Stealing Time: A Prescription For a Way Forward

A discussion of making the most of the next two years to win for the HIV community.

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I remember sitting with Peter Staley as he was working on titles for his memoir. He ran me through a few options, the reasoning behind each of the options, and what he hoped to convey. Ultimately, he did not pick this title, but the concept and name, *Stealing Time,* stuck with me; Peter describes his life's work with the notion that he is *Stealing Time* back for his own life and his community. I realized that much of my work was built on similar thoughts. I wanted time back for the lives interrupted, *stealing time* back for my community, time back with loved ones, and time back to achieve wondrous things, both great and small. It is all a question of time and what we do with it. What openings and opportunities can we create to bring time back for lives that have been or could be interrupted? Politically, we must do better at *stealing time*. This new year offers a year to set ourselves up to grab larger pieces of it back and be accountable to those we represent. If the goal is to be a thief of time, we must use the asset wisely. For years discussion of building new congressional champions has been floated. Still, without the time and attention, the effort never becomes as intentional, coupled with the expanded opportunities that the last few years of legislation have opened up.

We need a deeper bench of lawmakers. We need the next Nancy Pelosi on both sides of the aisle. Champions that will find creative ways to work our needs into the places where synergies are possible. We should make lists of targets and develop strategies for each individual's engagement based on available resources that link local efforts and the federal push. We can map out the opportunities for increased related services (housing, nutrition, employment, and primary healthcare) and infrastructure in critical districts but are not direct HIV dollars. We know conditions that further the pandemic is not bound to HIV specifically. And we should build champions that understand the syndemic approaches required to end the HIV epidemic and change the conditions that increase individuals' and communities' vulnerabilities. This will mean creating messaging and resources that clearly explain the overlapping nature of our work in other areas and how the two areas can benefit from the greater synergy of the work. We should seek to create in-district events that bring together our partners and prospective champions.

Additionally, we should supercharge these moments by coordinating and bringing in local legislatures and policymakers. We want to ensure that what happens in Washington can be translated and supported by the state and local to advance our issues. We could coordinate site

visits with new partners aligned in the intersections where the people we work on behalf of live, work, and play. We often speak of the intersectionality of the HIV work period and how structural interventions show up in our efforts to end the epidemic. Now is the time to leverage those structural interventions to eliminate the barriers that impede our progress. Expanding access to affordable housing can improve HIV treatment outcomes if having a safe place to live makes it easier to stay on treatment and remain healthy. When we invest in skills training so unemployed people can work and earn a living wage, we can help the communities where people with HIV live. When we treat all people with dignity and respect and stop attacks on LGBTQ+ people, we can lessen the harmful effects of substance use disorders. Showing people how HIV, the prevention of HIV, and the care for people living with HIV are linked to other work people do. And that together, we can all achieve more.

In the political sense, we need to *steal time* on the legislative side, getting our key legislative asks attached to vehicles that will move quickly. We must be prepared and ready to act when windows open. This means being willing to set community priorities and then leveraging the united resource of the majority of the community to achieve passage through our collective effort. We must embrace the pain that can come with great change and acknowledge that laws must evolve to be right-sized for the moments we find ourselves in. The Ryan White program stands out as a piece that needs reauthorization. There is no denying that this process will be painful and contentious.

Moving large pieces of programming and adjusting priorities can feel like there are a set of winners and losers. Historical patterns have changed, and things must adapt to address systems that aren't addressing new challenges. We must remain open to what is required to ensure the Ryan White program has the tools and resources to meet its goals. However, we must also recognize that it and the epidemic have changed since its last authorization. We must evolve it to face the realities of our current learnings on HIV. And yes, funding is a big part of this, but it is not the only thing. We must be willing to move people from relying on just the payer of last resort to a place of stability. We should not expect people to live on a program designed as a last resort. We can do a better job of moving people toward sustainable programs. The good news is that we have learned a lot of what we want to need to keep from the last few years, but that needs to be codified by law. Though passage in this Congress seems unlikely, we can still work with our allies to help move us forward so that when the moment comes, we are ready. And if we want to think big introducing an HIV Omni bill to fill the gaps left by The Ryan White program.

There are laws in regulations that could be honed to meet the needs of the HIV programs, from more expansive prevention interventions at the CDC. More could be done at HUD to integrate housing as a healthcare model or have a program that has a more status-neutral focus but works around risk factors. And one of my pie-in-the-sky dreams authorities that would allow COB to bill services to primary healthcare, to name just a few options.

Finally, we must ensure we maximize the position of our allies in this administration. . We must bring the full force of our community to bear and educate them about what these comments mean, the opportunity, and what we hope to accomplish with their support. Our community has a

massive network of connections and coordinating sign ones, and comments from not usual suspects can be beneficial depending on the rule. Then when the rule finalizes with the administration, we need to make sure that we tell everyone about the change and what it means for their lives.

We also need to work on parts of the administration that are slower movers and bring the community to demand that they deploy strategies that address the intersections of our lives. For instance, agencies like the Centers for Medicare & Medicaid Services, where many of the at-risk and those living with HIV can find care and insurance, may not be the best players in understanding their essential role in HIV. In some ways, we need them more than they need us. As important as Medicaid and Medicare are for people with HIV, we account for a very small share of what these programs spend. But, our communities are part of syndemics that impact whole communities, and heightened responsiveness to HIV services and the other needs of our communities will have spillover effects in reducing other health threats. Large segments of our community could access essential services through these programs. This is why it's vital to optimize them to respond to the needs of those living with and affected by HIV. Also, we would only represent a small part of the enrollment participants, and engagement could have massive effects on the health and well-being of millions.

We need a CMS to come to the table because that is where most undiagnosed or non-medically suppressed people might access some care. CMS should have better data-sharing agreements to improve care in various states and localities. These data-sharing agreements should be hardwired into the efforts which report progress on HIV, including drug access, food and nutrition, housing (if you get creative), and overall health and wellness that affects communities aligned with population targets set out in the National Strategy.

This is how you could *steal time* for the next two years: essential conversations allow us the opportunity for offense rather than playing defense to the situations that come our way. It's a chance to build scaffolding to ensure that we make it true to the critical benchmarks of 2025. A lot has been disrupted in the last few years but realigning and getting ourselves back on track and making necessary investments is within our grasp. Targeted efforts can re-accelerate the engine and galvanize the momentum we had to end this epidemic. Can we find the innovation we need to bring to three sites of actions designed to do one thing to steal time? We need a clear legislative agenda that looks at model policy for both the national and state levels. We need a pathway to recruit more people to support and believe we can end this epidemic, which is a matter of political will in many ways. We'll have to collaborate with our friends in the administration to give us everything we can get in the next two years. We will set ourselves up for a milestone, previously stolen from us, to end the epidemic by 25. However, the next two years, four then seven years, will be critical in defining our ability to steal back as much time as possible for our communities, our friends, family, and even the nameless stranger worthy of our care.
