

Haystack Advocacy Empowerment Initiative (AEI)  
2021 Speaker Series – February 11, 2021  
**Matt Salo**, Executive Director  
NATIONAL ASSOCIATION OF MEDICAID DIRECTORS (NAMD)

Haystack Project (**HP**) hosted a lively and informative moderated discussion with Matt Salo, Executive Director of the National Association of Medicaid Directors (NAMD).

### Introduction

Matt Salo started with some context about how the Medicaid program covers some 80 million Americans, including at least half of all births, the majority of long term care, and the majority of behavioral and mental health services provided in the country. He noted the budgetary constraints states face while balancing this coverage. Matt acknowledged it is difficult to find details across the state Medicaid programs because they are all so different and, as they balance budgets and their respective political processes, the programs are often changing rapidly.

### Questions & Answer Session:

1. Asked about the evolution in the last 5-10 years where even access to treatments for extremely rare conditions are now **heavily managed in Medicaid**, Matt noted Medicaid programs are no strangers to complex and difficult health conditions. “Medicaid can set up an ‘ICU in a living room’ at a cost of approx. \$300,000 per year. But it is the tremendous growth in new treatments and vaccines, that while creating a lot of good from a health outcomes perspective, has created unprecedented costs.” Matt described his Medicaid directors facing the tough choices of spending in one area driving the need for savings in other areas, and having to find balance. “A few years ago, there were little blips of innovation popping up and excitement. We could handle that, and we didn’t bat an eye. But the post-21<sup>st</sup> Century Cures world, when our federal policy started to drive innovation, the costs became enormous.”

2. Matt was not immune to the concern that **PBMs and other intermediaries** might contribute to rising drug costs. He noted after our call that NAMD and others monitor this closely. However, he also said PBMs try to mitigate costs for the state Medicaid plans. Asked about what costs in the system *besides innovation* could be removed, Matt said every potential access decision comes down to (i) the financial exposure and (ii) “what’s the rock-solid proof that this actually works, and does what it says it’s going to do over an extended period of time.” He added that he understood the need for a different approval pathway at FDA for conditions where there may be only 300 patients. However, he also said FDA would not acknowledge insufficient evidence for liability reasons, and in fact, there is clinical trial data that is “not as complete,” that “forces us to pay for an extraordinarily expensive drug when the medical directors are saying the evidence is not the same.”

“Our folks would say if a product offers a tremendous amount of hope, we have to translate that to access.” He proposed a possible approach when the barrier is cost: “Maybe we cover it on Day 1 and continue to test it. At the core of this, we don’t think it’s appropriate to be paying a million dollars a year for something we’re doing the research on as we’re paying for it. What is a reasonable price to cover it [initially, versus] when it shows its working as expected, then maybe we should be paying more? The federal government is making policy decisions to prioritize innovation without practical way to pay for it.” He asked for our help in getting the federal government to either pay for it or to manage the costs.

3. Switching topics, Matt talked about the massive shift to **managed care in Medicaid**. “The Medicaid population in general is very different from the typical commercially insured managed care community, representing the most sick and complicated individuals – this is a significant challenge to address. “The failures and inabilities to get managed care ‘right’ were a much bigger problem at the outset of the movement, but that’s more than 20 years ago, and [Medicaid programs] have learned a lot since then.” Although we don’t really want “unmanaged” care, or “uncoordinated” care, Matt acknowledged “managed care” can seem threatening to people who are used to cobbling together various services for their health care. But consider, he asked, if FFS sometimes feels like “fee for service” or “fend for self?!”

The discussion turned to specific questions patient orgs had sent in:

4. Medicaid does not require private insurance to **match coverage** for long-term services and supports (LTSS).

5. Medicaid does generally have a 90 day look back period for relevant Medicaid covered services.

6. Asked about how Medicaid handles **transition issues**, for example from pediatric to adult health care, Matt noted it’s a “weak spot.” Medicaid deals with many types of transitions (e.g., exiting foster care, temporary coverage for low-income mothers to give birth). He asked for our thoughts and recommendations. Some state Medicaid programs do a better job than others with regards to certain transition issues.

7. Responding to a question about **Medicaid picking up cost sharing** only if someone has employer-based insurance, Matt noted the complexities. “If someone is medically eligible for Medicaid, they are eligible for ALL Medicaid benefits... and Medicaid’s benefits can be rich!” He explained that even if another plan is primary, the person is still eligible for all Medicaid services. This means when private/commercial plan coverage runs out, Medicaid **MUST** wrap around. The act of having to continually perform this cross checking for wrap around is administratively “gargantuan.” Creating systems for standardized Medicaid wrap around would decrease this administrative burden.

8. Matt talked about some well-run state-specific aging and disability programs, but that NAMD never dictates what a program(s) should be doing. Rather, a state program will come to NAMD for direction or guidance. We discussed ways in which HP may highlight specific programs.

9. On **COVID** flexibilities – “I haven’t received a lot a lot of feedback on interstate utilization. There are lots of flexibilities that are likely to go away post-COVID, but perhaps a ‘new normal’ will develop in the middle.” Cost equivalents may be achieved between large academic institutes that could help patients see out-of-state specialists at in-state rates, but this is likely a policy issue.

10. On **ICER** – “ICER seems like a solid organization trying to supply comparability and comparison information to increase drug pricing transparency and reduce cost. There’s nothing more opaque than drug pricing.”

11. Asked about a forum to **hear from patients** at the NAMD annual meeting, Matt responded that has not historically been done. “But NAMD is working to increase the patient voice.” Matt noted that NAMD is open to our participation and ideas on how to include Haystack Project and

the patient perspective as part of their annual meeting, held for 1.5 days in November each year in DC. We also noted our request for quarterly conversation as an option as well.

HP thanked Matt for generously sharing 80 minutes of time with us and concluded the session with a question about what HP can do for NAMD in terms of policy issues. Matt took the opportunity to ask that we articulate to the Federal government the need to do more regarding prescription drug pricing. "The current pathway is not sustainable. If we want people to have access to therapies, we have to acknowledge that cost = access." The cost of innovation needs to be addressed.