

Public Policy and the Cascade of Care: Opportunities for clinicians and researchers to engage in the policy dialogue in strategic ways

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Overview

Health care providers and researchers offer a needed perspective and can play an important role in impacting policy at all levels.

Sometimes, however, it feels as though well meaning people are either intimidated by the policy process or they do not understand how to engage effectively.

The purpose of this talk is to strategize together on how to use this moment in time to increase engagement in care to get more people to viral suppression and to reduce the disparities in which people with HIV are able to lead long, happy, and healthy lives.



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Unique moment



As Ambassador Birx stated yesterday, this is our time and we either will or we won't make some things happen to dramatically curb the impact of HIV on the global community.

In the US, we have a supportive Administration, and the excitement created by our National Strategy and scientific advancements pointing to the need to get people in care and on treatment just as we implement the ACA. This has created opportunities for action...that won't last forever.



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My background and perspective

Currently, I am a Distinguished Scholar and Program Director of the National HIV/AIDS Initiative at the O'Neill Institute for National and Global Health Law at Georgetown Law

Former Director, White House Office of National AIDS Policy (ONAP) and Senior Advisor on Disability Policy

Long history of policy research and advocacy on HIV, disability, Medicaid, Medicare, and other health care financing issues



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1



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What makes advocacy effective?

(triage vs. scattershot)

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It is important to have the right strategic goal

To get what you want, you often need to figure out what activity will have the biggest impact or what is the right thing to ask for...

both in terms of doing or asking for something that is meaningful and asking for something that policymakers can deliver.

1



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It is important to target the right policy maker

Sometimes it is important to try to influence the highest level person you can get to, but not always.

- Depending on the issue, it may be best addressed at the federal, state, or local levels
- Political appointees and career staff play different roles.
- Not every decision is a White House decision.
- Senior leaders often want to defer to agency staff.
- Sometimes, however, it is important to target many people at many levels.

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Does a problem require a legislative or administrative solution?

Relatively few laws get enacted each year, and given the current environment, passing legislation can be difficult, if not impossible. Nonetheless, some issues truly require legislative solutions.

And, not all issues require governmental solutions.

Telling a story with human impact is very effective

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Policy details and funding levels are important, but policy makers are moved by human impact.

Blunt political force is rarely able to achieve the desired policy goal... Generally, it is important to make policy makers want to do what you are asking of them.

Even if strong and persistent advocacy is needed to motivate policy makers to act, persuading policy makers that your idea is right is often critical to success.

Anchoring policy in research evidence is also critical

HIV can be politically difficult because it involves sex, drugs, and rock and roll...so many of the issues we face are uncomfortable for politicians to address because they expose cultural fault lines. Big issues of contention include what, when and how to educate young people about sexuality, health promotion and disease prevention. Or, when and whether we should use public money to provide sterile syringes to people who inject drugs.

All of these issues are much easier for politicians to do what you want if you can provide an evidence-base for why a policy will produce a desired impact.

When thinking about the ACA or other health policy issues, solid research evidence can also be what can breaks the log jam between competing views of the role of government or the most effective public policy.



Multiple areas for intervention

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Public-Private Partnerships or Direct Funding Initiatives are important: Developing initiatives that build on or directly support an Administration or agency priority can be a fruitful way of meeting shared goals.

Building and maintaining legislative support for programs is an important form of advocacy

Monitoring agency rulemaking processes and providing technical input through public comment may be an overlooked way to influence policy

Public education about issues and patient education efforts are also critical

Of course, direct engagement with public officials is also a critical form of advocacy

Stick to what you know

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Often, a clinician's greatest strength comes from relating a policy issue to how it impacts the real lives of patients or explaining why a complex issue can be understood in more simple terms, but as with any other stakeholder, you need to guard against losing your credibility.

Experience from clinical practice is important and compelling, but acknowledge that it can be narrow. One setting does not necessarily reflect what is happening across our large and diverse health system—and it is not the only perspective that policymakers must consider.

A positive, solutions-oriented discussion will often get one further than voicing resentment and disgruntlement with changes in the health system.

2

How does this
relate to the
cascade of care?



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What type of change are you seeking?

There are numerous ways to inform and leverage the policy dialogue. Understanding your goal and your role will help you to be more effective.

- **Measurement and monitoring:** Are you able to bring new data to the table to document or make sense of a problem? Are you able to provide context for why issues exist?
- **Big picture policy:** Does the issue involve a big picture issue...should we reauthorize the Ryan White program?...Should a state expand Medicaid? Beyond caring about patients, what special knowledge or perspective do you have to help shape how policy makers should tackle an issue?
- **Implementation challenges:** Are you talking to an implementer?...Why go to a legislator for an implementation problem?

Improving HIV diagnosis

(In the US) we are doing relatively well at increasing diagnoses, compared to other stages of the cascade. We do a lot, but more should be done. Policymakers need help setting priorities and understanding opportunities:

- Are more efforts needed to increase HIV screening in clinical or community settings? Or both?
- What will it take to meaningfully move from a USPSTF “A” rating to an actual increase in the routinization of HIV screening in clinical settings?
- Researchers have talked about the promise of interrupting transmission clusters within sexual networks. Should this be an interesting idea or should this be central to a jurisdiction’s testing strategy?
- How important is 4th generation testing? What will it take to expand its use? How many acute cases of infection should we be identifying through this new technology?



Supporting engagement in care

When policymakers hear about engagement in care, they sometimes think this AIDS activism run amok. In Ryan White, some people still talk about dog walking...and they wonder why people with HIV seemingly get all of these “extras” that no other group of sick or needy people get. How can you help people understand that we are talking about discrete and cost-effective investments?

- While we generally want to avoid comparing people with HIV to other needy groups, in what ways are people with HIV different from other needy populations?
- Are there core services that people really need? If insurers or legislators want to save money and give as little as needed, what are those things that people truly need?
- Can we differentiate between populations to show that some people need more services than others?
- Can you document engagement successes?



2



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Starting treatment and maintaining viral suppression

As discussed at this conference, recent advances in prevention and care seem to only exacerbate existing health disparities. As we get more people virally suppressed and rollout PrEP, increased uptake of key interventions seems to always benefit groups that already had the best access and achieved the best outcomes.

- Given competing demands for policy attention and money, how do we build on great work with Data to Care and other initiatives to more effectively monitor who is accessing care and treatment nationwide?
- What is treatment fatigue and how can policies address it?
- How do we get big programs, i.e. Medicaid, Medicare, marketplaces, to adequately focus on HIV care and taking steps to support effective viral suppression?

Final thoughts

2



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Policies at all levels impact the ability to deliver a high standard of HIV care.

- You have an important role to play in advancing effective policies
- Engaging in policy does not require you to enter a 'House of Cards' episode
- If your engagement in policy development permits you to to 2 or 3 things, pick wisely...which things will have the biggest impact?
- You offer an important perspective and you may be seen as an important authority on what is needed. Make sure you speak from what you know and can back up what you say.

Thank you!



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