SOCIAL WORKERS POSITIONING FOR THE FUTURE...
THE POLICY & POLITICS OF PALLIATIVE CARE:
A WASHINGTON PERSPECTIVE

11th Annual Palliative Care Social Work Conference
Denver, CO
April 12, 2019

ANDREW L. MACPHERSON
PRINCIPAL
HEALTHSPERIEN, LLC
1) Statement of Problem … What *Should* Motivate Policymakers
2) Important Context: Health Care Reform Policy and Politics Today
3) Discussion of Key Palliative and End-of-Life Care Federal Legislation & Regulation – And the Critical Role of the Social Worker
4) Prognostications, Analysis, & the Future…
BUT FIRST…

Source: My Mom’s Facebook Account (used without permission)
Accessed: This morning
THE ULTIMATE QUESTION (AND OBJECTIVE)

How do we redesign our health care system to be fully responsive to one’s goals, values, and wishes – especially at the end-of-life?
Palliative care means patient and family-centered care that optimizes quality of life by anticipating, preventing, and treating suffering. Palliative care throughout the continuum of illness involves addressing physical, intellectual, emotional, social, and spiritual needs and to facilitate patient autonomy, access to information, and choice.

-Centers for Medicare & Medicaid Services
**THE PROBLEM:**

*(AND WHAT SHOULD MOTIVATE POLICYMAKERS TO ENGAGE)*
**THE PROBLEM:**
**“THE BIG GAP”**

<table>
<thead>
<tr>
<th><strong>What People Want</strong></th>
<th><strong>What They Get</strong></th>
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<tr>
<td>1. Be at home with family, friends</td>
<td>Recycled through the hospital</td>
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<td>2. Have pain managed</td>
<td>Often unwanted, ineffective treatment</td>
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<td>3. Have spiritual needs addressed</td>
<td>Often die in hospital, in pain and isolation</td>
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<td>4. Avoid impoverishing families/beiing a burden</td>
<td>At great cost to families and the nation.</td>
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THE PROBLEM:
THE “CONVERSATION” AND PHYSICIAN TRAINING

• A recent study show that approximately **42% of individuals** have had discussions on end-of-life issues.

• Yet **only 23%** put their care directives in writing and/or legal/medical (aka POLST) documentation.

• And **a full 90%** said that they physicians never asked about this issue.

Source: John H. Hartford Foundation
THE PROBLEM:
AMERICANS HIGHLY CONCERNED ABOUT TREATMENT OPTIONS

How concerned are you about not having adequate treatment options at the end-of-life?

Concerned: 27%
Not Concerned: 73%

Source: Cambia Health, 2014
Where do individuals wish to die? And where do they actually die?

Where They Wish to Die
- 70% Home
- 30% Other/No Pref

Where They Actually Die
- 68% Home
- 32% Other/No Pref

Source: California Health Care Foundation, 2016
The (Most Obvious) Problem: Cost Implications

Distribution of Traditional Medicare Beneficiaries and Medicare Spending

<table>
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<th>Total Number of Traditional Medicare Beneficiaries:</th>
<th>Total Traditional Medicare Spending:</th>
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<td>35.4 million</td>
<td>$343 billion</td>
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- **10%**
  - 90%
  - Average per capita Traditional Medicare spending: $9,702

- **57%**
  - 43%
  - Average per capita Traditional Medicare spending among top 10%: $55,763

- **43%**
  - Average per capita Traditional Medicare spending among bottom 90%: $4,584

NOTES: Excludes Medicare Advantage enrollees. Includes noninstitutionalized and institutionalized beneficiaries.
AND YET CONGRESS IS CUTTING HOSPICE RATES

Source: NPHCO, The Medicare Hospice Benefit
“High-quality palliative and hospice care is fundamentally not just a return on investment, but a return on humanity.”
IMPORTANT CONTEXT:

HEALTH CARE REFORM POLICY & POLITICS TODAY
**FIRST, SOME PERSPECTIVE...**

**DOCTOR SAID I NEED TO RELAX**

**SAYS I'M TOO JUMPY**

And yet...

**NEVER in the history of calming down has anyone**

**EVER calmed down after being told to calm down.**
HEALTH CARE POLICY IN WASHINGTON TODAY...

MUELLER REPORT!

PBM Reforms

Affordable Care Act Reforms

Premiums & Cost-sharing

Powerful Crosscurrents

Short-Term Plans/AHPs

Single payer!

ACA Lawsuit/Constitutionality

Drug Pricing

Presidential Election!
PALLIATIVE CARE AGENDA IN WASHINGTON TODAY...

✓ Bipartisan
✓ Bicameral
✓ Data and Experience-Driven
✓ Forward-looking & Focused on Innovation
✓ Affected By, But Not Infected By Broader Political Challenges
‘Midterm exit polls: Health care is top issue for voters’

‘A plurality of 41 percent identified health care as the issue most important to their vote, which Democrats made the centerpiece of their campaign in races throughout the country.

‘Asked which party would better address Americans with pre-existing conditions, 58 percent said Democrats versus 34 percent who said Republicans.

‘ECONOMY TAKES BACK SEAT

‘The set of issues voters prioritized this year looked very different than exit polls of past elections, where the economy was typically a larger focus.’

NOTABLE STATISTIC:

TRUMP APPROVAL RATING DROPPING

Disapprove: 54.9%
Approve: 40.2%
Republican Voters:
“Do you want President Trump to face a primary challenger in 2020?”

- 43% Yes
- 49% No
- 8% ?

Source: Monmouth University Poll, February 2019
Reform the reform: Changes to the Affordable Care Act?

House oversight hearings on the Trump administration’s recent ACA regulations and guidance that could weaken the insurance marketplaces are inevitable with shift in leadership.

Addressing the soaring cost of drug prices has already begun to take center-stage.

More visible efforts by progressive Democrats in the House to advance Medicare-for-all/Single Payer/Public plan concepts.

The pressure from the Administration to advance policy via regulation will continue to escalate. We can expect a much higher level of oversight over the CMMI initiatives and the agency’s reforms overall, for example with changes to the Medicare program through rulemaking, but overall trajectory of approach will remain the same.
KEY HEALTH CARE POLICY ISSUES
COMMITTEES LEADERSHIP

Senate Finance
Committee Chair: Chuck Grassley (R-IA)
Ranking Member: Ron Wyden (D-OR)

Energy & Commerce
Committee Chair: Frank Pallone (D-NJ)
Ranking Member: Greg Walden (R-OR)
Subcommittee on Health Chair: Anna Eshoo (D-CA)
Subcommittee Ranking Member: Michael Burgess, M.D. (R-TX)

Health, Education, Labor & Pensions
Committee Chair: Lamar Alexander (R-TN)
Ranking Member: Patty Murray (D-WA)

Ways & Means
Committee Chair: Richard Neal (D-MA)
Ranking Member: Kevin Brady (R-TX)
Subcommittee on Health Chair: Lloyd Doggett (D-TX)
Subcommittee Ranking Member: Devin Nunes (R-CA)
CONGRESSIONAL ACTION:
ADVANCED ILLNESS, PALLIATIVE CARE, AND HOSPICE
Establishing Innovative Models of Care
- The Patient Choice and Quality Care Act of 2017 (S.1334/H.R.2797)
- The Removing Barriers to Person-Centered Care Act of 2019 (S.829)
- Independence at Home Act of 2017 (S. 464)

Strengthening the Palliative Care Workforce
- Palliative Care and Hospice Education and Training (PCHETA) Act (H.R.647)
- The Compassionate Care Act of 2017 (S. 2961)

Improving Access to Medicare Advantage Benefits
- Creating High-Quality Results and Outcomes Necessary to Improve Chronic (CHRONIC) Care Act (S.870) (Enacted)

Empowering Consumer Choice
- Medicare Choices Empowerment and Protection Act of 2017 (S. 618)

Supporting Caregivers
- Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act (H.R. 3759) (Enacted)

Improving Access to Hospice
- Rural Access to Hospice Act (S. 980)
- Medicare Patient Access to Hospice Act of 2017 (H.R. 1284) (Enacted)

Leveraging the Aging Network
- Reauthorization of the Older Americans Act
Who?

- Reps. Roe [R-TN], Bluemenauer [D-OR] and many more

What?

- Establishes demonstration for interdisciplinary care team to provide hospice-like care in the home setting upstream from hospice
- Requires the Secretary in consultation with stakeholders to prioritize quality measures that impact the advanced illness population (focus on patient-centeredness, family caregiver-centeredness, accuracy of care plans, including documentation of individual goals, preferences, and values)
- Promotes and provides support for discharge planning
- Public education campaign, national hotline, online training tools and supports
To amend title XVIII of the Social Security Act to provide for advanced illness care coordination services for Medicare beneficiaries, and for other purposes.

IN THE SENATE OF THE UNITED STATES
June 12, 2017

Mr. Warner (for himself, Mr. Isakson, Ms. Baldwin, Ms. Collins, Ms. Klobuchar, and Mrs. Capito) introduced the following bill, which was read twice and referred to the Committee on Finance

A BILL
To amend title XVIII of the Social Security Act to provide for advanced illness care coordination services for Medicare beneficiaries, and for other purposes.

SEC. 5. ENHANCING COVERAGE OF ADVANCE CARE PLANNING SERVICES.
(a) Definition.—Section 1861 of the Social Security Act (42 U.S.C. 1395x) is amended by adding at the end the following new subsection:
""Advance Care Planning Services"
"(1) The term 'advance care planning services' means services identified as of the date of enactment of this subsection as Current Procedural Terminology (CPT) codes 99497 and 99498, and such codes as subsequently modified, that are furnished by a physician or other eligible practitioner (as determined by the Secretary).
"(2) For purposes of paragraph (1), the term 'eligible practitioner' includes, in addition to a practitioner eligible to bill such CPT codes as of the date of enactment of this subsection, an individual who—
(A) is a clinical social worker (as defined in subsection (b)(1)); and
(B) possesses—
‘Palliative Care and Hospice Education and Training Act of 2019’
H.R. 647

Who?

- Sponsored by:
  - 138 sponsoring Members in the House of Representatives; 96 Democrats, 42 Republicans
  - 285 cosponsors in 115th Congress!
  - Senators Tammy Baldwin [D-WI], Shelley Moore Capito [R-WV], Susan Collins [R-ME], Angus King [I-ME], Chris Coons [D-DE], Lisa Murkowski [R-AK], Chris Murphy [D-CT] Jerry Moran [R-KS], John Boozman [R-AR], Kirsten Gillibrand [D-NY]
- Introduced: January 17, 2019

What?

- Focuses on workforce development for palliative care
  - Fosters palliative care and hospice education centers.
  - Establishes national campaign to inform patients, families, and health professionals about palliative care benefits and services
  - Directs NIH to expand national research to improve delivery of palliative care to patients with serious illness.
Who?

- Authored by:
  - Senators Sheldon Whitehouse [D-RI]
- Introduced: March 14, 2019
- Referred to Senate Committee on Finance
- Hearings held before the Senate Special Committee on Aging

What?

- Amends title XI (General Provisions) of the Social Security Act to establish an alternative payment model for patient-centered care with respect to Medicare beneficiaries with advanced illnesses.
- Through the voluntary pilot program, the Centers for Medicare & Medicaid Services (CMS) shall enter into demonstration project agreements with advance care collaboratives to provide high quality Medicare services.
Older Americans Act Amendments

- OAA up for reauthorization in September 2019
- C-TAC has worked with the National Association of Area Agencies on Aging (n4a) on amendment proposals
- Submitted draft proposal language to Senate HELP Committee
  - Definitional areas – add “advanced illness”
  - New Leadership Activities for the Administration for Community Living (ACL) – convene advisory council and submit recommendations to Congress
  - Authorize new pots of money that could be made available on a competitive basis to AAAs to do innovative work on advanced illness.
  - Education and Training – Geriatric Workforce Enhancement Program (GWEPs) and Project ECHO virtual trainings – cross education of Aging Network and advanced illness care providers
‘CREATING HIGH-QUALITY RESULTS AND OUTCOMES NECESSARY TO IMPROVE CHRONIC (CHRONIC) CARE ACT’

Who?
- Sens. Hatch [R-UT] and Wyden [D-OR] and every member of the Senate Finance Committee

What?
- Extends Independence at Home demonstration by 2 years
- **Includes GAO study on “longitudinal care planning”**
- Permanently authorizes SNPs
- Expands testing of MA Value-Based Insurance Design test model.
- Allows MA to provide additional telehealth benefits to enrollees and, to chronically ill enrollees, certain supplemental health care benefits.
- Allows prospective, voluntary assignment of Medicare fee-for-service beneficiaries to accountable care organizations (ACOs), and
- Allows ACOs to operate beneficiary incentive programs.

*SIGNED INTO LAW FEBRUARY 2018!*
Medicare Advantage Supplemental Benefit Changes to Improve Quality of Life for the Seriously Ill

- Expanded “primary health related” definition and follow-on CMS guidance represents important opportunity to provide expanded benefits to those with serious, advanced illness:
  - **Home-based palliative care**: Home-based palliative care services to diminish symptoms of terminally ill members with a life expectancy of greater than six months not covered by Medicare (e.g., palliative nursing and social work services in the home not covered by Medicare Part A).
  - **In-home support services**: In-home support services to assist individuals with disabilities and/or medical conditions in performing ADLs and IADLs within the home to compensate for physical impairments.
  - **Support for caregivers of enrollees**: Respite care provided through a personal care attendant or the provision of short-term institutional-based care, as appropriate.
  - **Transportation**: Transportation to obtain non-emergent, covered Part A, Part B, Part D, and supplemental benefit items and services to accommodate the enrollee’s health care needs.
Many groups working with payers to promote uptake

2019
- At least 40% of plans will offer new types benefits (Avalere)
- CMS: 12 insurers offering through 160 plans in 20 states
- Small number offering home-based palliative care in 2019 (29 plans)

Expect much greater uptake in 2020
PHYSICIAN-FOCUSED TECHNICAL ADVISORY COMMITTEE (P-TAC) AND THE ADVANCED CARE MODEL (ACM)

Background
Building on evidence-based models, the ACM delivers comprehensive, person-centered care, including:

- Concurrent curative and palliative treatment
- Care coordination across care providers and settings
- Comprehensive advance care planning
- Shared decision making with patient, family, and providers
- 24/7 access to clinical support

Target Population
The ACM target population is comprised of fee-for-service Medicare beneficiaries with advancing chronic condition(s). To be enrolled:

- One or more chronic conditions
- Recurrent or extensive disease: acute care utilization, functional decline and/or nutritional decline
- High 1-year mortality risk

Payment
The ACM offers a new advanced alternative payment model. Its components include:

- PMPM care management fee
- Shared savings and risk through population-based payments that reward performance
- Incremental integration with existing value-based payments and APMs
- Physician-focused payment to support participation by specialists and primary care providers, including small physician practices and in rural areas

Outcomes
The expected impact for ACM beneficiaries are:

- Improved patient and family engagement,
- Enhanced shared-decision making
- Coordinated care that aligns with patient preferences,
- Symptom management,
- Prevention of avoidable and unwanted hospitalizations or low value treatment
- Prevention of unwanted futile care at the end of life.
RECENT ACTIVITY – BIPARTISAN SUPPORT FOR NEW MODEL
On March 26th, 2018, members of PTAC unanimously recommended C-TAC’s Advanced Care Model for testing. Notably, the model submitted by the American Academy of Hospice and Palliative Medicine (AAHPM), which represents a variety of hospice stakeholders (but especially physicians on hospice care teams), was also recommended by the PTAC, though not unanimously.

In June 2018, Secretary Alex Azar indicated his support for the model submitted by C-TAC, writing, “I am particularly interested in the two serious illness models submitted by the Coalition to Transform Advanced Care (C-TAC) and the American Academy of Hospice and Palliative Medicine (AAHPM).” He further emphasized the importance of demonstrations of models serving the advanced care population.

Update: Model announcement likely April 22, 2019 at the American Medical Association in Washington, D.C.
But Wait, There’s More...
Stakeholders of all stripes very engaged (lobbying, communications, information sharing, coalition-building)

- National Partnership for Hospice Innovation (NPHI)
- Coalition to Transform Advanced Care (C-TAC)
- Patient Quality of Life Coalition
- Supportive Care Coalition
- Foundations fully engaged
- You!
Question: Does the Affordable Care Act allow a government panel to make decisions about end-of-life care for people on Medicare?

Source: Kaiser Family Foundation, 2014

*Rounding by study authors leads to greater than 100 percent value*
Encouraging Words From Secretary Azar

Senate Finance Committee Hearing on the Nomination of Sec. Azar:

Senator Warner: An issue that Senator Isakson and I have been working on for a long time is advance care planning and end-of-life issues, and CMS obviously made a major step forward a few years back where they went ahead and put a coding in for that consult. I would just like to get you on the record in terms of [...] recognizing we don’t want to limit anyone’s choices, but we want to honor and respect peoples choices about care planning or end of life issues.

HHS Nominee Azar: I think it’s a very important part of all of our personal care management in life as we think about our life and our health care and our family members that we engage in that kind of thoughtful, directive planning of what do we desire. As you said, it’s not about imposing any one’s views on someone else it’s actually about ensuring systems respect that individual’s choices, and enabling that is very important for us.
Challenging and divisive broader health reform context results in lots of grand standing and policy development, but only incremental policy changes:

- Drug pricing, Medicare extenders, Medicare for ___??,

States begin to innovate and are a “lab” for change – e.g., Medicaid buy-in, block grants?

Medicare Advantage continues to aggressively expand and experiment with new benefits

Important palliative and home-based primary care models announced at HHS

Elements of palliative care legislation such as Patient Choice and Quality Care Act included in a moving vehicle such as Older Americans Act reauthorizations or Medicare extenders (must pass)

We see some version of palliative care and advanced illness care reform signed into law – PCHETA?

President Trump Resigns!

(OK…wishful thinking…but at least palliative care legislation will likely pass!)
THANK YOU!

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