Washington Update

Cooley's Anemia Foundation

Patient-Family Conference

July 7, 2017

Lyle Dennis, Partner

Cavarocchi Ruscio Dennis Associates, LLC

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Agenda for Today

Where have we been and where are we going?

- Introductory Remarks
- Washington Update
- Outlook for Remainder of 2017

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About CRD Associates

Extensive experience, effective solutions

- Firm founded in 1980
- 20 professionals
- 60 clients – many public health, science and patient advocacy groups
- 20th year working with CAF
- CAF Team consists of:
  - Lyle Dennis, Partner
  - Zara Day, Senior Policy Associate

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Research Issues:
FDA, NIH, CDC, HRSA

- FDA – ELPFDD meeting on July 5
- NIH – Actively engaged in increasing research funding
- CDC – Retaining funding for patient identification and related work
- HRSA – Working with MCHB
- All – Multi-Agency meeting on May 3, 2017

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Washington Update

The more things change . . .

- New Administration and New Congress
- FY 2018 Appropriations
- Other Congressional priorities
- American Health Care Act

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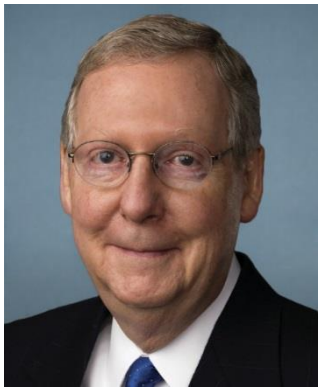
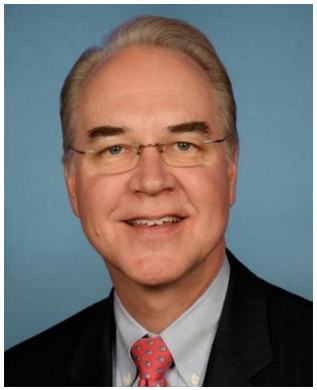
New Administration and New Congress

New faces, new priorities




- ACA Repeal and Replace
- Less control in Washington → more flexibility for states and plans
- Reduction of administrative burden in federal health programs

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FY18 Appropriations

Need to fit a year-long budget process into 5 months!

- Trump Administration "skinny" budget released mid-March and full budget released mid-May
- Trump Administration priorities do not equal Congressional priorities
  - NIH cuts, for example
- Sequestration returns – unsure if budget parity will remain
- Outlook: too early to tell; uncertain at best, but will be a tough year to retain/increase funding

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ACA Repeal and Replace Process To Date

How did we get here?

- January: Congress passes reconciliation instructions in budget resolution
- March 6: AHCA language released
- Goal: Final vote on House floor by end of March
  - First vote pulled when there was insufficient support
- April: Negotiations continue, amendments drafted
- May 4: House passes AHCA: 217 to 213

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ACA R&R - continued

- Action turns to the Senate.
- McConnell names 13 Republican senators to draft the bill – in secret.
- No committee review; no hearings.
- Scheduled to come to the floor June 29, but pulled for lack of support.

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What would the R&R do?

Most concerning policies for Thals

- Continuous coverage requirement makes pre-existing condition protections meaningless
- Essential health benefits' state waiver undermines ban on lifetime and annual caps
- Patient and State Stability Fund could help with reinsurance but facilitates high risk pools
- Medicaid reforms and expansion phase-out jeopardizes coverage for 20+ million people.

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What will the Senate do?

Now or never?

- Significant political pressure to repeal ACA vs. significant political pressure to maintain ACA.
- 52 Republicans/48 Democrats – 50 + VP required to pass.
- 19 Republicans come from states that expanded Medicaid.
- Multiple groups – including CAF – have expressed concerns about the bill.
- The Jimmy Kimmel test?

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Grassroots advocacy will be key!

Will pressure be maintained?

- Considerable grassroots opposition to the BCRA.
- Considerable opposition from health care stakeholders (CAF to AMA).
- Each Republican Senator is extremely important → your advocacy matters!

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Any Questions?

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Additional detailed slides

- Continuous coverage requirement
- Essential health benefits
- Patient and state stability fund
- Phase out of Medicaid expansion
- Changes to Medicaid financing

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Continuous Coverage Requirement

Large premium hikes for people with pre-existing conditions

- Repeals ACA individual and employer mandates → new continuous coverage requirement
  - Anyone who lapses in coverage 63+ days must pay 30% penalty for a year when they reenroll in individual market coverage OR
  - If state applies for waiver, plans could set premiums based on health status for a year (MacArthur amendment)

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Essential Health Benefits

EHB changes undermine many patient protections

- ACA defined 10 broad categories of services that plans have to cover
- States can apply for waiver to define essential health benefits (EHBs) (MacArthur Amendment)
- Why is this concerning?
  - Plans can offer skinny coverage
  - Ban on lifetime and annual caps, out-of-pocket maximum only apply to services defined as EHBs
    - **Affects all private insurance plans** since large employer and self-insured plans can set their lifetime/annual caps based on any state's EHBs

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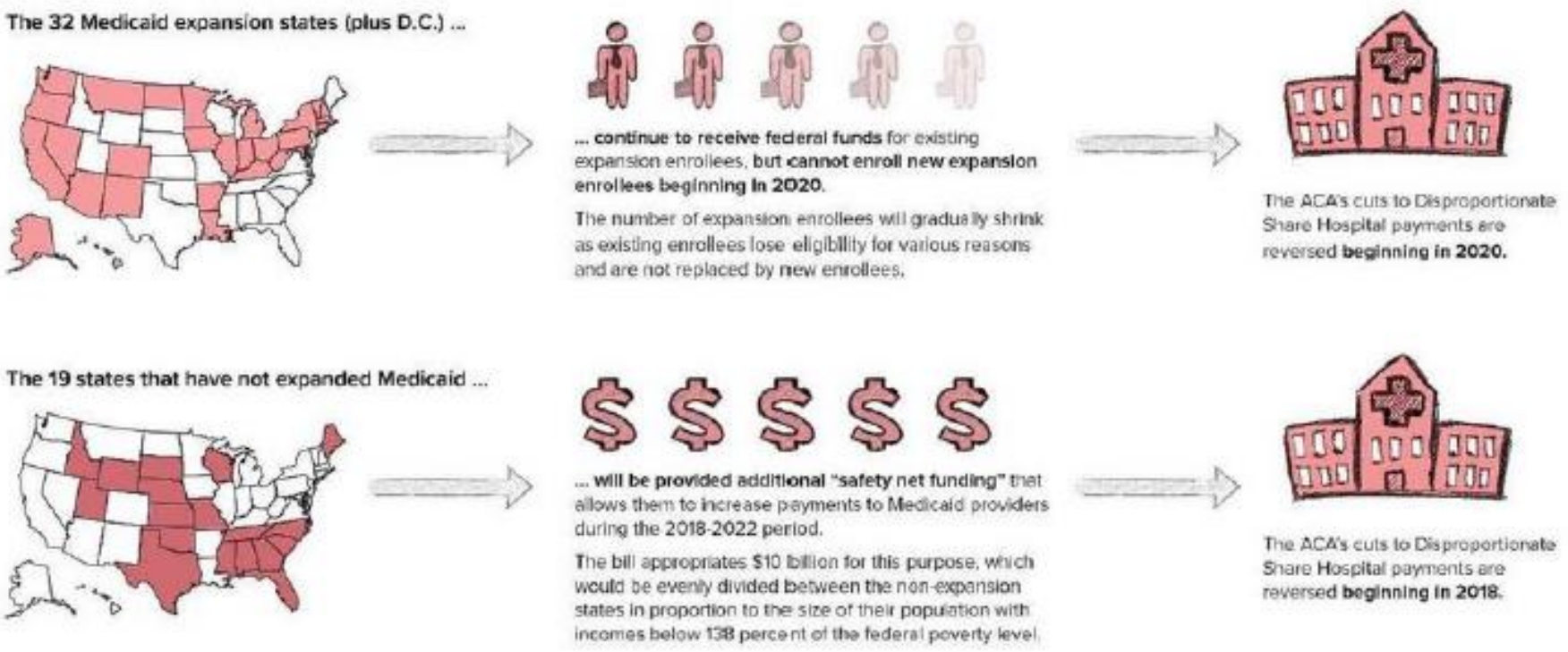
Patient and State Stability Fund

Opportunities and challenges

- $130B/10 years for states to stabilize insurance markets and benefit individuals
  - $15B/9 years for “invisible” high risk pools (Palmer/Schweikert)
  - $8B/5 years for people in waiver states that pay penalty based on health status (Upton/Long)

Phase Out of Medicaid Expansion

CBO estimate: 14 million to lose coverage by 2026



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Changes to Medicaid Financing

How do states respond to decreased federal funding?

Figure 7

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