center for Mental Health Law

• Founded in 1972, as the Mental Health Law Project, one of the first public interest law firms in the United States
• Engages in legal and policy advocacy on behalf of people with mental health and other disabilities
• Our litigation and advocacy work is systemic, focused on building effective mental health systems that are individual-focused, responsive, provide necessary resources, and are supported by the political will necessary to be successful
2017 – What We Learned

• The Disability Community has an important (and powerful!) say in debates about health care
2017 – What We Learned

• Many people learned much more about:
  • Medicaid and how important it is to people with disabilities
  • Pre-existing conditions, lifetime and annual limits, essential health benefits, risk pools, catastrophic plans, etc.
  • How to contact members of Congress and make your voice heard
  • Congressional procedure, especially regarding budget resolutions
    • *Budget resolutions expire on September 30*
2017 – What We Learned

And sometimes, it comes down to one vote, from someone you weren’t expecting.
2018 - What We’re Expecting

• No current budget resolution, but Congress is still active
• Opioid bills, ACA “fixes” (meaning threats to pre-existing conditions protections), Money Follows the Person, etc.
• REMEMBER: Per Capita Caps and Block Grants for Medicaid were defeated by 1 vote and passed the House 217 - 213
• Midterms elections are Nov. 6 2018 (195 days)
• And there is a lot of action currently happening at the Administrative agencies
And Graham-Cassidy . . .

IT KEEPS COMING BACK!
What to Expect in Health Care Policy: Can We Start with the Silver Lining?

David Machledt, Sr. Policy Analyst

www.healthlaw.org  @NHeLP_org

April 19, 2018
About NHeLP

• National non-profit committed to improving health care access and quality for low income and underserved individuals and families

• State & local partners:
  • Disability rights advocates – 50 states + DC
  • Poverty & legal aid advocates – 50 states + DC

• Follow us on Social Media
  @nhelp_org on Twitter &
  @NHeLProgram on Facebook
Overview

I. The Silver Lining

II. Dark Clouds (1115 waivers)

III. Darker Clouds: Implications for People with Disabilities

IV. Putting on Your Raincoat and Making a Splash: How to Get Involved
Section I.

Health Policy Outlook
People really like Medicaid!

<table>
<thead>
<tr>
<th>Questions</th>
<th>Favorable View</th>
<th>Working Well</th>
<th>Expand Medicaid</th>
<th>Decrease Medicaid Spending</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
<td>74%</td>
<td>52%</td>
<td>56%</td>
<td>12%</td>
</tr>
<tr>
<td>No</td>
<td>21%</td>
<td>32%</td>
<td>37%</td>
<td>85%</td>
</tr>
<tr>
<td>Don't know</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Source: Kaiser Family Foundation Health Tracking Poll—Feb. 2018
…and also the Affordable Care Act

Reached its highest popularity ever in Feb. 2018, at 54% favorable, with 42% unfavorable.

- 42% favorable and 44% unfavorable in Jun. 2016
- 33% favorable and 49% unfavorable at nadir in Nov. 2013

Despite efforts to undermine open enrollment, 11.8 million people signed up in 2018 (just a 3.7% drop from 2017)
Medicaid is now kitchen table talk!

(At least at my kitchen table)

Health care polled as the “most important issue” for 2018 campaign.

Advocacy raises awareness
- Medicaid is biggest payer of long term care
- Medicaid is less expensive than private coverage

These folks totally rock!
Opportunity knocks?

State level
- Medicaid as new “public option” on Marketplace?
- Ballot initiatives for Medicaid expansion (ME, UT, ID?)
- State level individual mandate

National level (more long term)
- “Medicare extra” and other proposals
- Renew Money Follows the Person and Balancing Incentive Program 2.0
Section II.
1115 waivers: Experiment or backdoor cuts?

Medicaid is tailored for low-income populations

• e.g. Low cost sharing and premiums
• Transportation to medical appointments, if needed
• Robust services for children and adolescents (EPSDT)

Innovations can drive better, more efficient care, but…

Waiving key guardrails can have predictable consequences.

Visit healthlaw.org to access publications related to this topic
1115 waivers background

1. 1115 scope has expanded dramatically and now accounts for 1/3 of Medicaid spending;

2. Under previous Administration, 7 states received waivers as part of Medicaid expansion
   - Premiums with lockouts and waiting periods
   - Retroactive eligibility waivers, waiver of transportation to medical appointments (NEMT)
   - Higher cost sharing
Structure of 1115 demonstrations

1. Is it experimental? What is it testing?
2. Is it likely to assist in promoting Medicaid objectives?
3. Is it within the scope of § 1115 authority?
   - Waive compliance with requirements of Social Security Act § 1902
   - Only to extent and for period needed
   - Special limitations (Cost sharing, budget neutrality)
Source: Center on Budget & Policy Priorities
Waivers from bad to worse

Indiana in 2015
- Premiums with lockouts
- Waiting period
- Higher cost sharing
- Tiered benefits
- No transportation
- Healthy behaviors
- No retroactive eligibility

Indiana in 2018
- All the prior waivers save for higher ED copays
- Work requirements
- Lockout for late redetermination
- Smoking surcharge
Section III.
Why 1115 matters for people with disabilities

1. Some waivers affect the whole Medicaid program
   - E.g. retroactive eligibility, closed formulary

2. People with disabilities in Medicaid expansion will be disproportionately affected

3. If these waivers are acceptable, then what is not?
Collateral damage – Exemptions for disability & frailty

• The process of identifying, screening, & verifying exemptions for people with disabilities increases red tape and lowers enrollment.

• Sanctions disproportionately impact people with disabilities and serious medical conditions
Multiple disability distinctions

ADA Disability:
Major Life Activity
Impaired

Medically Frail:
Significant ADL limitation

Social Security: At least
12 months or death/
No substantial gainful activity
Multiple disability distinctions

• **Activity of Daily Living (ADL)** – eating, personal hygiene, transferring, dressing, maintaining continence
  • DOES NOT INCLUDE driving, managing finances or medications, household chores, communication, working

• **Major life activity** – includes “caring for oneself, performing manual tasks, seeing, hearing, eating, sleeping, walking, standing, lifting, bending, speaking, breathing, learning, reading, concentrating, thinking, communicating, and working.”
Different distinctions, Different standards

• Medically frail exemption applies to most (not all) harmful waivers, though timing matters

• “Good cause” exemption for individuals or caregivers in a family of someone with ADA disability
  • Applied monthly (in KY, IN, AR)
  • Disability (or caregiving) impedes ability to meet the requirement
  • Not routinely exempt from premiums, lockouts, etc.

• Process and timing matters…
Medical frailty variation

Defined in federal regulation…but:

• In Indiana, more than 20% of enrollees are classified as frail. State uses a screen with scoring algorithm.
• In Arkansas, only 7.6% of enrollees are medically frail. State uses a questionnaire.
• In Kentucky, no screen yet exists.
Collateral damage – Purged by paperwork

Reasons for Non-Payment of Premiums, Healthy Indiana Plan Basic Members

- Could not Afford: 34%
- Confusion on payment process: 24%
- Did not know payment required: 25%
- Other: 17%

Adapted from Lewin Group, Indiana HIP 2.0 POWER Account Contribution Assessment

Visit healthlaw.org to access publications related to this topic
Collateral damage – Work requirements

1. **People with disabilities** who should be exempt lose coverage due to documentation or verification issues.
2. **People facing substantial barriers to work** due to health or functional status may not qualify as exempt.
3. **People with disabilities** facing substantial barriers to work will not receive adequate employment supports.
4. **Low-wage workers** will lose coverage due to unstable hours and reporting/verification problems.
5. **Caregivers** may not be exempt, or may have to document their caregiving hours as work activities.

Visit healthlaw.org to access publications related to this topic.
Section IV.

Health Policy Outlook
Advocacy and enforcement

There are a lot of different ways to be involved:

- coalitions
- evidence
- comms
- plaintiffs
- amicus
- comments
- letters
- hearings
1115 commenting tips

• State must respond to comments and explain changes made
• Number and quality of comments matter in negotiations and potentially in litigation
• Substantive comments on the potential policy impacts
  • Expert evaluation
  • Personal stories
  • Relevant bodies of research

Visit healthlaw.org to access publications related to this topic
Helpful 1115 resources

- NHeLP waiver page for 1115 tracker, sample comments, legal/policy analysis, & approved waiver fact sheets;
- CBPP, Kaiser Family Foundation, and CLASP
  - How Might Older Nonelderly Medicaid Adults with Disabilities Be Affected By Work Requirements in Section 1115 Waivers?
  - Section 1115 Medicaid Demonstration Waivers: A Look at the Current Landscape of Approved and Pending Waivers
  - Medicaid Waivers Should Further Program Objectives, not Impose Barriers to Coverage and Care
  - The Effects of Premiums & Cost Sharing on Low Income populations

Visit healthlaw.org to access publications related to this topic
Death by 10,000 Cuts

- This administrative agencies have kicked into high gear
- Primarily, the Department of Health and Human Services, but Treasury and Labor also have jurisdiction over parts of the ACA
- We are seeing many of the legislative proposals we saw last year resurrected by the agencies:
  - Just yesterday, the comment period closed on the Short Term, Limited Duration Health Plans proposed regulation
- While some proposals are resurrecting legislative ideas from the last year, agencies are also working on new proposals
Death by 10,000 Cuts

Short Term, Limited Duration Health Plans

• Both a bill and a proposed regulation
• The Improving Choices in Health Care Coverage Act (Sen. John Barrasso, R-Wyo.)
• Regulation proposed: expanding sale of health plans that could discriminate against people with disabilities/pre-existing conditions, did not have to cover EHB, and will (as the Administration admits) create a separate risk pool and raise premiums for people in the Marketplace
Death by 10,000 Cuts

Notice of Benefit and Payment Parameters for 2019
- Final Rule issued April 17, 2018
- Gave states considerable flexibility to define EHBs (delayed until 2020), authorized cross-category benefit substitution
- Defer to states on Network Adequacy
- Changes Navigator requirements for Marketplaces
- Increased maximum allowable cost-sharing by 7%
- Medical Loss Ratio changes
- NBPP for 2020 (September?)
The Medicaid Managed Care Regulation

- Obama Administration Rule finalized in 2016
- Included an enrollee bill of rights provision, medical loss ratio, expanded information and transparency for beneficiaries, network adequacy standards, medical necessity standards, more focus on LTSS, expanded institutional bias in mental health services, etc.
- The Trump Administration is revising the regulation
Death by 10,000 Cuts

There is often a big difference between how a proposal is talked about and what the proposal does.

From the Administration’s letter authorizing work requirements in Medicaid:

“CMS, in accordance with principles supported by the Medicaid statute, has long assisted state efforts to promote work and community engagement and provide incentives to disabled beneficiaries to increase their sense of purpose, build a healthy lifestyle, and further the positive physical and mental health benefits associated with work.”

From the CCD Letter in response:

“We are particularly concerned that CMS is using decades of disability-driven employment policy to justify the imposition of work requirements.”
ACA Section 1557
• Expanded non-discrimination in health care sector
• Including accessibility, reasonable modifications, and discrimination in benefit design
• Consortium for Citizens with Disabilities comments: “This intersection of disability and other minority and protected classes points to the direct need for Section 1557 and the importance of strong enforcement and implementation to the fullest extent of the law going forward.”
Religious Refusal Notice of Proposed Rule Making

- Currently being finalized (comments were due Mar. 27)
- Expands the ability of health care providers and staff to refuse to serve, treat, or provide particular services due to religious objections
- Concerns about how this interacts with the rights of people with disabilities under the ADA, Section 504, or other civil rights laws to receive health care services
Death by 10,000 Cuts

Public Charge Notice of Proposed Rule Making
• Pending at the Office of Management and Budget
• Applies to legal immigrants or parents of United States Citizens
• Would deny citizenship to individuals who rely on Medicaid, earned-income tax credit, food stamps, or other safety net programs
• Specific, and discriminatory, impact on people with disabilities
2018, 2019, and beyond . . .

- You have power! Use it!
- Capitalize on popularity and continue to educate.
- Ask questions and understand the policy.
Questions?