

# Illinois Getting to Zero Community Engagement Input Analysis

The Illinois Getting to Zero Community Engagement Committee conducted several presentations to share the Framework with and garner feedback from community members. The findings were as follows:

## Identified Strengths of Framework

- There is a high level of belief of HIV treatment as a valuable tool. (95%)
- Many community members feel PrEP is a useful prevention device. (92%)
- Majority of community believes we can get to 20/20 increase. (69%)

## Identified Areas for Development

- Only slightly more than half of those queried believed that we could reach Functional Zero by 2026. (53%)

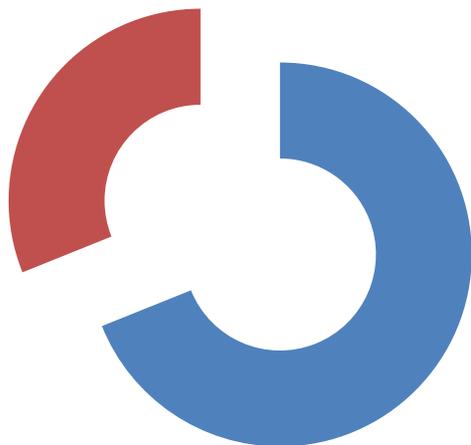
The IL CE Committee included an opportunity for community members to share their views of the HIV epidemic throughout the decades. That feedback is presented below.



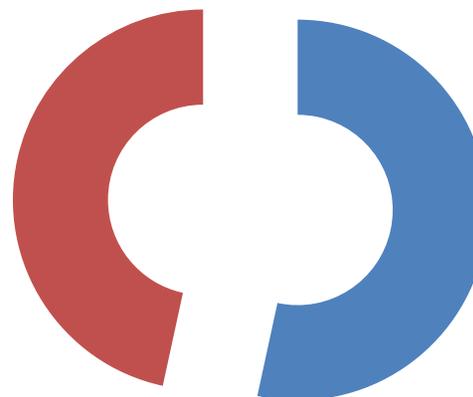
# Illinois Getting to Zero Framework Results (July 2017)

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**Chart A:** How many believe we can reach 20/20 (69%)



**Chart B:** How many believe we can reach GTZ by 2026 (53%)



## Survey results reflect:

- **Chart A:** Majority of respondents indicated they believed Illinois could reach a 20% uptake in both PrEP and ARV treatment (69%).
- **Chart B:** Almost **HALF** of respondents disagreed that we could reach Functional Zero via 20/20 by 2026 (53%).

# Feedback Summary

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## **Concerns regarding the IL GTZ Framework**

Many presentation groups enthusiastically agreed that there is good news in the last year regarding the research that states Undetectable = Untransmittable. However, some individuals offered push back. They felt that U = U was not concrete and cautioning others within the group that this research did not reveal 100% protection. In one case, a robust discussion came about with some citing research directly from Bruce Richman of New York. The point of outstanding clarification was related to the amount of time one needs to have a sustained undetectable viral load to be unable to transmit the virus. Some group members also questioned the demographics of the U = U research participants, specifically if they included those at high risk, such as those in the Ball Community.

Presentation group members also raised several questions regarding the GTZ formula. Inquiring where the information/formula was found and what were the denominators of the 20% projection.

Group members further discussed the proposed BARS modeling based on all people living with HIV, compared to the focus of groups like CAHISC which may consider that too general. Therefore, many members stressed the importance of exploring what “functional zero” would look like for the state level with a more targeted lens.

Some group members posed state surveillance dependability questions. Others felt confident with IL GTZ references to IDPH data sources.

A few group members mentioned the year 2030 being a more probable year to reach functional zero.

## **Concerns regarding the IL GTZ Leadership**

Several group members objected to the current make up of IL GTZ members and discussed the importance of having leadership represent the people affected most. Their stance being that there is no chance at authentic system change without fair representation.

Another large group of members inquired about the IL GTZ effort for statewide input and how it would be amplified in the next stages of development.

## **PrEP Education**

Too many group members still do not know what PrEP is or what it does. 1-2 people at each community meeting didn't know about PrEP, and this is not including service providers/professionals.

Group members posed concerns regarding if we have the tools to lobby the insurance companies to make sure PrEP is covered.

Some group members were reassured by current support such as PrEP being covered by Medicaid right now and Gilead having an insurance assistance program. The PrEP for IL campaign was also mentioned, where there is opportunity to coordinate efforts between the state of IL and Gilead.

In addition, a couple groups had some general questions regarding PrEP such as, “What is the youngest age someone can receive PrEP in the state of IL?”

### **Systemic Issues**

One member expressed concern over this GTZ plan focused primarily on PLWHA who are having sex...there's also corporate interests...there are prison lobbyists who don't want condoms in prison. Without a critical lens of things that maintain poverty, school closings, it's not just the people's fault, it's systemic. Need to attack corporate interests,

cited the “CHAT” study, which found that alcohol use, as well as promiscuity, were not as relevant with African American MSM, as compared with White counterparts.

- Getting paid on time x 2 laughter

- Change in mindset; getting our elected officials to embrace prevention which speaks to funding.

- Conversation hasn't started yet

- No follow through, hope is there but let's keep it going, false promises, e.g. program ending.

- VH: - When referring people, they would make it to the medical appointment but there are other factors affecting their adherence, e.g. mental health. If we want to prevent new infections, especially in the LGBTQ community, there are more stressors affecting engagement in care. Services are more limited

- Housing issues, employment, access to a living wage. What's the priority for the client?

- Outside of ryan white system, a lot of patients are with private doctors, very important to get their buy in. no real support from them, they are a huge portion of this issue.

### Suggestions on Best Practices

Lots of discussion over provider buy in- provider bias as a barrier to progress. More provider education and pressure to comply with progressive steps. Best Practices: Some group members proposed applying a “best practices” approach by looking at agencies with successful viral suppression rates, such as the VA with 90% virally suppressed.

PrEP messaging should not push away or stigmatize people living with HIV. Shameful, condescending and judgmental messages can be stigmatizing, which makes it hard to maintain treatment regimens. It makes you feel like you made a mistake and were wrong for this to happen.

## Specific comments also included:

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Treating HIV has become easy, but it's all the supportive services around it, e.g. i can't get the people to the dr. because of the mental health. Systems on paper look great, but in reality not enough funding for mental health and our patients are suffering because of it and then I look like I'm not following up, but there's really not enough support to help the clients stay in care. I'm promising my patients, based on what you promised me. It would be nice to not be stomped on from both directions.

# 2017 GTZ Community Feedback Themes

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Community Group	Date	Questions or concerns about GTZ formula and/or plan.	Tap into existing best practices (ex: Near elimination of perinatal infections, those with high viral suppression, and other GTZ plans)	PrEP education needed	Issues are systemic Policies/funding, lack of buy-in from providers, ACA and insurance)	Leadership needs to reflect people most affected	Remember specific populations (re-entry, aging, and mental health)	Planning groups needed throughout the state
BTAN	5/9/2017	X		X	X	X		
CAHISC Steering Committee	5/10/2017		X		X			X
SPC	5/11/2017	X	X		X			X
SHARP	5/15/2017	X		X	X	X		
Men & Women in Prison Ministries	5/26/2017	X	X	X	X		X	
CAHISC	5/31/2017	X	X		X		X	X
West Side Ministers Coalition	6/1/2017			X				
Region 1 & Region 7	6/16/2017		X		X		X	X
IL GTZ Webinar	6/29/2017	X	X	X		X		X

# Recommendations

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- The subsequent IL GTZ taskforce must have ample input from across the state of Illinois while focusing to include the eastern and southern parts of the state to balance the initially heavy Chicago representation.
- The IL GTZ plan will need to specifically outline how it intends pioneer new ways of including diverse state/local departments to collaborate for the purposes of Getting to Zero.
- The Exploratory Group will need continued support to maintain the initiative's momentum. It will benefit greatly from a full time, dedicated support person to encourage and coordinate membership communication. Ideally, the support person will be funded with thoughtfulness to conceivable competing interests and potential public examination of subsidy sources.