

**CaraConference 2020**

# **HIV: Now + Next**

**September 21–25**



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in the fight against HIV/AIDS**

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MONDAY, SEPTEMBER 21

# Building an Effective Ending the HIV Epidemic Plan

Introduction: Linda Seiter | Moderator: Adam Reilly

Presenter: Sara Semelka

HIV:  
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# ALL TOGETHER NOW: BUILDING AN EFFECTIVE ETE PLAN

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AIDS Foundation Chicago, Getting to Zero Illinois

September 2020



# A BIT ABOUT ME

**Sara Semelka**

she/her

Sr. Project Manager  
AIDS Foundation of Chicago





# LEARNING OBJECTIVES FOR THE DAY

## Sharing the Getting to Zero Illinois process with ...

- Building crucial alliances with partners to ensure an effective, impactful ETE plan rooted in community, accountability and efficacy
- Navigating the creation and maintenance of inter-governmental partnerships
- Creating, evaluating and examining community engagement activities in attempts to go beyond transactional, extractive community encounters and move into co-creation
- Coordinating workgroups across sectors to create an actionable plan
- Securing funding to support the work of ETE plan creation

# WHERE WE'RE FROM



- **Medicaid** expansion state
- **Republican** governor from 2015 – 2018, **Democratic** governor inaugurated in January of 2019
- Home to ~**12.7 million people**. Biggest population concentration is in **Chicago**, (2.7 million); **suburban** area around Chicago is home to about 8.5 million people; **small towns and rural areas** are home to the rest of the 1.5 million Illinoisans





# ILLINOIS HIV PREVALENCE, 2018

**Estimated 42,500  
people living with HIV  
(36,413 diagnosed)**



47% Black  
27% White  
20% Hispanic

Sex at birth:  
80% Male  
20% Female

12% 20 – 29 y/o  
20% 30 - 39 y/o  
68% 40+

Since 2009, HIV diagnoses in Illinois down 21%, or an average of 2.4% per year.

New diagnoses among 20-24 year olds significantly increased.

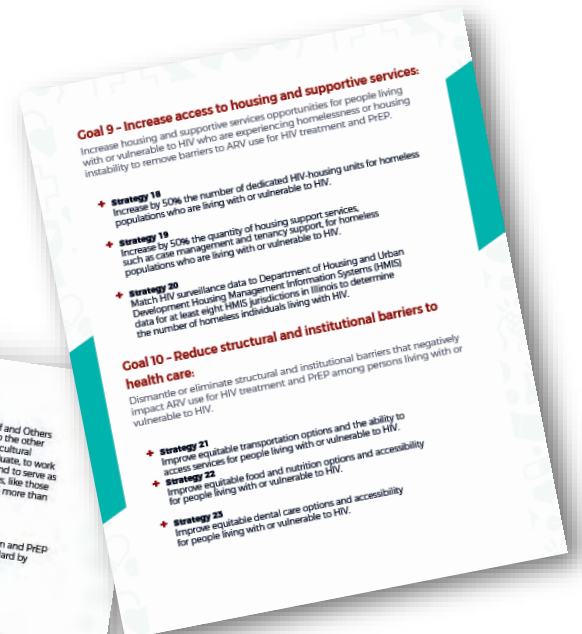
New diagnoses among Hispanic/Latino MSM up 53%.

In 2018, the HIV diagnosis rate among Black males was 2 times higher than the rate among Hispanic/Latino males and nearly 8 times higher than the rate among White males.

# OUR PLAN



What Do We Mean By "Zero"?



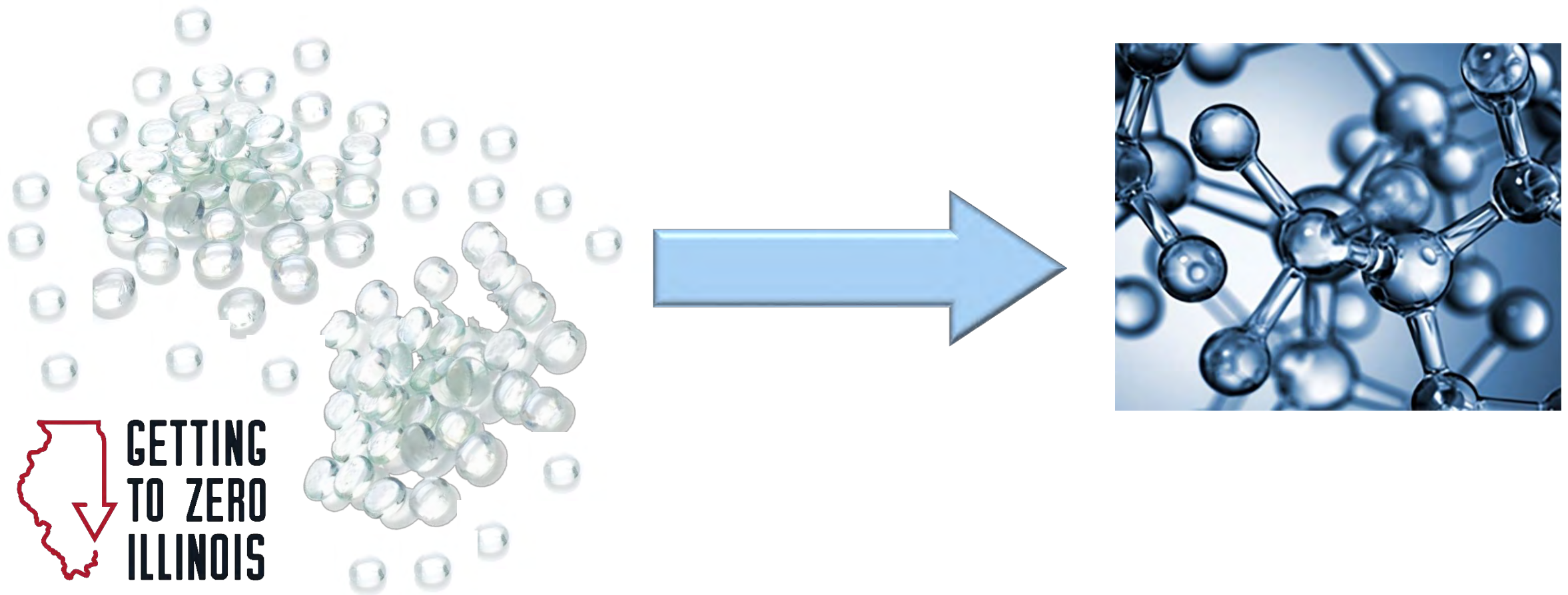


# LESSONS LEARNED ALONG THE ROAD





# STRUCTURE



# STAFFING



# TIMELINES

Planning

Engagement

Analysis

Drafting

Synthesis

Feedback

Editing





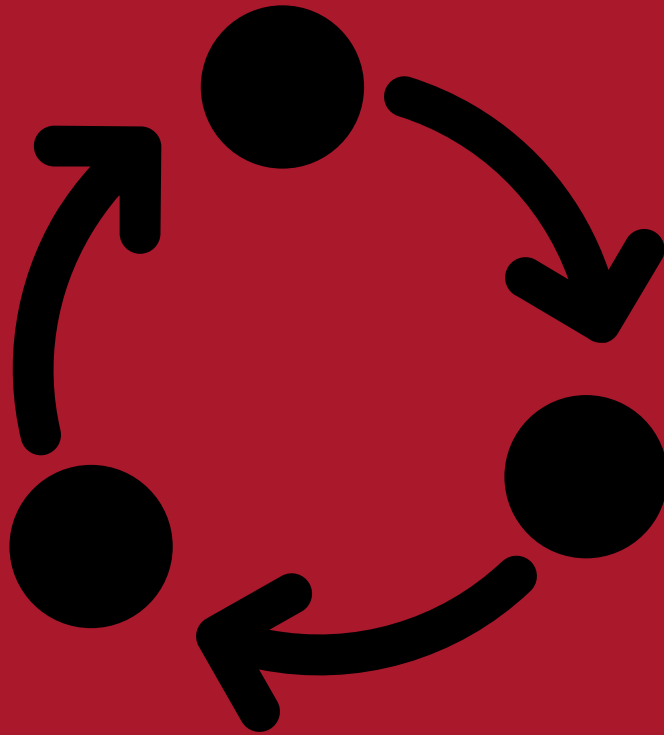
# POLL QUESTION

**What area do you think will provide the greatest challenge when it comes to creating a plan?**

- A. Community engagement
- B. Analyzing gathered data
- C. Drafting/writing/editing the plan
- D. Something else (feel free to write it in the chat!)



# BUILDING ALLIANCES



# WHAT WORKED – WHO

**Bringing city and state governments together**

**Getting buy-in from other key players**

- **Health departments**
- **Hospital systems**

**Use existing relationships to:**

- **Get and find champions**
- **Get others excited**





# WHAT WORKED – HOW

Present at community group meetings, made ourselves available to show up at *their* spaces, present and answer questions

Regularly-scheduled calls and posting notes on Basecamp kept people in the loop whether they could join or not, which sustained momentum



Doing one-on-one outreach, met people where they are at, demonstrating how contributing to an ETE plan will **support** their **values** and align with their **goals**

# LESSONS LEARNED

- **If at first you don't succeed – try, try again!**
  - Building alliances will take a long time and is always ongoing. There are staff turnovers, new leadership and political shifts that will allow you to keep working to build relationship
- **If you don't have the relationship, find someone who does!**
  - We still don't have strong relationships in the southern half of the state, and we are working on building those up this year.



# INTERGOVERNMENTAL PARTNERSHIPS



# THE IMPORTANCE

- **What are the benefits of governmental partnerships?**
- **Defining the partnerships - who is doing what**
  - **Lay out responsibilities from the outset**
    - Who is dedicating staff to the effort?
    - Who is contributing resources/money?
    - Who is taking the lead on staffing workgroups, administrative tasks, convening meetings?
- **Planning bodies**
  - **What it looks like in Illinois**
    - CAHISC
    - IHIPC





# THE CHALLENGE

- What do you do if your relationship with a governmental agency/department is adversarial?
- What if the relevant governmental agencies do not get along with each other?



# COMMUNITY ENGAGEMENT



# WHAT WORKED

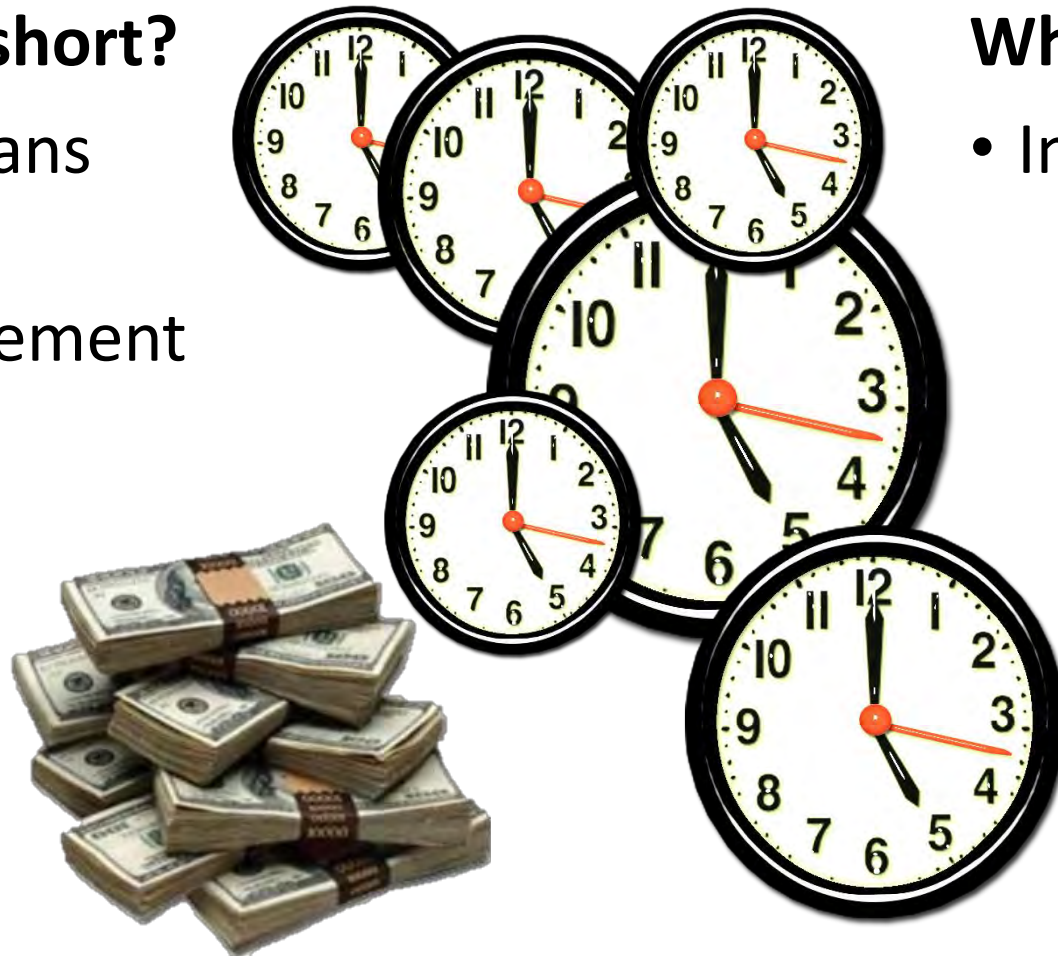
- Attending USCA, listening and networking with other EHE planning folks
- Reviewing the Denver Principles and MIPA practices
- Using our champions to connect with communities
- Planning
- More planning
- Organizing materials and creating tools



# LESSONS LEARNED

## Where did we fall short?

- Engagement of trans women
- Downstate engagement
- Data analysis



## What does it take?

- Investment!
  - Time (a lot)
  - Money (not as much as you might think)



# GTZ-IL LEADERSHIP

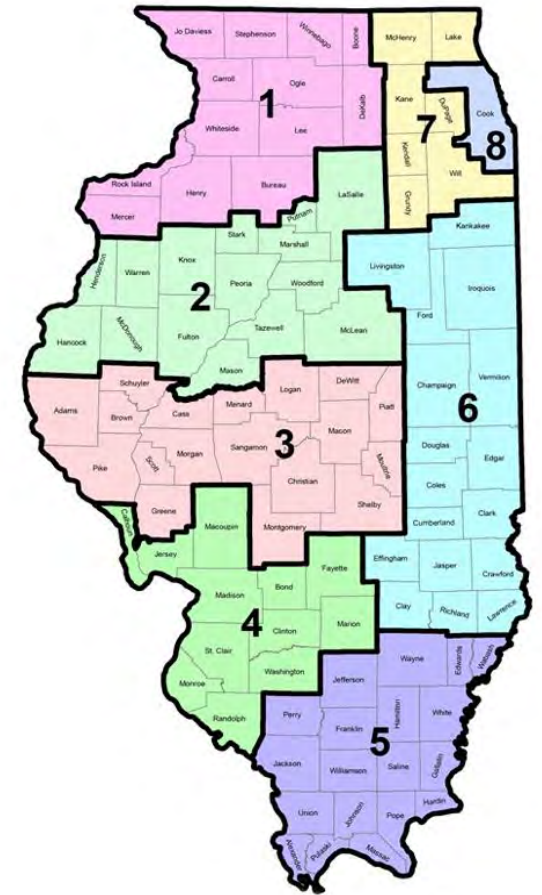


# COMMUNITY ENGAGEMENT



## TOWN HALLS

- One in each of Illinois' eight regions, and two in the Chicago area
- 320 participants in total
- 100 pages of typed notes





# COMMUNITY ENGAGEMENT

## FOCUS GROUPS

Black gay, bisexual  
or same-gender-  
loving men

Transwomen of  
color

People re-entering  
communities from  
the justice system

People living with  
HIV that are 50+  
years old or long-  
term survivors

Spanish-speaking

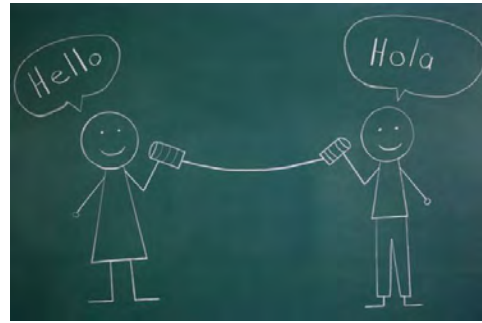
Latino Men

Mothers living with  
HIV



# COMMUNITY ENGAGEMENT

## SURVEY



Online and  
on paper

In English and  
in Spanish

24 questions  
about yourself  
and Getting to  
Zero ideas

Open for  
24 weeks

408 total  
responses





# POLL QUESTION

**What community engagement methods would or have made the most sense in your process?**

- A. Survey
- B. Focus groups
- C. Larger listening sessions or town halls
- D. Something else (please share in the chat!)



# LANGUAGE ACCESSIBILITY



**Plan to add money and time to your process if you are going to publish not only your plan, but supporting materials and engagement materials (focus group fliers, surveys, etc.) in languages other than English.**

**We had materials translated into Spanish. We did not plan on that from the outset, and had to get creative with grant funding. We lucked out, but it's better to plan from the beginning!**

# TOOLS WE USED



- Focus group organizing chart
- Focus group flyer
- Focus group sample email
- Town hall flyer
- Town hall role list
- Town hall check list
- Town hall full meeting facilitator guide
- Town hall small group facilitator guide

# CHALLENGES



- **Tight timelines**

- Did 7 outside-of-Chicago town halls all in one month
- All focus groups done within 6 weeks
- All data analysis done in one month

- **Organization**

- All focus groups done within 6 weeks, all 7 were done in conjunction with community partners (hooray!), which required a lot of coordination. Money, consent forms, invoices, audio recordings, email lists were all over the city





# WORKGROUP CREATION



# WHAT WORKED



- **Building from the core group – using connections and suggestions**
- **Reaching out individually**
- **Following up. Many times.**
- **Casting a wide net**
- **Providing support**



# TOOLS WE USED

- **Flyer to recruit co-chairs**
- **Flyer to recruit members**
- **Kickoff slide deck for workgroups**
- **Recommendation template**
- **Timeline and accountability tracker**







# CHALLENGES

- **Creating and maintaining momentum**
- **Group editing**
  - **This is time consuming and takes a lot of support**
  - **Set a process up upfront, lay out clear expectations and establish open lines of communication**
- **At first, we struggled with how to let group leaders take true ownership – what to leave on their plates and what to take off**
  - **You're going to provide a lot of support for the unsexy stuff: calendar invites, Doodle polls, conference lines, sending out agendas, sending out notes**

# HOW THE PLAN CAME TOGETHER

Committees met  
throughout  
the summer of 2018

Community feedback on the  
recommendations was  
collected in the fall of 2018

A smaller editing team created  
a draft plan released on  
World AIDS Day 2018

Community feedback  
was gathered on draft plan  
to develop the final  
version, released May 2019





# THE PRODUCT – WWW.GTZILLINOIS.HIV



# GUIDING PRINCIPLES

**We cannot end the epidemic unless we make progress for all populations impacted and tackle injustices:**

- Eliminating Stigma
- Dismantling Racism
- Prioritizing Trauma Prevention & Trauma-Informed Care
- Practicing Cultural Humility
- Focusing on Data to Achieve Outcomes



**WORKFORCE**

**EQUITY**

**LINKED  
CONDITIONS**

**W**

**E**

**L**

**H**

**E**

**S**

**HEALTH CARE**

**EFFICIENCY**

**SURVEILLANCE**

**PLAN PRINCIPLES**



# OUR STATE GTZ PLAN INCLUDES ...

**5** guiding principles

**6** domains

**22** goals

**78** strategies



**...TO END THE HIV EPIDEMIC IN  
ILLINOIS**

# 10 FOCUS AREAS FOR 2019-2020

- Strengthen peer workforce
- Expand HIV testing
- Increase PrEP linkages
- Deepen cultural humility
- Root interventions in evidence-based research
- Build social communities
- Integrate health care programs
- Improve STI screening
- Assess and monitor our goals
- Boost ARV usage





# UPDATE FOR 2020

- **Workgroups take a lot of work**
  - *A lot of work*
- **We will likely cut down the number of workgroups**
- **Each group will need to find their own rhythm, cadence and ways of working**
- **There are alternatives to workgroups that we are exploring:**
  - 30-minute project-specific check-ins
  - One-on-one consultations with GTZ staff or partners a few times twice per quarter
  - Quarterly 2-hour meetings
  - Monthly email check-ins on project goals ...
  - Monthly video call check-ins on project goals





# SECURING FUNDING



# WHAT WORKED



- Starting small
- Leveraging existing funding relationships and board members
- Funder breakfast
- Creating a funding pool
- Being organized, showing the intersectionality, demonstrating our broad and deep alliances

# CHALLENGES



- It can be a tough sell to get money for :
  - Administrative tasks
  - Unrestricted dollars
  - Planning
- Quantifiable deliverables
- Timelines
- Connecting HIV to larger/broader health issues, as well as non-health issues that factor into social determinants of health



# WHAT OTHER QUESTIONS DO YOU HAVE?





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**Getting to Zero Illinois**

**[www.gtzillinois.hiv](http://www.gtzillinois.hiv)**

