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# Implications of Navigator Funding Changes on People with HIV: Navigator Perspectives

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The Affordable Care Act (ACA) requires healthcare marketplaces to establish “Navigator” programs to assist individuals with outreach, education, and enrollment in insurance coverage. For states using the federal marketplace (currently 34) the Centers for Medicare and Medicaid Services (CMS) provides navigator funding and manages the program. However, recent funding cuts to the program have meant that grantees have had to assess and, in some cases curb, the services they provide.<sup>1</sup> We examined the potential impact of these funding cuts on people with HIV, a population that has experienced significant gains in insurance coverage under the ACA, with, in many cases, the help of navigators. Several of the federal navigator grantees were AIDS Service Organizations (ASOs) and/or organizations that identified people with HIV as a population they would specifically work with. This issue brief analyzes funding data and findings from stakeholder interviews with these navigator grantees to assess their role in serving people with HIV as well as the potential impact of cuts going forward.

## Background

Federally funded navigator organizations are currently operating under a three-year grant, 2015-2017. While earlier this year, CMS announced that \$60 million would be available for the third and final year of navigator funding, an amount comparable to each of the first two years under the grant, it later released awards amounting to a \$26 million or 41% cut, with several organizations losing funding altogether. CMS explained that year three funding would be “based on [grantee] ability to meet their enrollment goals during the previous year” but did not detail the specific metrics to be used to calculate the award.<sup>2</sup> A recent Kaiser Family Foundation [report](#) found that in many cases services offered by navigator programs will be disrupted, including by cutting services to certain populations and geographic regions and curtailing the types of assistance they provide. They also found that as confusion around the continuation of the ACA “coupled with a shortened open enrollment period, increases demand for the consumer education and in-person enrollment assistance Navigators provide. At a time when more help may be needed, the funding reductions are likely to reduce the level of in-person help available to consumers during this fall’s open enrollment and throughout the 2018 coverage year.”

We sought to examine the impact of proposed cuts on people with HIV and the organizations that serve them. People with HIV face unique medical needs and vulnerabilities, and were more likely to be uninsured prior to the ACA compared to the population overall.<sup>3</sup> As such, the availability of enrollment assistance was particularly important for this population. Aware of this, some navigator groups specifically identified people with HIV as a target population for assistance under their grant (11 out of 103, or 11%). To assess the impact of navigator

funding cuts on these entities, we analyzed changes in funding levels and conducted interviews with key stakeholders.

## METHODS

We examined the CMS notification of 2016 navigator grant awards, which included grant application summaries, to identify organizations that specifically targeted their enrollment assistance to people with HIV either directly or indirectly through sub-grantees.<sup>4</sup> We included grantees in the following three categories:

- Grantees that are AIDS Service Organizations (ASO);
- Grantees that identified an AIDS Service Organization as a sub-grantee; and/or
- Grantees that specifically identified serving people with HIV as a target population

Using this 3 pronged test, we identified 11 “HIV navigator entities” out of 103 grantees overall (11%). Based on funding data released by a third party, we examined changes in their 2017 awards, compared to 2016.<sup>5</sup> In addition, we conducted interviews with representatives at 11 navigator organizations, including both named grantees and sub-grantees. Most of the 11 were primary grantees (9); the remaining 2 were sub-grantees. Organizations represented all regions of the U.S., except for the Northeast but were most likely to be located in the South. All participants were asked to discuss: why they decided to include people with HIV as a target population (and for ASOs, why they sought a navigator grant); the role that navigators played for people with HIV; their reaction to the cuts; the impact the cut would likely have on their organization; and the impact the cut would likely have on people with HIV. Interviews were conducted in September and October 2017.

## Findings

### HIV NAVIGATOR PROFILES AND FUNDING

In 2016, the 11 HIV navigator entities received \$15,889,012 overall, ranging from \$489,170 to \$5,813,294 (a similar amount as 2015). In 2017, their funding was cut by 42% overall to \$9,244,768, a comparable percentage cut to that experienced by other navigators.<sup>6</sup> Cuts ranged from just over \$1,000 to more than \$1 million and the percentage of the cut ranged from less than 1% to over 90% compared to the previous year. None lost all of their funding.

Several of the grantee organizations interviewed for this report were AIDS Service Organizations (ASOs) (4 of 11), organizations specifically dedicated to serving people with HIV and each existed prior to the ACA. Many were well situated to begin enrollment work as they were already working as case managers or collaborating with HIV clinics to provide similar services. In addition to the ASOs, 7 other organizations elected to include people with HIV as one of the target population for their grant or identified an ASO as a sub-grantee.

### DECISION TO FOCUS NAVIGATOR WORK ON PEOPLE WITH HIV

Navigator organizations had a range of reasons for seeking out the grant. Participants discussed the importance of having navigators familiar with the needs of HIV positive people. They discussed the value in having special expertise when it came to health plans, their ability to develop lasting relationships with consumers, and foster connections with Ryan White HIV/AIDS Program entities and other community organizations serving people with HIV.

**ASOs were motivated to apply for navigator grants to engage their existing and vulnerable client population of people with HIV.** They spoke of taking advantage of the opportunities presented by the ACA for their clients.

Once the ACA took away the ban on getting insurance if you have preexisting conditions it was an amazing route forward for our clients living with HIV who previously...[be]cause they had a preexisting condition we would have a really hard time getting them into a comprehensive health insurance plan. Once that ban was lifted, we had new opportunities to get our clients with HIV health insurance.

They were particularly interested in helping those who had limited experience with insurance in the past and saw themselves as being able to provide both insurance education and enrollment assistance to their clients. One ASO navigator indicated, for example, that they applied for the grant because leading up to the ACA they had already had “a statewide network of trusted partners” and knew that that these “trusted entities within communities” would be where consumers would turn to become educated on the ACA. They believed that they were well situated to provide the leadership needed to bring these groups together under a statewide navigator grant. Finally, ASO navigators also mentioned the value that an additional funding stream would bring to their organization, in supporting their ability to serve people with HIV.

**Non-ASO navigators identifying people with HIV as a target population did so because of their perceived need to assist this population.** One navigator entity is a health association with a health center partner working near an area hard hit by the opioid epidemic. Due to the relationship with that health center and a desire to reach individuals affected by the opioid epidemic at higher risk for HIV, they included people with HIV as a target group. Other organizations sought to include the most vulnerable members of their community as target populations and believed people with HIV to be such a group. One organization, for example, stated that they included people with HIV in their grant because the Obama Administration had emphasized reaching underserved populations and they believed this group met that criteria. Some participants talked about wanting to leverage existing relationships with AIDS Service Organizations under the grant. One group traditionally focused on another health condition predominately serving the African American community, said while it has not been the focus of their work, they made efforts to address the needs of HIV positive people in the past. They included people with HIV in the grant, and in their past work, because they believe addressing healthcare access needs of this population fits in with their overall mission to address health disparities within the black community.

**Stakeholders cited the value in enrolling consumers at a place where they were already receiving services and feared that reducing HIV specific navigator assistance would add to confusion around enrollment.** HIV navigators saw themselves as providing a consistent place to go for trusted information year after year. Those that lost or shrunk their capacity to offer this service were worried that even if they referred clients to other enrollment sites, they might not go. Navigators found that consumers were more comfortable engaging in settings that were familiar and believed that this facilitated a smoother enrollment process.

[Navigators with HIV expertise] know the questions to ask, they know the plans that will cover the services that they need, they have personal relationships with the case managers that are assisting these consumers. It is a huge value. Personalized service. You aren't just someone who walks in from the street. You have a name and you are connected to someone that knows a little bit about you.

One navigator also believed the convenience factor associated with enrolling in coverage at an ASO where consumers were already receiving services lead to their enrollment success.

I think it is just a natural thing that they can be more honest and we were trusted and it was easy, if you are already there for a case management appointment, why not go ahead and try to get health insurance.

Another organization had their navigators attend sensitivity training to help ensure that when staff met with people with HIV, or any other condition, they created a welcoming environment. They did various role-playing with their staff including addressing concerns of enrollees with different health conditions. They made an effort to explore the “various issues individuals may come in with so [staff could] work to address their own prejudices” in advance. This navigator was concerned that others navigator entities would not approach working with diverse community members with the same degree of sensitivity.

On the other hand, ASOs also mentioned that they did have to work around the stigma that HIV-negative enrollees unfamiliar with HIV clinical or support settings might feel in seeking enrollment services. Some worried that individuals might not want to seek enrollment assistance within a known HIV services location. To address this ASO grantees and sub-grantees often offered enrollments outside of their own settings and rebranded parts of their facilities.

Actually, for us I think being an ASO doing the work has been a bit more challenging ... because of the stigma so we have really tried hard to distinguish ...[our enrollment work as separate from the HIV services we provided] so people can feel comfortable coming to us and comfortable with our help.

**Participants also discussed the importance of having expertise related to which health plans work best for people with HIV in terms of access to medications, providers, and interoperability with Ryan White.**

Navigators discussed that while making sure providers are in-network and medications are on formulary is import for anyone enrolling, this is especially the case for someone with HIV. Participants cited the high costs of HIV treatment, which could run thousands of dollars a month, and the need to ensure that plans not only cover prescribed drugs but also do so with affordable cost-sharing. They also discussed the importance of staying engaged with HIV treatment as a way to promote individual health and to provide the preventative benefits associated with achieving viral supression. They see affordable accessible coverage as a facilitator for staying engaged in care.

The main problem is that people living with HIV/AIDS they have very specific medications that they need to take and doctors that they need to see... they need to stay on their medications and see their doctors frequently in order to stop it from advancing into AIDS so those drugs alone cost thousands of dollars a month so having a navigator help them work through those questions that they have, understand what's available to them, which plans make sense for their needs, I mean it is essential for that population.

In some cases, HIV navigator entities conducted reviews of all the regionally available marketplace plans so they could understand which ones represented the best options for people with HIV. In one instance, an HIV sub-grantee who lost their funding employed the single individual who did a plan analysis for the entire state network of ASOs. The main grantee hoped that the ASO would be able to continue this service without navigator funding but was unsure.

Since Ryan White Programs and especially AIDS Drug Assistance Programs (ADAPs) can assist clients with the costs associated with insurance coverage (e.g. premiums and cost-sharing) in certain circumstances, navigators with HIV care expertise also played an important role in relaying information about these services to enrollees. Navigators with HIV expertise often had a specialized understanding of how to enroll consumers in Ryan White assistance and knowledge of which plans could be used with Ryan Whites premium assistance.<sup>7</sup> Many worried about what would happen if consumers enrolled without this specialist knowledge in the future.

**Navigators serving people with HIV at ASOs and other community based organizations felt they had the opportunity to provide more in-depth assistance than they would if their clients were seeing navigators at sites exclusively devoted to processing enrollments.** Several explained that it often took many visits to get a client enrolled. Others talked about how their role extended beyond just enrollment clients in coverage to conducting insurance education.

[Clients] may need to interact with staff several times until they get the help they need, people come back to us for anything in the world from dealing with old medical bills that should have been covered to an argument that they are having with their doctor, or if they get dropped or things like that.

One organization described their navigators giving out their personal cell phone numbers so clients could reach them. They doubted that other entities would be similarly committed to ensuring a vulnerable population had this level of support and did not know if they could continue without funding.

[Navigators] provided their cell phone numbers. They were on call day and evening if [clients] had questions, even for emotional support. We may not be able to provide that same type of assistance. We just don't have the funds to be able to do it.

Navigators believed that providing additional attention and ongoing education was especially important for people with HIV, many of whom were unfamiliar with how to use and enroll in insurance. Several organizations talked about offering "insurance 101" to their clients and providing ongoing education

throughout the year. One group would print out and walk through the Summary of Benefits and Coverage for each person enrolled in the marketplace. This group also conducted three way calls with pharmacies so clients would learn how to make those call on their own in the future. These navigators emphasized the ongoing need to remind clients about how to maximize the benefits of coverage.

We saw a need for that 101 assistance...We also saw a population that wasn't used to insurance, had a lot of questions on how to use it, best practices. We saw a lot of people who were going to emergency rooms for things like colds. We did a lot of 101 counseling individually, like going through the summary of benefits with clients but then also doing larger kind of like health insurance 101, what is a deductible, what is coinsurance, what is the difference, what are costs you are responsible to pay, what are costs the health insurance will pay.

**Navigator entities serving people with HIV often forged close relationships with community partners, including Ryan White clinics and health departments, as well as sheriff's offices, and providers.** In several instances, participants or their sub-grantees co-located within clinics or health departments to provide those seeking HIV care or support services with enrollment assistance. These relationships appeared to be especially meaningful in Ryan White clinics and ADAP offices. One grantee said their navigators worked very closely with ADAP when the issuer serving most ADAP clients left the market. Together they assessed the remaining available marketplace options and transitioned clients from the plan that was terminating to new coverage. Ryan White Programs in several settings relied on co-located navigator services to ensure that their clients received enrollment help with individuals familiar with these programs and the general needs of people with HIV. Another grantee began offering co-located services at just a couple ADAP offices (upon ADAPs request) but both parties found the relationship so fruitful that the navigator expanded to offering services at all ADAP enrollment sites in later enrollment periods.

These navigators sometimes offered enrollment services within HIV clinics as a way of meeting HIV positive individuals where they were comfortable and already seeking services. In some cases, these navigators said patients would not necessarily have known they were an outside entity.

We wanted to make it really accessible, we would also have standing appointments at the ...clinic and other places too. That was really key for us, making sure we regularly went to the places people living with HIV might be, if it wasn't our office.

Navigators also made sure community partners such as health departments and hospital infectious disease clinics were aware of their services so they could refer HIV positive clients to them for enrollment assistance. They attended pride events, community celebrations, and ran workshops with other local groups. After the funding announcement, however, a number of navigators said they had to cut back on how much work they could do with these outside partners and, in some cases pulled back on offering co-located services.

## REACTION TO FUNDING CUT

Participants described seeking out navigator work for altruistic reasons and working hard to ensure vulnerable populations had access to health coverage and health care. They said that the funding cuts threatened to negatively impact both the capacity they had worked so hard to build up and the communities they served.

**The majority of the participants we spoke with were very “surprised,” calling the cuts they received “a shock on every level,” “devastating,” and “a big blow.”** Most said they had no indication from CMS or project officers that cuts were coming. Several reported only positive feedback from their project officers leading up to the late August announcement, which made significant cuts particularly confounding. Several reported they were explicitly told they were “doing a great job.” One navigator group who faced a cut nearing 60% had received only positive feedback from their project officer and had even been asked to mentor other struggling navigator grantees and to sit on national enrollment panels.

[The cuts were] a huge surprise, devastating because our contract officer kept reassuring us with how pleased she was with the great work we were doing. As a matter of fact, [we were]... asked to mentor two other organizations who were not doing well. We were asked to be panelists on national conferences on navigation and coverage to care educational workshops so you know we were very taken by surprise.

One organization, also taken aback when they learned of the cut, said they heard news of the cuts from a reporter before hearing from CMS.

Oh yeah [the cut was a surprise]. We had absolutely no clue. [The] poor [reporter] was actually the one who told me about the cut because we hadn't heard anything...[he] called to find out what I thought about the cuts to the navigator grants and I was like 'what cuts to the navigator grants?' ...We had no prior knowledge before they held the press conference so the press actually knew about the cuts before the grantees did. The only information we received about the cuts was the press release, that's it.

Among those interviewed, only one stakeholder who experienced a very small cut explained that they were not surprised as they thought they were being rewarded for the productive enrollment work they had been engaged with and believed that they had met all their targets.

**Many participants were confused by the justification (ability to meet enrollment targets) CMS had used to defend the cuts.** Some navigators explained that they worked with vulnerable populations with complicated lives. They felt punished for making the choice to reach out to those with the greatest need who sometimes took a longer time to enroll and sometimes did not complete enrollment. One HIV navigator was frustrated that they had been encouraged to be aspirational in their goal setting as they now felt they penalized for that optimism. Others said that they were meeting or exceeding targets and were confused that CMS had justified cuts based on failure to achieve these very goals. Navigators were left second guessing their work and wondering whether only certain enrollments counted towards their goals (i.e. Medicaid enrollments vs. marketplace enrollments). Based on their own experience and in talking to others, one stakeholder

wondered how the awards had been calculated saying “we still don’t know where [CMS] got the numbers.” A separate group echoed this stating “we really don’t have a clear understanding of how these decisions were made or what metrics were used to make the determination.” Another wondered whether they were using the same metric as CMS to assess goal achievement and questioned whether there were calculated motivations behind the agency’s funding approach.

It doesn’t look at all like the federal government actually calculated the cut that way which tell us that it was all political and it wasn’t a decision made by anyone who does this for a living.

**Several organizations discussed the timing of the award notifications.** They noted learning of award cuts as they were in the thick of preparing for the fifth open enrollment period and that short notice meant rethinking their activities, their staffing, and their ability to fund sub-grantees just 8 weeks before enrollment began. Another participant explained they were upset that these cuts came in the final year of a three-year funding period. After two years of grant-funded enrollment work, they felt they had found their feet, building up expertise and fostering partnerships with organizations that serve people with HIV. They felt they had become a trusted source of enrollment assistance for people with HIV and that the cut effectively undid their hard work in the final year of funding.

[The cut] was obviously a really devastating blow. I think the timing of it is especially hard because we have spent so much work now going into the third year of this grant...building up partnerships, building... the client base – expects these services of us now. I was really committed to doing whatever we could to maintain our commitment to our partner agencies and our clients that were expecting to have us be available to them.

**While the loss of funding weighed heavily on the minds of navigators, they noted other confounding factors that left them worried about their ability to enroll and engage consumers.** They pointed out that the cuts, the short notice of the grant award, and the condensed open enrollment period formed a triad of enrollment barriers they would have to overcome.

I think [people with HIV] will be impacted greatly, we have only half the crew in half the locations from which to serve the same population and more. We also have a shortened open enrollment. It is almost like everything is working against us to assist the same number of people that we would have been able to assist had we not gotten these cuts. We may not be able to reach everyone we need to reach. We are going to try to do it but taking into account that we got reduced by 50%, locations reduced by 50%, a shortened enrollment period. It’s going to be hard. It is nothing that we can promise that we are going to be able to get to all of them.

When trying to reach hard to reach populations... The shortened enrollment period is a big risk factor that may reduce the number that reenroll or may reduce the number of uninsured

enrolling. And then the incredible confusion of ‘is the ACA still the law?’...it is just such an uphill battle for – and the 90% cut in advertising- and for all consumers so that when you look at special populations it is even harder.

## IMPACT OF CUT ON HIV NAVIGATOR ORGANIZATIONS

Participants discussed how funding cuts would impact their organizations including in terms of staffing, ability to fund sub-grantees, reach into the community, and the activities they would engage in.

**Many of the HIV navigator entities we spoke with said that they had to let staff go almost immediately after learning about the funding cut.** Several had to cut more than 50% of their navigators. Depending on how the grant was set up this was sometimes internal staff but more often external staff located in other organizations receiving navigator funds as a sub-grantee. Several navigators reported letting go of their ASO sub-grantees. When a sub-grantee lost funding, in some cases their organization seemed able to take on the staff with other internal resources. In other cases, it was unclear to the named grantee what would happen to those staff members. We spoke to one sub-grantee whose funding was retracted because of the cut to the primary grant holder. While the navigator will be able to stay on with her organization, her work will shift at least temporarily to focusing on Ryan White and she may need to move out of case management altogether. At the time of the interview, she was trying to get approved as a Certified Application Counselor (CAC), a separate federal enrollment training program without funding, which would allow her to enroll the organizations existing clients. She was frustrated that the funds were cut before she could file for the navigator certification and as a result has to complete another and duplicative training process that might not come through for open enrollment.

I had done all my [navigator] recertification, I was ready to file for my recertification through the state but I had done all the training, everything. Then just to find out there was no more funding, that was it...[laughs]...I am just having to work backwards here, against the clock for the start of open enrollment.

Other organizations have cut staff hours. Several organizations funded some of their navigator sub-grantees or staff with short-term contracts for only the three months around open enrollment and others, typically a smaller group, for a full year (through the end of the grant period).

**HIV Navigator entities took different approaches in selecting which sub-grantees to let go or offer a retracted contract.** While some entities focused on funding only those who enrolled the greatest number of people in the past, others tried to cut only entities that they knew had other sources of funding, such as federally funded health centers. Some grantees tried to ensure their cuts did not disproportionately impact specific geographic regions while others focused their efforts on the most densely populated urban areas. Some navigator organizations prioritized generalist navigator entities, cutting groups specifically serving special populations, including people with HIV, while others tried to fund all groups, even if that meant funding at lower levels.

**Several participants streamlined their activities supported by navigator funding in light of grant cuts.** A few organizations focused most of their efforts on the open-enrollment period, culling activities outside of open enrollment such as working with clients on special enrollment periods or assisting during tax time. Two organizations that faced particularly large cuts said that they were choosing to focus on renewals this year rather than doing community outreach to encourage new enrollments. The organizations taking this approach felt their duty was to first serve their existing client base and were daunted even when limiting their focus to this group. One of the organizations additionally said they had gotten the message from CMS that reenrollments should be prioritized. Many of the groups were overwhelmed at the prospect of trying to assist the same number of people with less support than in the past.

Now we have half the crew trying to reenroll the same number of and enroll new ones...Since we do have a staff reduction we have had to reduce the number of locations we can have a physical presence in...so basically everything is cut in half but we are going to try and attempt to reenroll all those consumers [with HIV] that we helped last year plus reach out to the others. It's a daunting task.

Several organizations said they would have to reduce the level of community outreach, education, and event participation. Another strategy HIV navigators took was to reduce the number of sites where they had staff co-located at clinics and non-profits. Others who had bought paid media in the past said they would roll some of that back. One group said they would make a bigger push to get more earned media as a result.

**Groups that received relatively high grant awards discussed their privilege.** Some groups lost a significant share of their funding but because they had comparatively large grants to begin with, even after the cut, they were left with substantial funding to work with. One navigator lost little funding. These groups were the least likely to completely cut out specific aspects of their programming and worked to spread the cuts around so as not to focus the hit on any one organization, region, or population. One such navigator group said that they would “not stand there and makes a decision that one population is more in need or more deserving than another” in deciding how to realign their resources after the cut. However, they acknowledged that they were able to take this stand because they still had a large grant and noted, if they had less funding to work with, they would have had to approached dealing with their cut differently.

## IMPACT ON PEOPLE WITH HIV

Participants discussed how they believed the cuts would affect the consumers they serve with HIV. Navigators had an overwhelmingly pessimistic view of their ability to continue enrollment work and specifically serve people with HIV in the future. They were unsure about funding to continue work beyond the enrollment period and concerned about what the drop off in specialized navigator resources would ultimately mean for people with HIV. Navigators worried that the ultimate impact on people with HIV losing access to coverage assistance could be losing insurance and falling out of care, or in some cases, returning to Ryan White.

Some thought the loss of navigators with HIV expertise, including those located in familiar settings, might cause instability and that this could take emotional toll on clients and could potentially lead to loss of coverage.

I think there is going to be a lot of confusion. There is so much confusion and misinformation... Without [the HIV specific navigator]...resource to go to I don't know where people will be able to go...The impact and toll on somebody emotionally with all this instability that's happening...is a matter of life and death...All the people in our office are really concerned and it can be very emotional. I don't think we are really quantifying what this stress and concern is potentially doing as well.

**Navigators worried about losing a “safe space” where HIV positive consumers could comfortably disclose their serostatus during enrollment.** Recognizing that people with HIV sometimes face stigma in social institutions, including in health care settings, many of the navigators believed their enrollment services reduced barriers HIV positive individuals might face in a less welcoming or discriminatory environment.

I mean maybe the larger problem is that people who have HIV/AIDS face a lot of societal stigmas, they might be afraid to share with anyone that they are living with HIV/AIDS and so not having a navigator permanently housed at [an HIV sub-grantee location]... kind of changes the landscape in that they might not...feel comfortable seeking out the [assistance]...that they need ... It discourages them from enrolling....

One participant noted that if a navigator asks enrollees to disclose their medications and doctors in order to select an appropriate plan (which is important), it would effectively require someone with HIV to “come out” as positive. This navigator felt that going to an ASO might relieve some of the stress around that situation. Navigators who let ASO sub-grantees go due to the cuts worried about how that would affect safe access to coverage assistance for people with HIV and worried that these consumers may not want to get enrollment help elsewhere. Another navigator said that if someone was forced to go to an enrollment site not obviously friendly to people with HIV, it might be a barrier, especially if they had already been receiving this service at an ASO in the past.

In my experience once someone discloses their status, they *really* want to continue working with you. That's just one less person you have to go sharing your personal health business with...I think people do like minimizing that... I do think there would be an added level of either discomfort or maybe another potential emotional barrier to get you through the door.

**Many navigators were concerned that those enrolling without assistance, either as a result of the cuts or in future enrollment periods, might pick unaffordable plans and could ultimately fall out of care.** One navigator worried consumers would choose plans based on premiums alone and not look at provider or drug access. Others expressed concern that those who enroll without help would enroll in unaffordable plans, eventually drop coverage, and become disengaged with care.

A person that is HIV positive really needs to adhere to taking their drugs on a daily basis and a lot of medications are thousands of dollars a month and if they don't have the right plan they are

not going to be able to afford those medications and potentially could lead down the road to HIV progressing to AIDS...

One Navigator voiced concern about the burden Ryan White might face if people with HIV who had gained coverage dropped it and needed to turn back to the safety net program for care and treatment.

Well I guess there is always Ryan White as a payer of last resort. Where it's gonna impact us is, how many people [is Ryan White] going to be able to help if too many [people go back to the program for assistance].

**One participant with a former sub-grantee working in an area hard hit by the opioid epidemic worried about how the loss of that navigator would affect the local burgeoning HIV epidemic.** The individual funded to work in this region will stay on with the Community Health Center where they were located but traveling to the affected county will “no longer be in her scope of practice” so it is unclear if her enrollment outreach in that affected community will be able to continue.

**Many of the HIV navigator entities did not see themselves offering navigator assistance in the future without additional funding and worried people with HIV would not have access to knowledgeable enrollment assistance moving forward.** Given the reduction in funding this year and the messages they were receiving from an administration prioritizing dismantling the Affordable Care Act, many simply assumed this year's grant would be their last.

I fear that if nothing changes we are looking at discontinuing some of the really good partnerships that we spent time and effort building up. I don't know what open enrollment would look like next year but at this point we wouldn't have navigators or certified application counselors in house at this point.

Navigators believed that some of their sub-grantees who had engaged in case management and Medicaid enrollment work prior to the ACA with other revenue streams, such as Community Health Centers and hospitals, would continue these activities in the future. However, they were less certain about the ability of smaller non-profits, which had relied on the navigator grants, to continue this work, especially those serving vulnerable populations. They worried about where people with HIV would turn for knowledgeable enrollment assistance.

My main concern [was]... having known a lot of the clients that have been coming to us year after year for assistance trying to find plans that would serve them the best to suddenly not have someone there to help them. It is going to leave a lot of people in the dark. A lot of people find the healthcare.gov website confusing to work with or they just aren't sure what to look at with formularies and whatnot to make to make their antiretroviral medication affordable.

**Navigators expressed concern that people with and at risk for HIV many not enroll in the future.** They feared these groups would lose a contact point with health and social services as they lost

enrollment access points. They feared that losing contact with these community members would mean individuals would not only lose access to enrollment assistance but they also may lose access to other services their organizations offer. For example, one navigator organization tied enrollment events in with other community health events such as HIV testing, sometimes collaborating with the health departments. With the cuts, they were not sure they would be able to continue to operate these events moving forward and they feared that as a result there would be fewer people who would learn their HIV status as well as fewer people with coverage.

## Conclusion

This study presents findings from interviews with navigators serving people with HIV to assess how recent funding cuts could affect their ability to enroll and retain this population in coverage. Most of those we spoke with were stunned by the cuts and very concerned about their ability to serve this population moving forward. Those that were more confident in their ability to continue to assist people with HIV had alternative funding streams, experienced small cuts, or retained a large grant despite a substantial proportional cut. The participants in this study placed a great deal of value on the HIV specific enrollment experience they offered. In part, this stemmed from their knowledge about HIV treatment, ability to assess plan design for factors important to someone with the condition, and understanding of the Ryan White Program. However, beyond having a particular knowledge base, HIV navigator entities cited their ability to provide a safe and familiar setting where consumers knew they could discuss their coverage needs related to HIV free of stigma and discrimination as a unique asset. Most navigators were uncertain about what type of enrollment help and mid-year plan assistance people with HIV will receive moving forward, and some feared this could lead to loss of coverage. Navigators were concerned that people with HIV who enroll in plans without navigators with experience working with this population could enroll in unaffordable plans and ultimately fall out of coverage. Looking to the future, it will be important to continue to monitor how people with HIV enroll in coverage, whether they stay retained in care, and what happens if they do not.

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<sup>1</sup> Pollitz, K. Tolbert, J., and Diaz, M. Kaiser Family Foundation. *Data Note: Changes in 2017 Federal Navigator Funding*. 2017. <https://www.kff.org/health-reform/issue-brief/data-note-changes-in-2017-federal-navigator-funding/>

<sup>2</sup> Center for Medicare and Medicaid Services (CMS). Press Release. *Policies Related to the Navigator Program and Enrollment Education for the Upcoming Enrollment Period*. August 31, 2017. <https://www.cms.gov/CCIIO/Programs-and-Initiatives/Health-Insurance-Marketplaces/Downloads/Policies-Related-Navigator-Program-Enrollment-Education-8-31-2017pdf.pdf>

<sup>3</sup> Kates, J. and Dawson, L. Kaiser Family Foundation. *Insurance Coverage Changes for People with HIV Under the ACA*. 2017. <https://www.kff.org/health-reform/issue-brief/insurance-coverage-changes-for-people-with-hiv-under-the-aca/>

<sup>4</sup> Centers for Medicare and Medicaid Services (CMS). [https://www.cms.gov/CCIIO/Programs-and-Initiatives/Health-Insurance-Marketplaces/Downloads/2016-Navigator-Summaries\\_12-16-2016-Updated.pdf](https://www.cms.gov/CCIIO/Programs-and-Initiatives/Health-Insurance-Marketplaces/Downloads/2016-Navigator-Summaries_12-16-2016-Updated.pdf)

<sup>5</sup> See 3<sup>rd</sup> party Google Document detailing 2016 and 2017 navigator grant information: <https://docs.google.com/spreadsheets/d/e/2PACX-1vQXaqOVh4WGWakYpRv8otdmCxUzRF9kavTmo8AoGCRfSB2lJeZyrTrGp7RoE3EG64wFLD2TuO6kpp7X/pubhtml>

<sup>6</sup> See 3<sup>rd</sup> party Google Document detailing 2016 and 2017 navigator grant information: <https://docs.google.com/spreadsheets/d/e/2PACX-1vQXaqOVh4WGWakYpRv8otdmCxUzRF9kavTmo8AoGCRfSB2lJeZyrTrGp7RoE3EG64wFLD2TuO6kpp7X/pubhtml>

<sup>7</sup> Premium assistance is the mechanism by which Ryan White Program grantees are provide financial assistance to help with the cost of insurance (usually premiums and other cost-sharing).