Community
Engagement Report

HEALTHY ILLINOIS 2028

State Health Assessment

Illinois Department of Public Health
IDPH
Protecting Health, Improving Lives

UIC Policy, Practice and Prevention Research Center

Illinois Public Health Institute

Contents

List of Figures

List of Tables

Abbreviations

CHSA	Community Health Status Assessment
CoC	Communities of Color
CTSA	Community Themes and Strengths Assessment
IDPH	Illinois Department of Public Health
IPHI	Illinois Public Health Institute
LHD	Local Health Department
LGBTQIA+	Lesbian, Gay, Bisexual, Trans, Queer (or Questioning), Intersex, and Asexual
MAPP	Mobilizing for Action through Planning and Partnerships
NACCHO	National Association of County and City Health Officials
NAMI	National Alliance on Mental Illness
PLWD	People Living with Disabilities
PWLE	People with Lived Experience
SHA	State Health Assessment
SHIP	State Health Improvement Plan
SPHSA	State Public Health System Assessment

Acknowledgments

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1 Executive Summary

Purpose

Pursuant to Illinois Public Act 102-0004, Illinois develops a State Health Assessment (SHA) and State Health Improvement Plan (SHIP) every five years. A collaborative public/private cross-agency effort, the SHA and SHIP assesses and recommends priorities and strategies to improve the public health system, the health status of Illinoisians, reduce health disparities and inequities, and promote health equity. This report is a component of the SHA, designed to capture perspectives from public health practitioners and community members across the state to better understand community health issues and health equity priorities and understand their health challenges.

IDPH is leading the SHA/SHIP process in collaboration with the Office of the Governor's appointed SHA/SHIP Partnership, which includes representatives from state agencies with public health responsibilities and a range of public, private, and voluntary sector stakeholders and participants in the public health system. IDPH is working with the Planning Team—the UIC School of Public Health, Policy, Practice, and Prevention Research Center and Illinois Public Health Institute (IPHI)—to facilitate the partnership and to complete the SHA/SHIP process.

On behalf of IDPH, the Planning Team and the partnership, IPHI conducted 16 focus groups (71 total participants) with regional social service providers and local health departments (LHD). In addition, a total of eight focus groups (90 total participants) were completed with people with lived experience (PWLE) across the state. For the purposes of this report, people with lived experience are defined as "individuals directly impacted by a social issue or combination of issues who share similar experiences or backgrounds and can bring the insights of their experience to inform and enhance systems, research, policies, practices, and programs that aim to address the issue(s).[1] "There was a strategic focus to hear from communities that face the most health inequities, such as communities of color, immigrants and refugees, individuals living with disabilities, Lesbian, Gay, Bisexual, Transgender, Queer, Intersex, Asexual (LGBTQIA+) communities, and older adults. IPHI also conducted a focus group with Spanish speakers and with southern Illinois community members. The community engagement focus groups aided in better understanding community health issues and priorities related to health and equity priorities as well as infrastructure issues facing the public health system. The focus groups explored a range of key topics that included the identification of health priorities, availability of community resources and barriers encountered when seeking to access said resources, and the impact of the COVID-19 pandemic.

Key findings

The table below presents key findings by focus group type and topic.

Regional Social Service and LHD Focus Group Data

TOPIC	KEY FINDINGS
Emergent Community Priorities	Mental health, behavioral health, and substance use disorder were commonly noted as important health issues impacting communities. Cited structural access barriers included health insurance and availability of health care providers. Social access barriers included stigma around mental health and mistrust of the health care system. Participants spoke to the role of social and structural determinants of health as emergent priorities in communities, specifically housing, transportation, and food access.
COVID-19 Related Challenges	The pandemic has increased the need for behavioral health services across the state among both adults and children due to heightened feelings of isolation, trauma resulting from death and/or illness of a loved one, increased substance use, and lack of mental health support for parents and caregivers. The pandemic has impacted chronic disease management, Health care workforce shortages and perceptions about the importance of chronic disease management were noted as factors impacting health outcomes. Trust, awareness, and misinformation were highlighted as factors influencing communication between community, the health care system, and government. Participants shared concerns regarding high rates of unemployment caused by the pandemic that have resulted in lost income for many families and the inability to cover critical needs such as food and housing. Technology was cited as a barrier in learning about COVID-19 and how to access resources among populations with limited access to technology and usage knowledge.
Important Priorities from the 2020 Interim SHIP*[2]	Workforce Availability and Workforce Development was noted as the most important priority among participants. Capacity Building to Address New and Emergent Priorities was also frequently discussed. Participants cited the need for resource allocation to address health inequities and a concentrated focus on both service gaps and social determinants of health (with a special emphasis on affordable housing). Silos, limited funding, and communication were cited as important factors influencing coordination and collaboration within and across the public health system.
Opportunities to Address Structural and Social Determinants of Health (SSDOH)	Improving coordination across the public health system, which ensures diversity and promotes inclusive voices at the decision-making table. Training and educating communities and in the public health system. There's an opportunity to create training opportunities for public health staff around health equity and SSDOH. Building infrastructure for transportation and expanding access to those most in need. The transportation system needs to expand existing operations, create additional routes, and develop capacity to provide personal transportation to and from medical appointments. Generate resources and funding for a more holistic approach to improving health. Ensure that there are sources of funding for communities to assess and address identified needs.

People With Lived Experience (PWLE) Focus Groups

TOPIC	KEY FINDINGS
Top Health Priorities	Noted chronic conditions included diabetes, obesity, and heart disease. Chronic stress among home health providers and caregivers was a common theme for people living with disabilities (PLWD) and older adults' sessions. Noted behavioral health conditions included anxiety, substance use disorder, and depression. Limited access to needed services, medication, stigma, accessibility of services, and lack of diverse providers were highlighted as systemic issues. Community violence was elevated as a health priority in communities of color (CoC) and LGBTQIA+ sessions.
Social and Structural Determinants of Health (SSDOH) Challenges	Physical environment related challenges included living in food deserts, limited access to needed (social and health) resources, and personal safety. Barriers to accessing health care included transportation, health insurance, understaffing, and service availability. Provider knowledge and accessibility of services were noted as factors that impact whether individuals decide to engage in the health care system and overall patient experience. The existence and impact of racism and discrimination was highlighted as a critical challenge for individuals with lived experience. Culture, religion, homophobia, transphobia, and stigma serve as both social and structural barriers to receiving care.
Availability of Community Resources	Categories of available services included youth-specific resources, health care/direct services, support groups, adult education, and social services. Participants across all sessions experienced concern regarding the lack of needed services within the community where they reside. This elevated the challenge of transportation needed to access said services. Responses were region dependent—as there were examples of communities with a wide range and availability of resources and others cited as having limited or no resources for individuals to tap into.
Challenges Experienced When Trying to Access Community Resources	Financial and age eligibility requirements—either making too much money or being too young to qualify. Lack of knowledge of what's available in the community—there's no centralized place to gain knowledge about available services. Language barriers—services and written materials not offered in multiple languages. There is also a lack of bilingual staff members to provide support in real time to participants. Citizenship requirements—participants that are undocumented experienced fear of deportation. Long wait times—limited-service capacity needed to meet participant demand that results in long wait times. Lack of cultural competency among staff—existence of limited staff capabilities and knowledge needed to reach populations.

TOPIC	KEY FINDINGS
COVID-19 Related Challenges	High rates of unemployment and lost income for community members, resulting in reduced capacity to afford and/or to manage associated social and medical needs, such as housing, food, and medication. Mental health has been significantly impacted for youth and adults alike. Individuals reported experiencing isolation, anxiety, chronic stress, and depression. In addition, participants shared high occurrences of grief and trauma due to loss of loved ones. Findings highlighted an association between safety concerns around exposure and behaviors that result in long periods of no human connection and increased feelings of isolation. Said concerns were prevalent among PLWD and older adults. Existence of health care staffing shortages that contribute to long wait times, business closures, the shift from in-person to virtual care, and limited access to critical services. These shortages were more evident in areas with chronic access challenges prior to the pandemic. Technology served as both a facilitator (increasing access to others through Zoom, telehealth platforms, etc.) and barriers for individuals with limited knowledge in how to navigate these platforms and access to internet. Literature is limited for evidence-based care for trans health and LGBTQIA+ care—the pandemic has slowed this process and impacted decision-making among health care providers and patients alike.
Cited Resources Needed for Recovery	Resources span across seven categories: economic development, health care, financial support, education, transportation, technology, and recreational programming.
Proposed Solutions to Identified Challenges	Solutions fell largely into two categories that included shifts to the structural and social environment and enhanced learning opportunities across a range of audiences. There is a defined role for community as part of addressing solutions, including community organizing, volunteering, donating time and resources, and advocating for self and others.

Cross-Cutting Themes

Mental health was cited as an emergent priority to be addressed in future SHA/SHIP efforts.

Social and structural barriers related to health insurance coverage (or lack of), health care system workforce shortages, stigma experienced within and outside of the health care system, and transportation were noted as factors impacting the health and well-being of communities across the state.

The COVID-19 pandemic has had a significant impact upon the mental health of youth and adults alike. In addition, the pandemic has contributed to workforce shortages within the health care system.

Technology served as a barrier to participants feeling socially connected to family, friends, and health care professionals.

Training and education for public practitioners and building infrastructure to improve the transportation system were noted as potential solutions to improve the health and well-being of the community.

2 Introduction

Pursuant to Illinois Public Act 102-0004, Illinois develops a State Health Assessment (SHA) and State Health Improvement Plan (SHIP) every five years. A collaborative public/private cross-agency effort, the SHA and SHIP assesses and recommends priorities and strategies to improve the public health system, the health status of Illinoisians, reduce health disparities and inequities, and promote health equity. This Community Themes and Strengths Assessment (CTSA) report is a component of the SHA, designed to capture perspectives from public health practitioners and community members across the state.

IDPH is leading the SHA/SHIP process in collaboration with the appointed SHA/SHIP Partnership, which includes representatives from state agencies with public health responsibilities and a range of public, private, and voluntary sector stakeholders and participants in the public health system. IDPH is working with the UIC School of Public Health, Policy, Practice, and Prevention Research Center; and the Illinois Public Health Institute (IPHI) to facilitate the partnership and to complete the SHA/SHIP process.

SHA Framework

In 2021–2022, IDPH completed a comprehensive SHA using the Mobilizing for Action through Planning and Partnerships (MAPP) Process (Figure 1). MAPP utilizes four assessments to gain a comprehensive picture of community health.

Figure 1. The MAPP Process (NACCHO, 2013)

- **The Community Health Status Assessment (CHSA)** provides quantitative information on community health conditions.
- **The Community Themes and Strengths Assessment (CTSA)** identifies assets in the community and issues that are important to community members.
- **The State Public Health System Assessment (SPHSA)** measures how well different state public health system partners work together to deliver the Essential Public Health Services. The SPHSA is currently under revisions from the National Association of County and City Health Officials (NACCHO). Therefore, IDPH, IPHI, and UIC developed an adaptation of the SPHSA focused on health equity (the Health Equity Capacity Assessment) to complete this component of the MAPP Process for the 2021–2022 SHA.
- **The Forces of Change Assessment (FOCA)** identifies forces that may affect a community and the opportunities and threats associated with those forces.

Community engagement is a fundamental practice of modern public health, because communities, more than any other group, have the largest stake in improving health and well-being. Leaning on community knowledge helps the public health system better identify problems and generate community leadership to collectively and more effectively solve problems and promote health. For these reasons, the SHA/SHIP statute specifically requires using data "representing the population's input on health concerns and well-being, including perceptions of people experiencing disparities and health inequities." With the MAPP framework, the CTSA serves as the community engagement piece for the 2021–2022 SHA.

Assessment Methodology

To complete the CTSA assessment for the 2021–2022 SHA, the Illinois Public Health Institute (IPHI) partnered with IDPH and the UIC School of Public Health, Policy, Practice, and Prevention Research Center to capture perspectives from public health practitioners and community members across the state to aid in understanding community health issues and priorities related to health and equity as well as infrastructure issues facing the public health system.

3 Focus Group Recruitment Outcomes

On behalf of IDPH and the partnership, IPHI conducted 16 focus groups (71 total participants) with regional social service providers and local health departments across IDPH regional offices. See Table I below outlining recruitment outcomes. Of all the sessions, the West Chicago Region had the highest number of participants with 15, while the Bellwood and Rockford regions each had eight participants attend. One focus group conducted with the National Alliance on Mental Illness (NAMI) affiliates resulted in nine participants. IPHI conducted outreach through SHA/SHIP Partnership members affiliated with NAMI and Illinois Partners for Human Services as well as outreach to all Illinois local health department administrators. IPHI developed a focus group guide to ensure a systematic approach to conducting the sessions (see **Appendix 1: REGIONAL SOCIAL SERVICE AND LHD FOCUS GROUP GUIDE**). Posed questions that spanned topics such as identifying which priorities from the 2020 Interim SHIP*[3] to address over the next five years in the next SHIP, potential strategies needed to address identified priorities, and emergent community health priorities.

FOCUS GROUP	SOCIAL SERVICE PROVIDER	LOCAL HEALTH DEPARTMENT	TOTAL
Bellwood Region	7	1	8
Champaign Region	4	2	6
Edwardsville Region	3	5	8
Marion Region	1	4	5
Peoria Region	9	3	12
Rockford Region	7	1	8
West Chicago Region	9	6	15
NAMI Focus Group	N/A	N/A	9
	40	22	71

Table I. Regional Social Service Providers And Lhd Focus Group Participant Outcomes

The SHA/SHIP Planning Team conducted focus groups with people with lived experience (PWLE) on behalf of IPHI. A total of eight focus groups (90 participants) were completed with PWLE across the state. All focus group attendees received a $50 gift card to compensate them for their participation. This set of focus groups focused strategically on hearing from communities that face the most health inequities, such as communities of color (2 focus groups), immigrants and refugees, individuals living with disabilities, lesbian, gay, bisexual, trans, queer (or questioning), intersex, and asexual (LGBTQIA+), and older adults. IPHI also conducted a focus group with Spanish speakers. Upon initial review of recruitment outcomes by region, IPHI facilitated an additional focus group with individuals living in southern Illinois to ensure adequate representation across the state. In support of recruiting people with lived experience (PWLE), IPHI coordinated outreach efforts through regional social service providers and LHDs. These individuals were provided with outreach goals and recruitment flyers (see **Appendix 2: PWLE FOCUS GROUP RECRUITMENT MATERIALS**) to send out to their respective constituents. Similar to the approach used for the regional social service provider and LHD focus groups, IPHI developed a focus group guide in advance of sessions conducted with PWLE to ensure a systematic approach to the focus groups (see **Appendix 3: PWLE FOCUS GROUP GUIDE**). Focus group guide questions explored a range of topics, including the identification of health priorities, availability of community resources and barriers encountered when seeking to access said resources, and the impact of the COVID-19 pandemic. Table 2 below highlights recruitment outcomes from the eight focus groups conducted with PWLE. There were a

total 92 individuals that participated across these sessions. Regionally, Chicago and Chicagoland suburbs accounted for the largest number of participants, totaling 38 individuals (41% of total participants). Sessions conducted with communities of color (CoC) and LGBTQIA+ captured perspectives across four regions.

	FOCUS GROUP COUNTS BY REGION				
Focus Group Session	Chicago + Chicagoland Suburbs	Northern Illinois	Central Illinois	Southern Illinois	Totals
Older Adults	10	3	5	0	18
Communities of Color	9	3	5	1	18
Immigrants and Refugees	4	1	0	1	6
People Living w/ Disabilities	4	2	5	1	12
LGBTQIA+	9	1	5	1	16
Southern Illinois	N/A	N/A	N/A	19	19
Spanish Only	2	1	0	0	3
Totals	38	11	20	23	92

Table II. PWLE Focus Group Outcomes

4 Data Analysis

Upon the completion of the focus groups, staff conducted a preliminary round of manual, structural coding to identify “big bucket” themes and develop researcher reflections. Qualitative coding is an iterative process and requires several rounds of review before formal analysis is completed and interpretations can be put forth. From there, the coded data were grouped into themes using an inductive thematic analysis approach. Themes are identified by bringing together components or fragments of ideas or experiences, which are often meaningless when viewed alone.[4] Additional researcher memos were also developed during the coding process to help capture “Ahas,” themes and potential relationships in real time. After the data analysis process was completed, final results were presented to the SHA/SHIP Partnership, and the Planning Team led the group in a discussion to gather feedback and determine next steps for regarding future community engagement efforts.

5 Results

Regional Service Providers and LHD Focus Group Findings

A. Emergent Community Priorities

Participants were asked to discuss their thoughts regarding emergent priorities in their communities and experiences in learning from community members and clients about important health issues. Themes captured from the data are noted in Figure 2 below. Mental health, behavioral health, and substance use disorder were commonly noted as important health issues impacting their communities. In addition, challenges related to either not having health insurance or being underinsured and limited availability of providers and needed services were cited as access barriers. These access challenges were exacerbated in rural areas where there is a lack of local service providers available to meet the needs of communities. Lastly, mental health stigma and lack of trust were also cited as barriers influencing an individual's decision to engage in health care services or not. As one participant shared:

> *Mental health impact[s] almost everything, stigma [...], with COVID a level of distrust that has developed with the health care system—could be an issue with race, people in poverty, or experiencing disparities."*
>
> — SOUTHERN ILLINOIS

Figure 2.

Emergent Community Priorities

- Mental health, behavioral health, and substance use disorder were commonly noted as important health issues impacting communities.
- Cited structural access barriers included health insurance and availability of health care providers. Social access barriers included stigma around mental health and mistrust in the health care system.
- Participants spoke to the role of social and structural determinants of health as emergent priorities in communities, specifically housing, transportation, and food access.

Participants spoke to the role of social and structural determinants of health as emergent priorities in their communities, specifically housing, transportation, food access, and community and interpersonal violence. Data highlighted the increase of homelessness, concerns about the eviction moratorium ending, and limited availability of affordable and supportive housing for those in need. As for transportation, participants noted challenges with accessing medical transit and limitations of public transit in rural areas. Access to transportation made it difficult for community members to attend appointments and/or access resources not readily available in their local communities. Examples of participant responses supporting these findings included:

> *Will have thousands of families homeless when the eviction moratorium ends. Lack of education to understand what the moratorium is. What it is doing to their physical and mental health now that they are facing homelessness."*
>
> — CENTRAL ILLINOIS

> *Access to transportation. That is a major concern even to get the vaccine. Had to make huge effort to get folks the vaccine [especially] older adults and people with disabilities."*
>
> – CHICAGO AND CHICAGOLAND SUBURBS

Participants shared concerns regarding the existence of food deserts across the state where individuals are unable to get access to healthy food. The availability of home delivery services was mentioned, but also cited as a barrier to some due to associated costs. Furthermore, participants discussed how the challenge of accessing healthy food within their communities was exacerbated by transportation issues that are experienced by many families, especially those with limited financial resources and living in rural areas of the state.

B. COVID-19 Related Challenges

Focus group participants were asked the following question: "What are the main challenges that your community is facing now because of COVID-19?" Themes that emerged from the data are noted in Figure 3 below. Findings highlighted how the pandemic has increased the need for behavioral health services across the state among both adults and children due to heightened feelings of isolation, trauma resulting from death and/or illness of a loved one, increased substance use, and lack of mental health support for parents and caregivers. Participants shared concerns about the impact of the pandemic on the youth's social-emotional learning, instability caused by school closures/quarantine, and struggles with remote learning were cited as critical factors. Examples of participant responses are noted below.

> *People being affected by the death of a loved one or serious illness. Dealing with grief and trauma of losses."*
>
> – CHICAGO AND CHICAGOLAND SUBURBS

> *May have lost a family member or caregiver, unemployment, other kids have anxiety and fear thinking they are going to die etc. The number of kids who have lost a parent or caregiver (may be 146,000)."*
>
> – SOUTHERN ILLINOIS

> *Would never recommend an online class to a first-time student. The development at that age alone because there is a lack of connecting and accountability."*
>
> – SOUTHERN ILLINOIS

Figure 3.

COVID-19 Related Challenges

- **The pandemic has increased the need for behavioral health services across the state among both adults and children due to heightened feelings of isolation, trauma resulting from death and/or illness of a loved one, increased substance use, and lack of mental health support for parents and caregivers.**
- **The pandemic has impacted chronic disease management—health care workforce shortages and perceptions about the importance of chronic disease management were noted as factors impacting health outcomes.**
- Trust, awareness, and misinformation were highlighted as factors influencing communication between the community, the health care system, and government.
- Participants shared concerns regarding high rates of unemployment caused by the pandemic that have resulted in lost income for many families and the inability to cover critical social needs such as food and housing.
- **Technology was cited as a barrier in learning about COVID-19 and how to access resources among populations with limited access to technology and usage knowledge.**

According to participants, the pandemic has had a significant impact on chronic disease management for community members. Health care workforce shortages (including in-home and respite workers) contributed to provider access challenges for individuals seeking services. To not overburden the system, there was a shrinkage in the availability of preventive and/or elective services, resulting in perceptions of chronic disease management not being a priority for individuals and the health care system at large.

Trust, awareness regarding available resources, and misinformation about COVID-19 as factors impacting communication between the community, health care system, and government was a theme highlighted by the data. Both stigma around the COVID-19 vaccine and spreading of misinformation contributed to increased levels of frustration, mistrust, and confusion for community members; these factors collectively influenced decision-making around which preventive measures were taken by communities.

The pandemic resulted in high rates of unemployment for many families. Thus, impacting financial capacity and capabilities to afford social needs such as housing and food. While the eviction moratoriums have provided some relief, there is growing concern about covering rent and mortgage expenses while juggling other needs. These issues are especially challenging in rural communities where access to needed resources and transportation options are limited. Furthermore, participants highlighted an association between the pandemic's impact and an increase in homelessness. As one participant shared:

> *"COVID is not just the indirect cause of homelessness but the direct [cause] for many people we are seeing in eviction court."*
>
> — CENTRAL ILLINOIS

Adequate access to technology devices and internet and "know-how" around usage of said devices was disparate across community members. There was concern regarding technology accessibility among older adults, community members living in rural areas, and PLWD. These challenges contributed to increased feelings of fear among the community, limited knowledge about COVID-19, and where and how to get resources. As one participant stated:

> *Technology is a huge barrier. We have residents without internet access at all, residents that are unsure how to use technology to make appointments."*
>
> – SOUTHERN ILLINOIS

C. Important State Health Improvement Plan (SHIP) Priorities

Focus group participants were asked to share their thoughts about which of the following 2020 Interim SHIP Priorities (noted below) were most important to continue addressing over the next five years.

2020 Interim SHIP Priorities

- Public Health Workforce Availability and Workforce Development
- Capacity Building to Address New and Emergent Priorities (Social and Structural Determinants of Health, including racism)
- Improve Data Access, Use, Sharing
- Improve System Coordination and Collaboration
- Strengthen Ability to Investigate and Diagnose Health Issues

Themes highlighted in the data are noted in Figure 4 below. Public Health Workforce Availability and Workforce Development was highlighted as the most important priority among participants. Participants cited the following as areas of focus related to workforce:

- Burnout as a result of the COVID-19 pandemic.
- Noncompetitive salary/wages and reimbursement rates.
- Shortage of staff due to retention issues and limited incoming workforce.
- Shortage of mental health providers, especially bilingual staff, in rural areas.
- Noted below is a participant response supporting these findings:

> *Workforce was already an issue pre-pandemic. The trauma from the experience, including the amount of people who have been lost. Going to see an even greater drop."*
>
> – CENTRAL ILLINOIS

Figure 4.

Important SHIP Priorities Themes

- Workforce Availability and Workforce Development was noted as the most important priority among participants.
- Capacity Building to Address New and Emergent Priorities was also frequently discussed. Participants cited the need for resource allocation to address health inequities and a concentrated focus on both service gaps and social determinants of health (with a special emphasis on affordable housing).
- Silos, limited funding, and communication were cited as important factors influencing coordination and collaboration within and across the public health system.

Participants also provided the following strategies to support bolstering workforce availability and development:

- Standardizing the provision of tuition/loan reimbursement as an incentive.
- Hiring epidemiology staff in each LHD or in a regional capacity.
- Increase wages/salary for public health system staff.
- Train families/caregivers to assist in the care of their loved one in the home setting.

Another important priority to address in the coming years cited by participants included Capacity Building to Address New and Emergent Priorities. Participants shared that the lack of financial resources served as a barrier that impacted their abilities to adequately address health inequities. Furthermore, participants highlighted urgency in aligning funding to address service gaps and social determinants of health (with a special emphasis on affordable housing). As one participant stated:

> *This is a time to look at values to ensure resources are going the right way. Use this generational influx of resources to make a lasting difference."*
>
> – CHICAGO AND CHICAGOLAND SUBURBS

Lastly, Improve System Coordination and Collaboration was identified as an important priority; and silos, limited funding, and communication were cited as important factors influencing coordination and collaboration within and across the public health system. The use of more adaptable software for data (e.g., Salesforce, Tableau) and increased collaboration between providers, hospitals, and LHDs were named as strategies for enhancing access to data and system coordination. An example of participant response supporting this finding included:

> *Coordination and collaboration [are] key to building capacity. Keeping everyone in the loop and communication is big—knowing what's going on"*
>
> –CENTRAL ILLINOIS

D. Opportunities to Address Structural and Social Determinants of Health (SSDOH)

In addition to identifying 2020 Interim SHIP Priorities to focus efforts over the next five years, participants shared their thoughts on potential strategies that can support addressing SSDOH that included the following:

- **Improving coordination across the public health system** that ensures diversity and promotes inclusive voices at the decision-making table.
- **Training and educating communities and in the public health system.** There's an opportunity to creating training opportunities for public health staff around healthy equity and the SSDOH.
- **Building infrastructure for transportation and expanding access to those most in need.** The transportation system needs to expand existing operations, create additional routes, and develop capacity to provide personal transportation to and from medical appointments.
- **Generate resources and funding for a more holistic approach to improving health**. Ensure that there are sources of funding for communities to assess and to address identified needs.

People with Lived Experience (PWLE) Focus Group Findings

A. Top Health Priorities

Participants were asked to share details about health issues impacting their communities. In response, participants provided a range of health conditions and elevated several as priorities to be addressed as part of the SHIP. Figure 5 below captures themes highlighted in the data. Findings highlighted chronic conditions such as diabetes, obesity, and heart disease as top health priorities to be addressed. In addition, chronic stress was discussed as a health concern particularly among home health providers and caregivers.

Figure 5.

Top Health Priorities Themes

- Noted chronic conditions included diabetes, obesity, and heart disease.
- Chronic stress among home health providers and caregivers was a common theme for people living with disabilities (PLWD) and older adults' sessions.
- Noted behavioral health conditions included anxiety, substance use disorder, and depression. Limited access to needed services, medication, stigma, accessibility of services, and lack of diverse providers were highlighted as systemic issues.
- Community violence was elevated as a health priority among communities of color (CoC) and LGBTQIA+ sessions.

Mental health was also a common theme shared across all PWLE focus group sessions. Anxiety, substance use disorder, and depression were cited as mental health conditions. Participants discussed concerns about systemic issues that included proximity of services, limited access to needed services and medication, stigma within and outside of the health care system, and lack of diverse practitioners. An example participant response included:

> *[There are] a couple of treatment centers and outpatient. Nothing after treatment. The closest recovery support services is 43 miles from my home."*
>
> – SOUTHERN ILLINOIS

The issue of community violence was elevated as a health priority in communities of color (CoC) and LGBTQIA+ sessions. Participants shared concerns about feeling safe within their homes or communities at large due to high rates of crime and violence, particularly within city limits. There was also some discussion about the increase of interpersonal violence against queer people of color and the limited availability of resources to provide support in community areas outside of the city's northside region. The following represent participant quotes that support noted findings:

> *[There is a] lack of feeling of safety in neighborhoods, people don't want to leave their houses."*
>
> – CHICAGO AND CHICAGOLAND SUBURBS

> *Queer people of color are facing tons of violence. [There is] little to no support and institution to support queer people. The priority is Boystown and northside of Chicago."*
>
> – CHICAGO AND CHICAGOLAND SUBURBS

B. Social and Structural Determinants of Health (SSDOH) Challenges

Participants shared a range of social and structural determinants of health that play a role in health outcomes of Illinoisians. Figure 6 below highlights themes found in the data. Challenges related to the physical environment included residing in communities with limited healthy food options, limited access to resources (both social and health) needed to lead a healthy life, and concerns about personal safety in communities with high rates of violence and crime.

Figure 6.

SSDOH Challenges Themes

- Physical environment related challenges included living in food deserts, limited access to needed (social and health) resources, and personal safety.
- Barriers to accessing health care included transportation, health insurance, understaffing, and service availability.
- Provider knowledge and accessibility of services were noted as factors that impact whether individuals decide to engage in the health care system and overall patient experience.
- The existence and impact of racism and discrimination was highlighted as a critical challenge for people with lived experience.
- Culture, religion, homophobia, transphobia, and stigma are both social and structural barriers to receiving care.

Noted barriers impacting community members' capabilities in accessing the health care system included transportation, lack of health insurance coverage and/or being underinsured, system staffing, and service availability and challenges related to accessing telehealth.

Transportation was a common challenge discussed across all sessions. Participants highlighted that needed services were not conveniently located within proximity to where they reside, making travel necessary. In addition, transportation challenges often resulted in missed appointments, underutilization of available resources, and inability to access healthy food choices. Costs associated with transportation was also a factor impacting access.

Health insurance coverage served as both a barrier and facilitator when trying to access health care services. For those who were insured, they shared concerns about providers not accepting their insurance and their ability to pay high premiums and co-pays. Uninsured participants shared similar challenges in not being able to access needed services due to long wait times and/or pay for medications. As one participant stated:

> *Lack of actual health insurance for my clients who need medication [or] in crisis and have to wait weeks to see someone and be assisted. This could have determinantal effects."*
>
> – CHICAGO AND CHICAGOLAND SUBURBS

Provider knowledge and accessibility of services were noted as factors that impact whether individuals decide to engage in the health care system and overall patient experience. Participants in the LGBTQIA+ sessions shared challenges regarding limited provider baseline knowledge about intersectionality and how to adequately meet their needs. They shared experiences about being asked for resources by practitioners and needing to address their health needs independent of clinical expertise. As one participant shared:

> *Going to the doctor and they are asking us for resources. We give the resources we know...whenever we think of medical professionals, we should be able to reach out, but they don't always have what we are looking for."*
>
> – CENTRAL ILLINOIS

Findings associated with service accessibility challenges included the proximity of services relative to where individuals reside and lack of inclusive communication capabilities. Limited availability of needed medical services and service providers was a common challenge shared by participants that proved to be more significant in rural areas of the state where service options were deemed limited even prior to the pandemic. In the Southern Illinois focus group, there was discussion about the lack of specialty providers and the need to go across state lines to either Indiana or Missouri to access services. However, having Medicaid in Illinois was a barrier in these instances. As one participant shared:

> *A lot of the closest specialty providers are in St. Louis, which creates Medicaid insurance issues."*
>
> – SOUTHERN ILLINOIS

Furthermore, there was a call for enhanced system capacity for home health care and long-term care facilities, as both entities have experienced chronic workforce challenges. This results in long wait times and individuals going without care.

Individuals that participated in the CoC, PLWD, and Immigrants and Refugees sessions shared common challenges regarding language and communication barriers when trying to access the health care system and needed social services. These challenges ultimately impacted individuals' ability to schedule appointments, share challenges experienced with practitioners, navigate the system, and health literacy outcomes. Availability of translation and interpreter services was also a significant challenge.

The existence and impact of racism and discrimination was elevated as both a structural and social challenge among people with lived experience. Participants discussed concrete examples of unfair treatment exhibited by police (being harassed or frequently pulled over), employers (being passed over for professional opportunities, and health care providers (receiving subpar clinical care). These practices have impacted the mental health and overall well-being among affected individuals. As one participant shared:

> *Racism has affected a lot from being Black to a lot of discrimination from police. It has affected people mentally by not being able to go to the police station anytime there is a problem."*
>
> – NORTHERN ILLINOIS

Lastly, participants highlighted culture, religion, homophobia, transphobia, and stigma as important social and structural factors impacting the health and well-being of Illinoisians. Stigma was elevated as an area of concern due to its existence within the health care system, families, and community at large. According to participants, stigma contributes to individuals not feeling welcome within health care spaces, impacts patients' decision-making around health system engagement, and results in the provision of low-quality health care. Participants stated that the lack of advocacy and education (within and outside of the health care system) is needed to combat stigma. The following is a participant statement supporting said findings:

> *Knowing where you are going that you are going to be accepted. A lot of that preventive care wouldn't be sought because of the unknowing."*
>
> — CENTRAL ILLINOIS

C. Availability of Resources and Associated Access Challenges

Participants were asked to share the types of programs and services that were currently available in their communities that support the health and well-being of community members. Table III below is a visual representation of participant responses, categorized by service type. There was a total of five service categories that included youth-specific resources, health care/direct services, support groups, adult education, and social services. Examples of youth-specific services included afterschool programming and child care. Adult education resources largely included community colleges and English as a Second Language (ESL) courses.

YOUTH-SPECIFIC RESOURCES	HEALTH CARE/DIRECT SERVICES	SUPPORT GROUPS	ADULT EDUCATION	SOCIAL SERVICES
• Afterschool programming • Child care facilities • Park district programming (recreation) • Student-led LGBTQIA+ programming within schools	• Mental health—therapy sessions • Adult day service • Health care services for uninsured community members • Free and reduced clinic services • Physical health assessments and referral care • COVID-19 vaccinations • Planned Parenthood	• Senior services groups: technology accessibility, triad care • CoC support groups • CAPS • Church groups • Safe Space Alliance	• Community college • ESL courses	• Benefits sign up (LINK, SNAP, insurance) • Food pantries • Meals on Wheels • Caregiver relief • Housing/rental support • Utility assistance • Domestic abuse support • YMCA

Table III. Available Community Resources

Participants across all sessions expressed concern regarding the lack of needed services and elevated the challenge of transportation needed to access services. Responses were region dependent as there were examples of communities with a wide range/availability of resources and others cited as having limited or no resources for individuals to tap into. Requested services included programming for the queer community, certified nursing assistants, and technology education. Examples of challenges experienced when trying to access needed services included the following:

- **Financial and age eligibility requirements.** Either making too much money or being too young to qualify.
- **Lack of knowledge of what's available in the community.** There's no centralized place to gain knowledge about available services.
- **Language barriers.** Services and written materials not offered in multiple languages. There is also a lack of bilingual staff members to provide support in real time to participants.
- **Citizenship requirements.** Participants that are undocumented experienced fear of deportation.
- **Long wait times—**limited-service capacity needed to meet participant demand that results in long wait times.

- **Lack of cultural competency among staff.** Existence of limited staff capabilities and knowledge needed to reach populations, which results in negative participant experiences and a lower desire to engage in service offerings.

D. COVID-19 Related Challenges and Resources Needed for Recovery

The impact of the COVID-19 pandemic has resulted in a range of challenges for participants across all focus group sessions. Table IV below highlights themes captured in the data and respective evidence supporting findings.

THEMES	SUPPORTING EVIDENCE
High rates of unemployment and lost income for community members, resulting in reduced capacity to afford and/or manage associated social and medical needs, such as housing, food, and medication.	*"You know unemployment due to COVID which lead[s] to low income is a barrier for people in my community to access services."* — CHICAGO AND CHICAGOLAND SUBURBS
Mental health has been significantly impacted for youth and adults alike. Individuals reported experiencing isolation, anxiety, chronic stress, and depression. In addition, participants shared high occurrences of grief and trauma due to loss of loved ones.	*"My child was really depressed because he has been lonely and not being able to connect with his friends during COVID."* — CENTRAL ILLINOIS *"During the pandemic, the biggest problem was isolation for most older adults. Especially those who have no family or live by themselves."* — CHICAGO AND CHICAGOLAND SUBURBS
Findings highlighted an association between safety concerns around exposure and behaviors that result in long periods of no human connection and increased feelings of isolation. These concerns were especially prevalent among PLWD and older adults.	*"Due to my immune deficiency, I am at high risk of COVID and concerned about whether I will ever be able to return to general community. Omicron variant represents extreme concern for me."* — SOUTHERN ILLINOIS
Existence of health care staffing shortages that contribute to long wait times, business closures, the shift from in-person to virtual care, and limited access to critical services. These shortages were more evident in areas with chronic access challenges prior to the pandemic.	*"I find that I'm still trying to get a homemaker out to help us. I've waited for over a year and the folks that I'm working with they continue to tell me well we're shorthanded and can't guarantee anybody to come out."* — SOUTHERN ILLINOIS
Technology served as both a facilitator (increasing access to others through Zoom, telehealth platforms, etc.) and a barrier for individuals with limited knowledge of how to navigate these platforms and access to internet.	*"Being unable to go to doctors and hospital makes my sole access to community limited to Zoom and phone. During the pandemic, it's been hard to visit a doctor."* — NORTHERN ILLINOIS
Literature is limited for evidence-based care for trans health and LGBTQIA+ care. The pandemic has slowed this process and impacted decision-making among health care providers and patients alike.	*"Trans health doesn't have as much research by any means. Even with COVID, LGBTQ research is going to be even more delayed. For the vaccine, my partner waited until it was FDA approved because we weren't sure about mixing [it] with hormone therapies."* — CENTRAL ILLINOIS

Table IV. COVID-19 Related Challenges Themes

Cited resources needed to help participants with recovering from the pandemic are noted in Table V below. Resources span across seven categories: economic development, health care, financial supports, education, transportation, technology, and recreational programing. Examples of health care resources included mental health services and increased system capacity to serve more individuals. Student loan relief, utility assistance, and rental/housing assistance were highlighted as needed financial supports. Examples of economic development included the provision of living wage employment and employment resources that support job training and placement for future opportunities. Collective participant responses shared a desire for resources to be affordable and/or free to minimize access barriers.

RESOURCE CATEGORY	RESOURCE EXAMPLES
Economic Development	• Bringing business into communities and support job development • Living wage employment • Employment resources/job placement and job training
Health Care	• Affordable mental health resources • Increased access to group therapy sessions • Enhanced accessibility of telehealth and after-hours appointments • Increased capacity to see more individuals (both adults and children) for mental health services—more counselors
Financial Supports	• Student loan relief • Rental and housing assistance • Utility assistance • COVID-19 relief funds/money (food, insurance, personal needs, etc.)
Education	• Free classes (i.e., GED, ESL) • COVID-19 information (clinically accurate) • Empowerment programs for parents
Transportation	• Affordable or free transportation options to support accessing health care and/or needed resources • Shuttles • Government incentives/subsidies to expand access for all
Technology	• Technology support programming • Expand emergency broadband connection
Recreational Programming	• Art • Park accessibility to play sports • Low-cost programming for families and youth

Table V. Recovery Resources

E. Proposed Solutions and Role of Community in Erecting Solutions

Focus group data elevated potential solutions to challenges shared by participants. These solutions fell largely into two categories that included shifts to the structural and social environment and enhanced learning opportunities across a range of audiences. Participants discussed the need for the provision of equal treatment and access across communities, with a particular focus on using an equity lens to address barriers. There was also a call for greater advocacy for equal treatment within systems and communities at large to support needed shifts. According to participants, there's an opportunity to address language and communication barriers by increasing the number and availability of interpreters in the field to better support PLWD and/or whose primary language is not English. Lastly, there was a call to revamp policies and procedures to improve best practices for serving PLWD. Examples of participant responses supporting these findings included:

> *The primary challenge is language. People who speak Spanish can't find Spanish-speaking staff or information."*
>
> – CHICAGO AND CHICAGOLAND SUBURBS

> *[I am] working with one health care org that is revamping policies and procedures to improve best practices for the deaf and hard of hearing. The state isn't doing anything like this. We need to adopt both [a] top-down and bottom-up approach."*
>
> – CHICAGO AND CHICAGOLAND SUBURBS

Examples of potential solutions in the learning opportunities category included providing enhanced training for providers geared toward addressing LGBTQIA+ needs and erecting targeted efforts to increase the representation of LGBTQIA+ champions in the field to enable peer-to-peer learning. The need for generating training opportunities that emphasize the issues of racism and discrimination in the community and build awareness of its impact was also identified. Participants shared their desire to see increased access to resources that teach individuals how to advocate for themselves. Lastly, more learning is needed to better understand needs of PLWD among decision makers in government in support of aligning funding with identified needs. Examples of participant responses that support these findings included:

> *LGBTQ-specific therapist but someone already in a power role of mental health counseling—could be a service to the community also a leader and teacher."*
>
> – CENTRAL ILLINOIS

> *Cultural sensitivity training for those in the public sector—provide ongoing training annually."*
>
> – CENTRAL ILLINOIS

Findings elevated a role for the community in implementing solutions that improve the well-being of individuals across the state. Participants expressed an interest in being included in the planning, development, and implementation phases of problem-solving. It's critical to ensure that "lived experience" voices are being captured and there's alignment between needs and solutions. Community organizing—protesting, forming support groups, and educating fellow community members about available resources—were cited as concrete examples of how community members can serve as active participants in the solution and implementation process.

F. Cited Practices for Continued Community Engagement

IPHI is seeking to keep communities abreast of progress made toward priorities and solutions that will be documented in the SHIP. Participants were asked to share how they would like to be updated and named a range of media, such as electronic (social media, posting flyers on IPHI's Facebook and/or Instagram pages, and focus groups), traditional media (news, radio, and print via newspaper and magazines), and face-to-face (community roundtables and door-to-door outreach). Lastly, participants noted the importance of leveraging the reach of public officials, hospital systems, and community-based organizations to disseminate progress updates on their initiatives and proposed solutions through their established, preferred mechanisms.

G. Cross-Cutting Themes

- Cross-case analysis conducted elevated several key cross-cutting themes across both sets of focus groups that included the following:
- Mental health was cited as an emergent priority to be addressed in future SHA/SHIP efforts.
- Social and structural barriers related to health insurance coverage (or lack of), health care system workforce shortages, stigma experienced within and outside of the health care system, and transportation were noted as factors impacting the health and well-being of communities across the state.
- The COVID-19 pandemic has had a significant impact on the mental health of youth and adults alike. In addition, the pandemic has contributed to workforce shortages within the health care system.
- Technology served as a barrier to participants feeling socially connected to family, friends, and health care professionals.
- Training and education for public practitioners and building infrastructure to improve the transportation system were noted as potential solutions to improve the health and well-being of the community.

6 Conclusion

Over the course of 26 focus groups with more than 160 people representing community social service providers, local health departments, and community members from historically excluded groups, including communities of color, immigrants and refugees, LGBTQIA+ individuals, people living with disabilities, older adults, and Spanish-speakers, IDPH and the SHA/SHIP Planning Team were able to explore the concerns, perceptions, experiences, and priorities facing communities in their own words. The process elicited information about health priorities, systemic and structural barriers to health and well-being, community strengths and assets, the impact of COVID-19, and challenges in accessing resources and services.

The findings included a significant focus on social and structural determinants of health, with housing, transportation, healthy food access, violence, lack of trust in health systems, social isolation, and the impact of COVID-19 cited as significant issues impacting communities' ability to achieve optimal health and well-being.

In addition, community members and providers/local health departments identified access to health care services in general, including insurance and availability standing out as key barriers. When identifying health conditions of concern, mental and behavioral health—along with trauma and isolation emerging from COVID-19 for both youth and adults—often rose to the top in conversations. Other health issues were chronic conditions, stress, and substance use disorder.

Providers and local health departments were also concerned about workforce issues and public health infrastructure issues, trust in the public health system, and barriers related to technology and social media.

In addition to the social determinants of health cited above, the focus groups with people with lived experience also cited racism, discrimination, and homophobia/transphobia as core concerns. Older adults and people living with disabilities faced barriers accessing home health care and long-term care, and people for whom English isn't their primary language faced language and communications barriers.

By engaging communities in this way, the SHA/SHIP process can lean into the knowledge, expertise, and vision that people across Illinois have for what needs attention and how to prioritize action. This deep dive into community concerns and priorities, in combination with other data from the health status assessment, health equity capacity assessment, and forces of change assessment, serves as a significant source of information to inform the priorities and strategies of the 2022 SHIP.

Key findings from the focus group were compiled and shared with the SHA/SHIP partnership (see **Appendix 4: SHA/SHIP FINDINGS PRESENTATIONS**). The final community engagement report will be made available to Illinoisians via the IPHI website, www.iphionline.org, by April 30, 2023.

Endnotes

1 Engaging People with Lived Experience to Improve Federal Research, Policy, and Practice: Office of the Assistant Secretary of Planning and Evaluation. U.S. Department of Health and Human Services. https://aspe.hhs.gov/lived-experience

2* In 2020, IDPH and the SHIP Team completed a short-term Interim SHIP to meet statutory requirements, and to lay the groundwork for the full SHA/SHIP process (of which this report is a part) to be completed by the end of 2022 as required by P.A. 102-0004.

3* In 2020, IDPH and the SHIP Team completed a short-term Interim SHIP to meet statutory requirements, and to lay the groundwork for the full SHA/SHIP process (of which this report is a part) to be completed by the end of 2022 as required by P.A. 102-0004.

4 Aronson, J. (1994). A pragmatic view of thematic analysis. The Qualitative Report, 2, pp. 1–3.

7 Addendum

Introduction

Following the finalization of the State Health Assessment (SHA) Community Engagement Report, the SHA/State Health Improvement Plan (SHIP) Planning Team, on behalf of IDPH and the partnership, followed up with previous focus group participants to share the draft Community Engagement report, and invited individuals to participate in a debriefing focus group. The intent of the debriefing was to receive feedback on the data collected from previous focus group participants, to share data findings from the other assessments, and to solicit their input on the proposed SHIP priorities and potential solutions.

Five focus groups (50 total participants) were completed with people with lived experience (PWLE) from a subset of original focus group participants. As a result, a total of 40 (80%) participants identified as people of color and participants were geographically dispersed across the state. In an effort to prioritize voices from the rural communities, recruitment was staggered to provide a longer recruitment period for community members from central and southern Illinois.

	FOCUS GROUP COUNTS BY REGION				
Focus Group Session	Chicago + Chicagoland Suburbs	Northern Illinois	Central Illinois	Southern Illinois	Totals
September 13, 2022, 8 a.m.	6	2	1	2	11
September 13, 2022, 11 a.m.	11	0	2	2	15
September 14, 2022, 1 p.m.	7	1	2	4	14
September 14, 2022, 6 p.m.	4	2	1	2	9
September 14, 2022, 6 p.m. Spanish	1	0	0	0	1
Totals	29	5	6	10	50

Table VI: PWLE Follow-up Focus Group Outcomes

The planning team offered one focus group in Spanish, in which one community member attended. Focus group attendees received a $50 gift card to compensate them for their time.

The planning team developed a high-level summary of the key findings from the SHA to share with participants and developed a focus group guide to ensure a systematic approach to conducting the sessions (See Appendix 5: Community Report Back Focus Group Guide). Questions were purposed for gathering feedback on the presented data summary, determining the underlying root causes of the emerging health priorities, and providing possible solutions to include in the SHIP.

Feedback on the SHA data summary

When asked their thoughts on the key SHA findings, participants agreed the data revealed issues aligned with their experiences in the community. There was agreement across all focus groups that the emerging health priorities are consistent with their initial input from past focus groups.

Solutions and strategies to each health priority

When asked which needs are most important to improving the overall health of Illinoisians, all focus groups emphasized mental health, and its negative outcomes exacerbated by the COVID-19 pandemic, are among the most urgent health issues. Other issues emphasized were related to Social and Structural Determinants of Health (SSDOH) priorities, specifically transportation and access to care. Participants shared that transportation and access to care had the greatest impact on people living with disabilities and those who reside in more rural parts of the state.

Participants cited social stigma, limited provider availability, lack of awareness of resources, and proximity to health care providers as causes for ongoing challenges related to the emerging priorities. Examples of participant responses supporting these findings include:

> *It's difficult to take advantage of medical, dental, oral, mental health care when the only place that will take your insurance is 45 minutes away at minimum."*
>
> — PARTICIPANT FROM JERSEYVILLE

> *I have tried getting an appointment with a therapist and it took maybe like four or five months to set up an initial appointment with a therapist, and then finally when I did set it up, they no showed; and so, I couldn't really get the help that I needed."*
>
> — PARTICIPANT FROM CHICAGO

When asked what should be focused on to address these issues, participants offered solutions around transportation, access to care, and visibility of resources in their communities.

As one participant shared:

> *I think if there are community health workers there'll be outreach and things like that to the community...a lot of individuals are going to have this accessibility to people and having accessibility to people you know, they are going to have a lot more accessibility to services as well."*
>
> — PARTICIPANT FROM CHICAGO

Figure 7.

Community identified solutions to emerging health priorities

- Free ride programs and improvement of public transit systems, including holding transit authority accountable for arrival and departure time.
- Use of multiple platforms for community outreach, including social media, local community organizations, and flyers.
- Increased number of therapists and other health care providers.
- Integration of more virtual health service options.
- Increased public funding.

Conclusion

The key findings from the follow-up focus groups were consistent with the findings from previous focus groups. Community members agreed the COVID-19 pandemic has worsened outcomes for the emerging health priorities, especially mental health. All focus groups identified access to care is a persistent barrier in addressing needs around the emerging health priorities. Limited availability of health care providers, lack of awareness of available resources, and limited transportation options were cited as specific obstacles community members face when trying to access health care services. Community members offered ideas to improve transportation and emphasized that communication between communities and local health departments is critical in improving access to health care services.

By completing the follow-up focus groups, a more refined SHA report can be produced that continues to uplift the voices in the community. Collaboration with PWLE allows for deep insight into the needs of communities across the state. The input provided by PWLE will serve as a substantial resource during the development of the strategies for the 2027 SHIP.

8 Appendices

Appendix 1: Regional Social Service and LHD Focus Group Guide

IDPH SHA/SHIP Focus Group Guide

LHDs/Social Service Providers – October/November 2021

Date of Focus Group: ___ / ___ / _____		
Focus Group Type:		
Focus Group Moderator's Name:		
Assistant Moderator's Name:		
Number of participants:		
Time of Focus Group:	Start |__|__: __|__|	End |__|__: __|__|

Introduction: (10 minutes with a delayed start time waiting for new arrivals)

Introduce self and note-taker.
Thank you for registering to participate in this discussion.

The Illinois Department of Public Health (IDPH) is currently conducting a State Health Assessment (SHA) to inform a new five-year State Health Improvement Plan (SHIP). The SHA and SHIP process is a collaborative public-private cross-agency effort that includes an assessment and recommends priorities and strategies to improve the public health system, and the health status of Illinoisians, reduce health disparities and inequities, and promote health equity. IDPH is leading the SHA/SHIP process in collaboration with the appointed SHA/SHIP Partnership that includes representatives from state agencies with public health responsibilities and a range of public, private, and voluntary sector stakeholders and participants in the public health system. IDPH is working with the UIC School of Public Health, Policy, Practice, and Prevention Research Center and the Illinois Public Health Institute to facilitate the partnership and to complete the process.

On behalf of IDPH and the partnership, IPHI is gathering community input through 75-minute focus group meetings to better understand community health issues and priorities related to health and equity priorities as well as infrastructure issues facing the public health system.

As noted in our invitation for this focus group, **we are confirming your permission to record the conversation so that we can review the recording later** and identify themes that emerged within this focus group and across the other focus groups. In addition to the use of recording, my colleague here [name of Assistant Moderator] will be taking notes so that we can remember the conversation better later. We will not be using your names or any other identifiers that you share today. These conversations are confidential. Does anyone object to being recorded?

For a focus group to be most effective, we establish the following group norms:

- Only **one person speaks** at a time (best for audio recording quality).
- We **respect** all opinions (it's unlikely we will all agree on everything).
- There are **no right or wrong answers** or opinions.
- We ask that you please respect everyone's **privacy**.
- We ask that you **actively participate and feel free to speak candidly**. The purpose of this session is to hear your unique perspectives. Let's be sure to allow for everyone to get a chance to share.
- Please give everyone an opportunity to speak. If you have already spoken, consider making space and speaking less. If you haven't spoken, consider taking space and speaking more. We want to hear from everyone.
- When speaking, attempt to **build upon or add something not mentioned** in the conversation to save time.

You can use the chat and +1 to reinforce ideas.

Any questions or comments before we begin? [wait for questions]. Great. So, let's get started. **We are going to start recording now.**

Introductions (5 minutes)

Let's begin by introducing ourselves. Would you please share with the group your first name, organization, organizational mission/focus, and geographic location? **(Put instruction in chat)**

Current state of the public health system (15 minutes)

In 2020, IDPH did an update to their SHIP, and we conducted focus groups with LHDs only. We asked about the public health system. Public health systems are commonly defined as **"all public, private, and voluntary entities that contribute to the delivery of essential public health services within a jurisdiction."** You are all partners in the public health system—part of the ECO system.

As a result, the SHIP update has priorities focused on improving the public health system infrastructure such as: **(Post SHIP priorities in the chat)**

- Public Health Workforce Availability and Workforce Development
- Capacity Building to Address New and Emergent Priorities (Social and Structural Determinants of Health, including racism)
- Improve Data Access, Use, Sharing
- Improve System Coordination and Collaboration
- Strengthen Ability to Investigate and Diagnose Health Issues

1. **Which of these do you think will be most important to continue to address over the next five years?** (If not clear, ask Why?)

2. *(If not already answered)* **What are some priority strategies to address these?** Who should be involved?

Community Health Priorities (20 minutes) (BOLD questions are priority)

3. Based on your close work with the community and any assessment activities you have engaged in during the past 12 months, **what priorities are emerging in your community? What are you hearing are important health issues to your community members, clients, etc.?**

4. **What are the biggest barriers related to these issues?**

5. *If time permits* – What are feasible strategies to address these issues? What resource might be needed?

6. *If time permits* – How can your organization and the community help address the barriers and implement the solutions?

7. **What are the main challenges that your community is facing now because of COVID-19?**
   a. *If not previously answered* – What is the biggest impact that the COVID-19 pandemic has had on children and young people in your community?

8. *If time permits* – What resources have been helping your community through the pandemic?
   a. What supports does your community need to further help with recovery?

Social Determinants of Health and Structural Racism (10-15 minutes)

9. **How are your organizations addressing social and structural determinants of health?**
   a. What else could be done if you had the resources?

10. *If time permits* – How can the public health system address racism in Illinois?
    a. What are some examples of what is working?

11. **Social Connectedness**—More people than ever across all age groups are feeling lonely or isolated, like they have no one to talk to or have difficulty making friends. **What are some barriers in your community/the state to helping people feel connected to others?** Probe: Are those different for historically isolated communities like LGBTQIA+, people with disabilities, older adults, etc.?

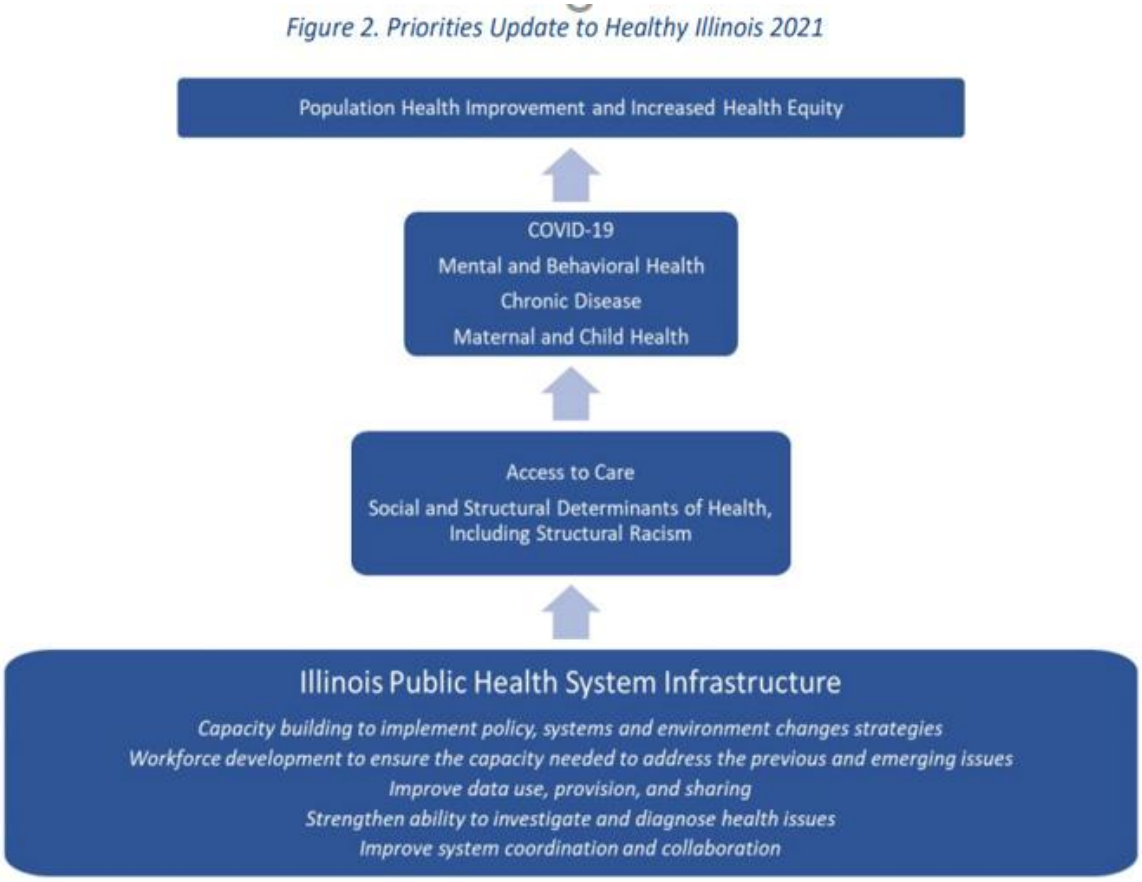
Anything Else? (2-5 minutes)

12. **Is there anything you think would be important to consider in the SHA for the next 5-year SHIP?**

If you think of something, please feel free to email Samantha.Lasky@iphionline.org.

Thank you very much for your time. We appreciate your input and support of this planning effort for the comprehensive SHA/SHIP!

We may be reaching out to some of you to help with planning focus groups directly with populations you serve. We will also keep you posted about the final report/summary of community input and the SHA expected by the end of February 2022.



Other Social Connectedness Questions

1. What makes it [easy/hard] to help people find the foods they need to support their dietary, cultural, and religious preferences in your community/region?

2. What barriers exist for people to access important nutrition and food security programs, like the Women, Infants, and Children (WIC) program, the Supplemental Nutrition Assistance Program (SNAP), and/or the Child and Adult Care Food Program (CACFP)?

3. What could help this county/region support a food system that promotes healthy, sustainable methods for growing, manufacturing, distributing, and consuming food?

4. What would help people get to their everyday destinations (like school, work, stores/errands) in an active way (like walking, biking, taking a bus/train)? Probe: What would promote physical activity for those without cars or access to public transportation or safe recreational activities (i.e., access to activity/facility and feeling of community safety)?

Appendix 2: PWLE Focus Group Recruitment Materials

YOUR VOICE MATTERS

Participate in a 60-minute online focus group to tell us about the health of your community

The Illinois Public Health Institute is conducting focus groups to understand the top health needs of different communities across the state. We are hosting focus groups with individuals living with disabilities. Your input is essential and will help decide which issues are most important to improve health and advance health equity across Illinois.

The focus group will be held online Thursday, December 2nd from 10:00 - 11:00 AM. Participants will have the option to join through video conference or telephone. Caregivers are welcome to attend alongside participants.

Focus group participants will be provided a $50 gift card for their time.
To sign up for a focus group session, please go to:
https://forms.gle/eLNMstQH6r5SxgLi8

YOUR VOICE MATTERS

Participate in a 60-minute online focus group to tell us about the health of your community

The Illinois Public Health Institute is conducting focus groups to understand the top health needs of different communities across the state. We are focusing our efforts on communities that face the most health inequities such as communities of color, immigrants and refugees, individuals living with disabilities, individuals living with mental illness, people struggling with housing instability, LGBTQ+, and low-income families. Your input is essential and will help decide which issues are most important to improve health and advance health equity across Illinois.

Feel free to select one of the sessions below. Online focus groups will be held:

November 18th: 9:00 -10:00 AM - Older Adults
November 18th: 5:00 - 6:00 PM – LGBTQIA+ Community
November 18th: 1:00 - 2:00 PM – Immigrants and Refugees (including migrant workers)
November 22nd: 9:00 - 10:00 AM – Communities of Color
November 22nd: 11:00 AM - 12:00 PM – Communities of Color
November 23rd: 6:00 - 7:00 PM – Spanish Only
December 2nd: 10:00-11:00 AM- People Living with Disabilities*
*Caregivers are welcome to attend alongside participants.

Focus group participants will be provided a $50 gift card for their time.
To sign up for a focus group session, please go to:
https://forms.gle/9SW23eLdmrrS2NDL6

SU VOZ IMPORTA

Participe en un grupo de enfoque en línea de 60 minutos para hablarnos de la salud de su comunidad

El Instituto de Salud Pública de Illinois está llevando a cabo grupos de discusión para conocer las principales necesidades de salud de las distintas comunidades del estado. Estamos concentrando nuestros esfuerzos en las comunidades que se enfrentan a las mayores desigualdades en materia de salud, como las comunidades de color, los inmigrantes y los refugiados, las personas que viven con discapacidades, las personas que viven con enfermedades mentales, las personas que luchan contra la inestabilidad de la vivienda, los LGBTQ+ y las familias con bajos ingresos. Su aporte es esencial y ayudará a decidir qué temas son los más importantes para mejorar la salud y promover la equidad en la salud en todo Illinois.

El grupo de enfoque se llevará a cabo en línea el martes 23 de noviembre de 6:00 a 7:00 PM. Los participantes tendrán la opción de unirse por videoconferencia o por teléfono. Se invita a los cuidadores a asistir junto con los participantes.

Los participantes en los grupos de enfoque recibirán una tarjeta de regalo de $50 por su tiempo.
Para inscribirse en una sesión de grupo de enfoque, vaya a:
https://forms.gle/A9AZ5tEQiWasSvyT8

Appendix 3: PWLE Focus Group Guide

Focus Group Guide – PWLE

1. **Welcome and introductions (7 min)**
    a. Explanation of purpose and process
        i. **Purpose:** Good morning (afternoon, evening). My name is Samantha Lasky and my colleagues and I will be leading our discussion today. Thank you for joining us today and for participating in a focus group several months ago. We represent the Illinois Public Health Institute and we are gathering community input to better understand community health issues and health equity priorities. We are seeking to better understand health challenges faced across the state and steps needed to address them. Our discussion will be focused on your individual experiences—we will gather your feedback on the State Health Assessment (SHA) data summary, and potential solutions to the emerging health priorities.
        ii. **Process:**
            - There are no wrong answers. You won't hurt our feelings or make us feel good with whatever opinions you might share. We are interested in hearing your point of view even if it is different from what others have expressed. So please feel free to speak open and honestly. If you are normally quiet and reserved, please take some space and share. If you are normally someone comfortable talking in groups, please make space for others to share.
            - When we speak about community it can have different meanings. For example, it can mean your family, the people you live or work with, the neighborhood you live in, a group of people you belong to. We are interested in hearing about your community, no matter how you define it.
            - **Adrian Blasi** will be a note taker for the discussion today. An overall summary of the information shared by the different discussion groups will be written and shared online. There will not be any names attached to the comments and ideas in the notes or in the final report. We would like to record today's discussion to ensure that we completely capture your input. **Is everyone ok with us recording the discussion?**
            - If you have any questions about how the information we collect today will be used or if you are unable to access the final report online, please feel free to contact **Samantha Lasky. Her contact information will be sent via email after this session.**
            - Are there any questions before we start?

2. **Participant introductions:** Share your first name and the community you represent or live in.

3. **SHA summary presentation (13 min)**

    Facilitator's note: *[As a preface to the presentation.] Share that the report we sent them with the invite to the focus groups is a draft based on the feedback we received in all of the focus groups. The other data we are sharing surfaced from other assessments, and we are preparing reports to summarize the data. All reports will be available on the IDPH website once final. We will send them a link when they are available. While all the assessment data is important, we are especially appreciative for all of their input.*

4. Questions about the SHA data summary presentation (5 min)

Facilitator's note: *We are interested in learning if the data presented in the community engagement report and the CHNA assessments align with needs voiced in focus groups a few months ago.*

a. What are some of your thoughts about the SHA data summary? (type in the chat)
   i. What stood out to you as we presented the data? (prompts: Were there any surprises?)
   ii. Overall, do you agree with these results? Why or why not? (consider doing this question as a quick round-robin)

5. Questions about solutions and strategies specific to each health priority (35 min)

Facilitator note: *In this set of questions, we are interested in hearing more about the challenges related to these priority issues and ideas to address the challenges. After looking at the data and identifying common themes from all the assessments, the issues on the screen are what emerged as priority needs. We are going to ask you questions about issues in the first two columns.*

a. Are the health priorities on the screen consistent with the needs of your community today? (5 min)
   i. Are there any priority needs missing? If so, what needs are missing?
   ii. Which needs are most important to improving the overall health of Illinoisians?
b. Why do you think these are the top health issues? (5 min)
   i. What is causing these issues?

Facilitator note: *We know that to make the best progress toward our state's community health goals, we need to focus on health equity. In the second column on the screen, we see these issues as underlying causes of the health issues and things that directly impact health equity.*

c. What are some of the populations or groups that are most affected by these health issues? (10 min)
   i. What is causing these issues to be greater in some communities over others?
   ii. What solutions are needed to address the needs of those most impacted health disparities?
d. What do we need to focus on to address these issues and make communities healthier? (15 min)
   i. What are some solutions to the challenges and the health issues?
   ii. What are some good things happening in your community that we can build on to address the issues on the screen?
   iii. What role does community have in implementing these solutions?

6. Closing question (5 min)

a. Is there anything else you would like to share about your personal experience that could help inform the next steps in creating plans to improve the health of Illinoisians?

THIS CONCLUDES OUR SESSION. THANK YOU AGAIN FOR YOUR TIME AND RESPONSES. YOU WILL RECEIVE AN EMAIL WITH YOUR GIFT CARD.

Appendix 4: PWLE Focus Group Follow Up Guide

Focus Group Guide – PWLE

A. Welcome and introductions (7 min)

a. Explanation of purpose and process

i. **Purpose:** Good morning (afternoon, evening). My name is Samantha Lasky and my colleagues and I will be leading our discussion today. Thank you for joining us today and for participating in a focus group several months ago. We represent the Illinois Public Health Institute and we are gathering community input to better understand community health issues and health equity priorities. We are seeking to better understand health challenges faced across the state and steps needed to address them. Our discussion will be focused on your individual experiences—we will gather your feedback on the State Health Assessment (SHA) data summary, and potential solutions to the emerging health priorities.

ii. Process:

- There are no wrong answers. You won't hurt our feelings or make us feel good with whatever opinions you might share. We are interested in hearing your point of view even if it is different from what others have expressed. So please feel free to speak open and honestly. If you are normally quiet and reserved, please take some space and share. If you are normally someone comfortable talking in groups, please make space for others to share.
- When we speak about community it can have different meanings. For example, it can mean your family, the people you live or work with, the neighborhood you live in, a group of people you belong to. We are interested in hearing about your community, no matter how you define it.
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- If you have any questions about how the information we collect today will be used or if you are unable to access the final report online, please feel free to contact Samantha Lasky. Her contact information will be sent via email after this session.
- Are there any questions before we start?

2. Participant introductions: Share your first name and the community you represent or live in.

3. SHA summary presentation (13 min)

Facilitator note: *[As a preface to the presentation.] Share that the report we sent them with the invite to the focus groups is a draft based on the feedback we received in all of the focus groups. The other data we are sharing surfaced from other assessments, and we are preparing reports to summarize the data. All reports will be available on the IDPH website once final. We will send them a link when they are available. While all the assessment data is important, we are especially appreciative for all of their input.*

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Facilitator note: *We are interested in learning if the data presented in the community engagement report and the CHNA assessments align with needs voiced in focus groups a few months ago.*

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b. Why do you think these are the top health issues? (5 min)
   i. What is causing these issues?

Facilitator note: *We know that to make the best progress toward our state's community health goals, we need to focus on health equity. In the second column on the screen, we see these issues as underlying causes of the health issues and things that directly impact health equity.*

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   iii. What role does community have in implementing these solutions?

6. Closing question (5 min)

a. Is there anything else you would like to share about your personal experience that could help inform the next steps in creating plans to improve the health of Illinoisians?

THIS CONCLUDES OUR SESSION.THANK YOU AGAIN FOR YOUR TIME AND RESPONSES. YOU WILL RECEIVE AN EMAIL WITH YOUR GIFT CARD.

Appendix 5: SHA/SHIP Findings Presentations

Regional Service Providers and LHD Focus Groups

SAMANTHA LASKY, IPHI

Focus Group Summary

- IPHI conducted 7 focus groups with regional social service providers and LHD's as well as 1 focus group is NAMI affiliates.
- Focus groups were conducted from October 26th to November 3rd.
- The focus groups were asked about:
  - Health and well-being barriers and priorities for the community
  - Community strengths and assets to leverage
  - System barriers/challenges to serving the community and potential solutions
  - Forces of change including threats and opportunities for the health of the community and those who partner with and provide services to the community

Overall Summary

- **Workforce** and **social and structural determinants of health** were most frequently discussed SHIP Update priorities
- **Mental and behavioral health** and **substance use disorder** were the most frequently discussed **health issue**
- Rural areas reported access to **transportation** and **workforce shortages** (providers, public health system) as **system barriers**
- Participants described **workforce expertise** and **system collaboration** as **strengths**
- **Misinformation** about COVID-19 and the vaccine as well as the increase of **mental/behavioral health** due to **quarantine** were frequently noted as threats

"Public health level and federal level (past and current present, Dr. Fauci, CDC) – there is a concern at national level of all the information and differences, concerns, frightening, and mixed information." – Edwardsville

"[We] provide linkages and MOUs to other organizations. [We have] empowered them." – West Chicago

Important SHIP Priorities (Next 5 Years)

- A majority of participants noted **workforce availability and development** as their main/most important priority.
- Participants cited the following as priorities related to workforce:
  - Burn out as a result of COVID-19
  - Non-competitive salary/wages and reimbursement rates
  - Shortage of staff due to retention issues and limited incoming workforce
  - Shortage of mental health providers, especially bilingual staff and in rural areas
- Capacity building was also frequently noted where folks cited **resource allocation** (to address health inequities) and focusing on **service gaps** including **gaps in SDOH** (affordable housing).
- **Silos, limited funding,** and **communication** were frequently cited as important for increasing coordination and collaboration.

"Workforce was already an issue pre-pandemic. The trauma from the experience, including the amount of people who have been lost. Going to see an even greater drop." - Champaign

"Coordination and collaboration [is] key to building capacity. Keeping everyone in the loop and communication is big - knowing what's going on" – Peoria

"This is a time to look at values to ensure resources are going the right way. Use this generational influx of resources to make a lasting difference." - Bellwood

Strategies to Address Priorities

- Participants noted a few strategies to address the priorities they identified as important.
- Workforce Availability and Development:
  - Tuition/loan reimbursement
  - Epi staff in each LHD or in a regional capacity
  - Increase wages/salary for public health system staff
  - Train families/caregivers to assist in the care of their loved one (at-home care)

"Have access to various data sets, we don't have an epi on staff or an expert to interpret. Trying to identify trends and share that data with the local community, we are only able to go so far." – West Chicago

- Data:
  - Use more adaptable software for data – e.g., Salesforce, Tableau
  - Collaborate with providers, hospitals, and LHD to access data

"What could improve communication between hospital and LHD, decrease or shorten the lag of data sharing." - Edwardsville

"It's hard for an NGO to be as competitive at other orgs – the benefits and wages don't compare – the funding aspect of that [is] to attract good talent and retain good people so we don't leave a gap in service." – NAMI, West Chicago

Most Frequently Cited Emergent Priorities in their Communities

"Mental health impact[s] almost everything, stigma [...], w/ COVID a level of distrust that has developed with the healthcare system – could be an issue with race, people in poverty or experiencing disparities." - Edwardsville

Participants noted the biggest barriers related to these issues:

- *Access to care, including insurance issues*
- *Communication, misinformation and awareness of services*
- *Resource availability*

Mental/Behavioral Health and Substance Use Disorder

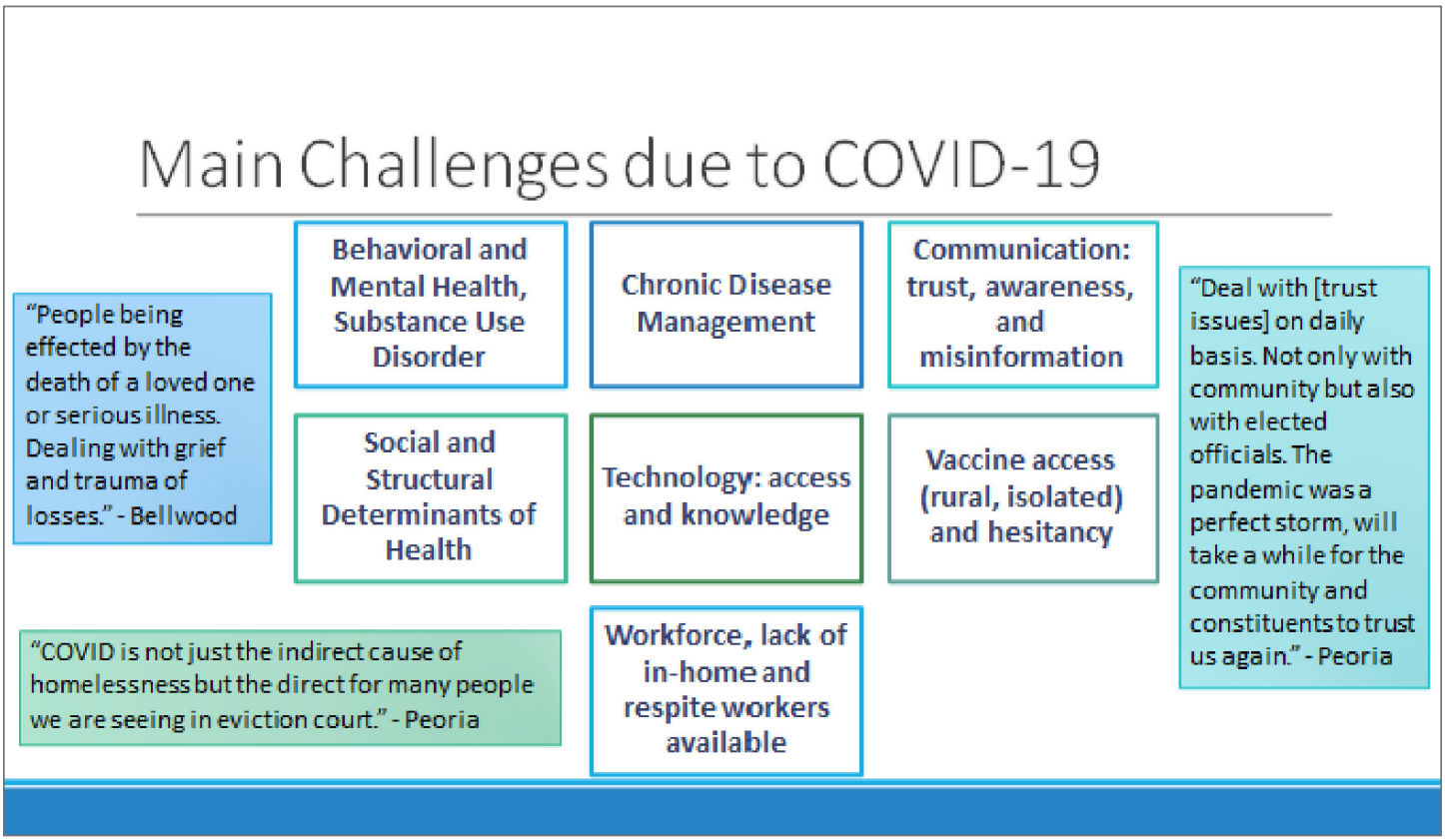
- Access to care, especially in rural areas
- Increased need (global pandemic) – social isolation
- Limited workforce/providers
- Stigma and lack of trust

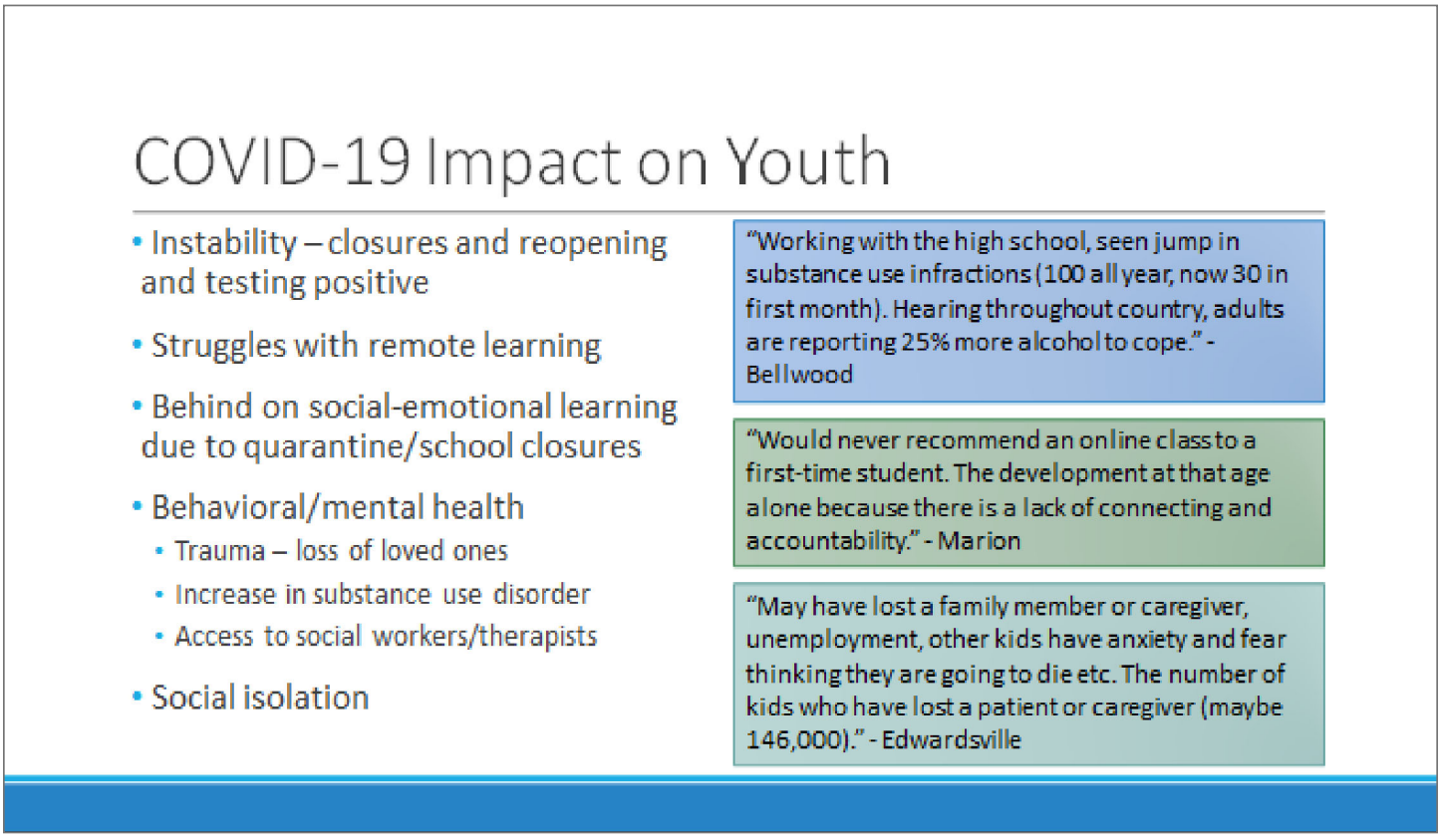
Social and Structural Determinants of Health

- Housing
  - Affordable and supportive housing availability
  - End of eviction moratorium
  - Homelessness increase
- Transportation
  - Access to medical transit
  - Public transit in rural areas
- Access to healthy food
- Community and interpersonal violence

"Access to transportation. That is a major concern even to get the vaccine. Had to make huge effort to get folks the vaccine[, especially] older adults and people with disabilities." – West Chicago

"Will have thousands of families homeless when the eviction moratorium. Lack of education to understand what the moratorium is. What it is doing to their physical and mental health now that they are facing homelessness." - Champaign


Main Challenges due to COVID-19
"People being effected by the death of a loved one or serious illness. Dealing with grief and trauma of losses." - Bellwood
Behavioral and Mental Health, Substance Use Disorder
Chronic Disease Management
Communication: trust, awareness, and misinformation
"Deal with [trust issues] on daily basis. Not only with community but also with elected officials. The pandemic was a perfect storm, will take a while for the community and constituents to trust us again." - Peoria
Social and Structural Determinants of Health
Technology: access and knowledge
Vaccine access (rural, isolated) and hesitancy
"COVID is not just the indirect cause of homelessness but the direct for many people we are seeing in eviction court." - Peoria
Workforce, lack of in-home and respite workers available


COVID-19 Impact on Youth
• Instability – closures and reopening and testing positive
• Struggles with remote learning
• Behind on social-emotional learning due to quarantine/school closures
• Behavioral/mental health
  • Trauma – loss of loved ones
  • Increase in substance use disorder
  • Access to social workers/therapists
• Social isolation
"Working with the high school, seen jump in substance use infractions (100 all year, now 30 in first month). Hearing throughout country, adults are reporting 25% more alcohol to cope." - Bellwood
"Would never recommend an online class to a first-time student. The development at that age alone because there is a lack of connecting and accountability." - Marion
"May have lost a family member or caregiver, unemployment, other kids have anxiety and fear thinking they are going to die etc. The number of kids who have lost a patient or caregiver (maybe 146,000)." - Edwardsville

SSDOH	Participant Quotes on Addressing SSDOH
Transportation	"Transportation has gotten significantly harder because of COVID. Could be why they aren't using those resources." – Marion "[We have] transportation with senior center, local health system and LHD. Connecting the dots in Freeport." – Rockford
Housing	"Work with several banks on prepurchase programs and down payment assistance for low income. Have big push for financial education for people to give that complete picture. Not sure how it would impact. Tenets rights program." – Rockford "[We are doing] work on fair housing to address housing discrimination." – West Chicago
Community and Interpersonal Violence	"People assume one part of the community is violent, hurts community as whole." – Champaign "Focus on getting people safe from family violence. COVID has seen increase of DV and limited choices." – West Chicago
Food Insecurity	"Lot of referring to partnering agencies. Food bank was running out a lot but now that is happening less. Seeing a lot of community donation." – Marion "Access to food, local funds to ensure access. Our community has established buckets where they are working with farms to drop off fresh food and vegetables to people who need." – Champaign

Opportunities to Address SSDOH

Improve coordination across the public health system

"Coordination has to happen with people who aren't at the table. People of color are not at the table." – Bellwood

"Pushing the transition coordination (when an older adult transitions out of formal care) and doing more partnerships and educating the community on what services are out there and available." – Peoria

Training and education with communities and in the public health system

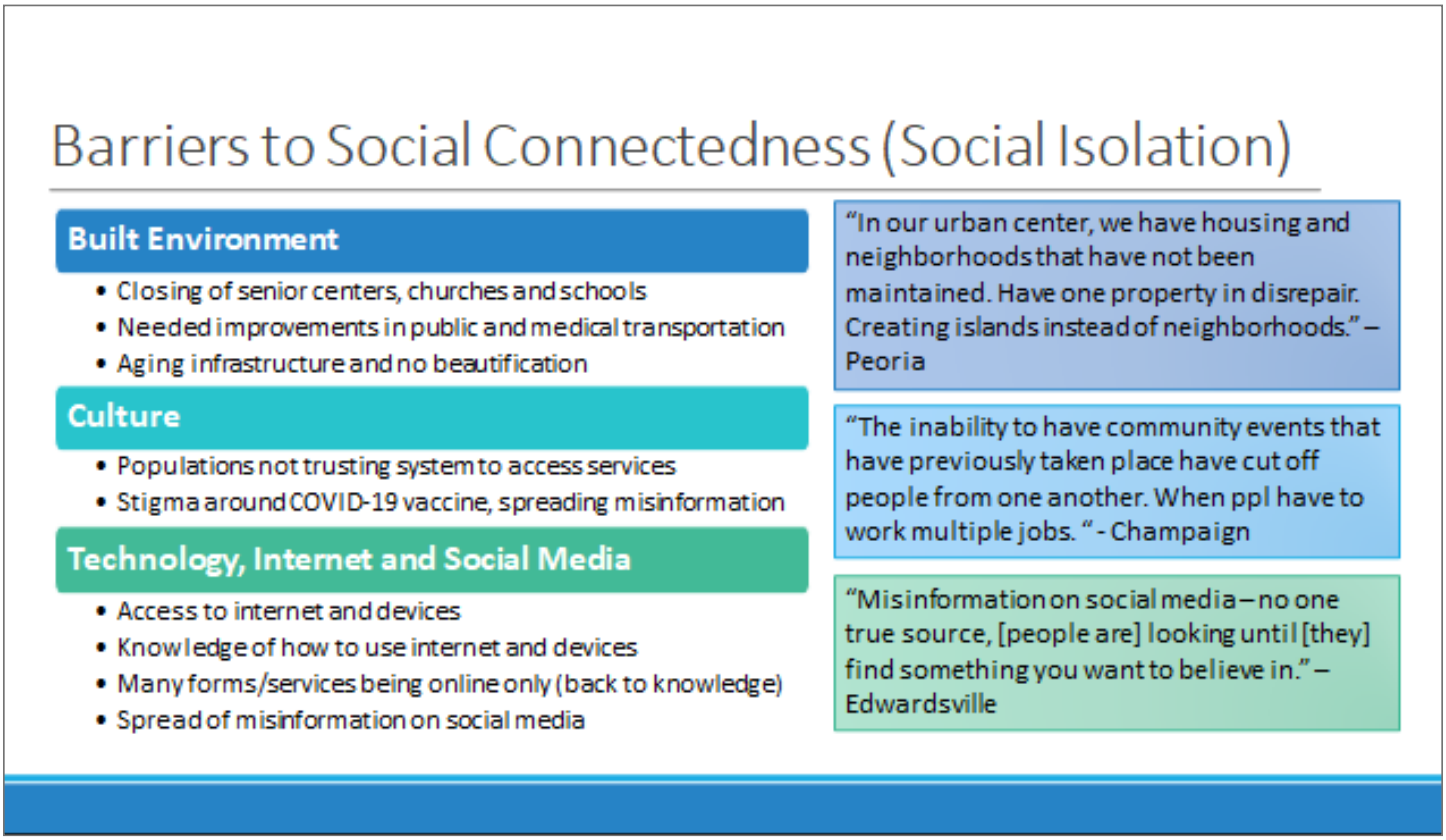
"Training opportunities for staff around HE and SDOH would be beneficial. As we come out of COVID, having more opportunities for learn about that." – West Chicago

Building infrastructure for transportation and expanding access

"Expand operations, add additional routes, pick people up individually for transportation to medical appointments." – Marion

Resources and funding for a more holistic approach

"Would make grants for communities to fill the needs. Knowing our community, properly assist to leverage community partners. Collective model. Instead of a one size fits all approach." – Peoria


Barriers to Social Connectedness (Social Isolation)
Built Environment
• Closing of senior centers, churches and schools
• Needed improvements in public and medical transportation
• Aging infrastructure and no beautification
Culture
• Populations not trusting system to access services
• Stigma around COVID-19 vaccine, spreading misinformation
Technology, Internet and Social Media
• Access to internet and devices
• Knowledge of how to use internet and devices
• Many forms/services being online only (back to knowledge)
• Spread of misinformation on social media
"In our urban center, we have housing and neighborhoods that have not been maintained. Have one property in disrepair. Creating islands instead of neighborhoods." – Peoria
"The inability to have community events that have previously taken place have cut off people from one another. When ppl have to work multiple jobs. " - Champaign
"Misinformation on social media – no one true source, [people are] looking until [they] find something you want to believe in." – Edwardsville

People with Lived Experience Focus Group Results

TIOSHA BAILEY
SHA/SHIP PROJECT CONSULTANT, IPHI
DECEMBER 21, 2021

People w/ Lived Experience (PWLE) Focus Groups Summary

7 focus groups conducted with a special emphasis on capturing voices from across the state + people living with disabilities (PLWD), communities of color (CoC), immigrant and refugee communities, older adults, and LGBTQ+ communities

Data collection period: November 18th - December 2nd

Questions explored:

-health priorities

-available resources + barriers experienced

-impact of COVID-19 + utilized resources + resources needed for recovery

-potential solutions to address challenges

-how to best keep communities abreast of SHA/SHIP progress

Participant Outcomes

	Focus Group Counts by Region				
Focus Group Session	**Chicago + Chicagoland Suburbs**	**Northern Illinois**	**Central Illinois**	**Southern Illinois**	**Totals**
Older Adults	10 (55%)	3 (17%)	5 (28%)	0	18 (25%)
Communities of Color (CoC)	9 (50%)	3 (17%)	5 (28%)	1 (5%)	18 (25%)
Immigrants + Refugees	4 (66%)	1 (17%)	0	1 (17%)	6 (8%)
People Living w/ Disabilities (PLWD)	4 (33%)	2 (17%)	5 (42%)	1 (8%)	12 (16%)
LGBTQ+	9 (57%)	1 (6%)	5 (31%)	1 (6%)	16 (22%)
Spanish Only	2 (67%)	1 (33%)	0	0	3 (4%)
Totals	38 (52%)	11 (15%)	20 (27%)	4 (6%)	73

Key Findings Summary

- **Unemployment** has been a long-standing challenge among CoC and immigrants and refugees (including migrant farm workers). However, this issue has been exacerbated due to the COVID-19 pandemic. The impact of lost income is impacting multiple areas of life for Illinois residents including **food insecurity, mental health, housing and health care system access.**
- FG findings for top health priorities + **SSDOH challenges** among PWLE are mostly consistent with those of cited by LHD and social service practitioners such as **transportation, housing, community violence, healthcare workforce shortages, and food insecurity.** Exceptions included:

- The existence and impact of **racism and discrimination** was a concern among communities of color and immigrant and refugee communities.
- Elevating the impact of **transphobia, homophobia, and interpersonal violence** among LGBTQ+ community
- Accessibility challenges related to **language + communication barriers** for PLWD and individuals whose primary language isn't English.
- Provider **shortages in home health sector and long-term care facilities** were major challenges cited by older adults and PLWD.

- There is a defined **role for community** as part of addressing solutions including community organizing, volunteering, donating time + resources and advocating for self and others.

Top Health Priorities

- The COVID-19 Pandemic was a common concern across all groups—impacting mental health, healthcare accessibility, employment, housing, and food security.
- Chronic conditions: diabetes, obesity, and heart disease

-Chronic stress among home health providers and caregivers was a common theme for PLWD and older adults' sessions

- Noted mental health conditions included: anxiety and depression. Limited access to needed services, medication, stigma, accessibility of services, and lack of diverse providers were highlighted as systemic issues.
- Substance use and addiction
- Community violence was elevated as priorities among CoC and LGBTQ+ sessions

Social and Structural Determinants of Health (SSDOH) Challenges

Physical Environment

- Food deserts
- Limited local access to needed resources (social and health)
- Personal safety (violence + COVID-19 transmission)

"Lack of feeling of safety in neighborhoods, people don't want to leave their houses."

Healthcare System Access

- *Health insurance* serving as both a barrier and facilitator when trying to access services.
- *Provider knowledge and lack of awareness of how to provide culturally competent care* were noted as barriers to effectively meeting patient needs
- *Understaffing and availability* of critical services including mental health, trans health and home health
- Quality of care being provided was a common concern among participants.
- While *telehealth* has expanded access and worked to decrease service disruption in most instances, navigating technology (Zoom platform "know-how"), broadband accessibility, and having needed supports
- *Home health* sector and long-term care facilities have experienced *provider attrition, minimal increases in financial incentives, and longer wait times.*

"Lack of actual health insurance for my clients who need medication [or] in crisis and have to wait weeks to see someone and be assisted. This could have determinantal effects."

SSDOH Challenges cont'd.

- **Transportation** was common challenge across all sessions—needed services are not located within proximity to where individuals reside, making travel necessary. Resulting in missed appointments, underutilization of available resources, and inability to access healthy food choices. Costs associated with transportation is also a factor impacting access.

Findings specific to CoC, Immigrants and Refugees, and PLWD Sessions

- **Language and communication barriers** impacted individuals' ability to schedule appointments, share challenges experienced with practitioners, navigate the system, and health literacy outcomes. Availability of translation services is a significant challenge.

SSDOH Challenges cont'd.

Findings specific to CoC and LGBTQ+ Sessions:

- **Culture, religion, homophobia, transphobia and stigma** serve as both social and structural barriers to receiving care—existence of stigma within the healthcare system, families, and community at large. Lack of advocacy and education needed to combat stigma.
- The existence and impact of **racism and discrimination** was highlighted as critical challenge for individuals with lived experience. Examples of unfair treatment exhibited by police, employers and healthcare providers.

"Racism has affected a lot from being Black to a lot discrimination from police. It has affected people mentally by not being able to go to the police station anytime there is a problem. "

"Knowing where you are going that you are going to be accepted. Lot of that preventive care wouldn't be sought because of the unknowing."

Availability of Resources

Youth-Specific Resources	Healthcare-Direct Services	Support Groups	Adult Education	Social Services
• Afterschool programming • childcare facilities • park district programming (recreation) • Student-led LGBTQ programming within schools	• Mental health—therapy sessions • Adult day service • Healthcare services for uninsured community members • Free and reduced clinic services • Physical health assessments and referral care • COVID-19 vaccinations • Planned Parenthood	• Senior services groups: technology accessibility, triad care • CoC support groups • CAPS • Church groups • Safe Space Alliance	• Community college • ESL courses	• Benefits sign up (LINK, SNAP, insurance) • Food pantries • Meals on Wheels • Caregiver relief • Housing/rental support • Utility assistance • Domestic abuse support • YMCA

Challenges with Accessing Resources

- Financial & age eligibility requirements – either making too much money or being too young to qualify
- Lack of knowledge of what's available in the community—reaching seniors is a particular concern
- Language barriers (particularly for Hispanic/Latino communities)
- Citizenship requirements-- fear of deportation.
- Long wait times
- Lack of cultural competency among staff
- Participants across all sessions experienced concern regarding the lack of needed services. Thus, elevating the challenge of transportation needed to access said services.
- Responses were region dependent—as there were examples of communities with a wide range/availability of resources and others cited as having limited or no resources for individuals to tap into.
- Requested services included programming for the queer community, certified nursing assistance, and technology education

COVID-19 Related Challenges

- Unemployment and lost income—inability to manage social needs
- Mental health has been significantly impacted for youth and adults alike. Individuals experiencing isolation, anxiety, chronic stress, and depression. High occurrences of grief and trauma due to loss of loved ones.
- Association between safety concerns around exposure and behaviors that result in long periods of no human connection and increased feelings of isolation. Said concerns were largely prevalent among PLWD and older adults.
- Healthcare staffing shortages—long-wait times, business closures, shift from in-person to virtual care, and limited access to critical services. Shortages more evident in areas with chronic access challenges prior to the pandemic.
- Technology is both a facilitator (increasing access to others through Zoom, telehealth platforms, etc.) and barriers for individuals with limited knowledge in how navigate these platforms and access to internet.
- Evidence based care for trans health and LGTBQ+ care is gray—the pandemic has slowed this process and impacting decision making among healthcare providers and patients alike.

Supporting Evidence: COVID-19 Related Challenges

- *"My child was really depressed because he has been lonely and not being able to connect with his friends during COVID."*
- *"During the pandemic, the biggest problem was isolation for most older adults. Especially those who have no family or live by themselves."*
- *"Being unable to go to doctors and hospital makes my sole access to community limited to Zoom and phone. During the pandemic, it's been hard to visit a doctor."*

Cited Resources Needed for Recovery

Economic Development
- Bringing business into communities + support job development
- Living wage employment
- Employment resources/job placement + job training

Financial Supports
- Student loan relief
- Rental + housing assistance
- Utility assistance
- COVID-19 relief $ (food, insurance, personal needs, etc.)

Transportation
- Affordable or free transportation options to support accessing healthcare and/or needed resources
- Shuttles
- Government incentives/subsidies to expand access for all

Healthcare
- Affordable mental health resources
- Increased access to group therapy sessions
- Enhanced accessibility of telehealth and after-hours appointments
- Increased capacity to see more individuals (both adults + children) for mental health services –more counselors

Education
- Free classes (i.e., GED, ESL classes)
- COVID-19 information (clinically accurate)
- Empowerment programs for parents

Technology
- Technology support programming
- Expand emergency broadband connection

Recreational Programming
- Art
- Park accessibility to play sports
- Low-cost programming for families and youth

Areas of Opportunities

Structural + Social Shifts

- Provision of equal treatment and access across communities: existence of adequate education and medication. Greater advocacy for equal treatment.
- Addressing language and communication barriers by increasing the number and availability of interpreters in the field (for PLWD and individuals whose primary language isn't English) Removing income barriers to needed resources.
- Revamp policies and procedures to improve best practices for serving PLWD.

Education + Learning

- Enhanced training for providers geared toward addressing LGBTQ+ needs and erecting targeted efforts to increase the representation of LGBTQ+ champions in the field to enable peer to peer learning.
- Generating training opportunities that emphasize the issues of racism and discrimination in the community and build awareness of its impact.
- Better understand needs of PLWD as it impacts funding decisions at the government level
- Increase access to resources that teach individuals how to advocate for themselves

"LGBTQ-specific therapist but someone already in a power role of mental health counseling—could be a service to the community also a leader and teacher."

"Cultural sensitivity training for those in the public sector—provide ongoing training annually."

Role of Community in Erecting Solutions

- Participants expressed in an interest in being included in the planning, development and implementation phases of problem solving. Ensuring that "lived experiences" voices are being captured and there's alignment between needs and solutions.
- Community organizing- protesting and making sure voices are being heard, forming support groups, and educating fellow community about available resource and serving as resource in removing experienced barriers
- Donating and raising resources to support important causes
- Advocating for self and others

"Social capital is already one of my community's biggest assets. People spread the word about different resources that are available and look out for each other in general."

"This is only one part of developing solutions, this can't be the only part we contribute to the development of overarching solutions. Include us as part of the actual development of solutions."

Cited Practices for Continued Communication

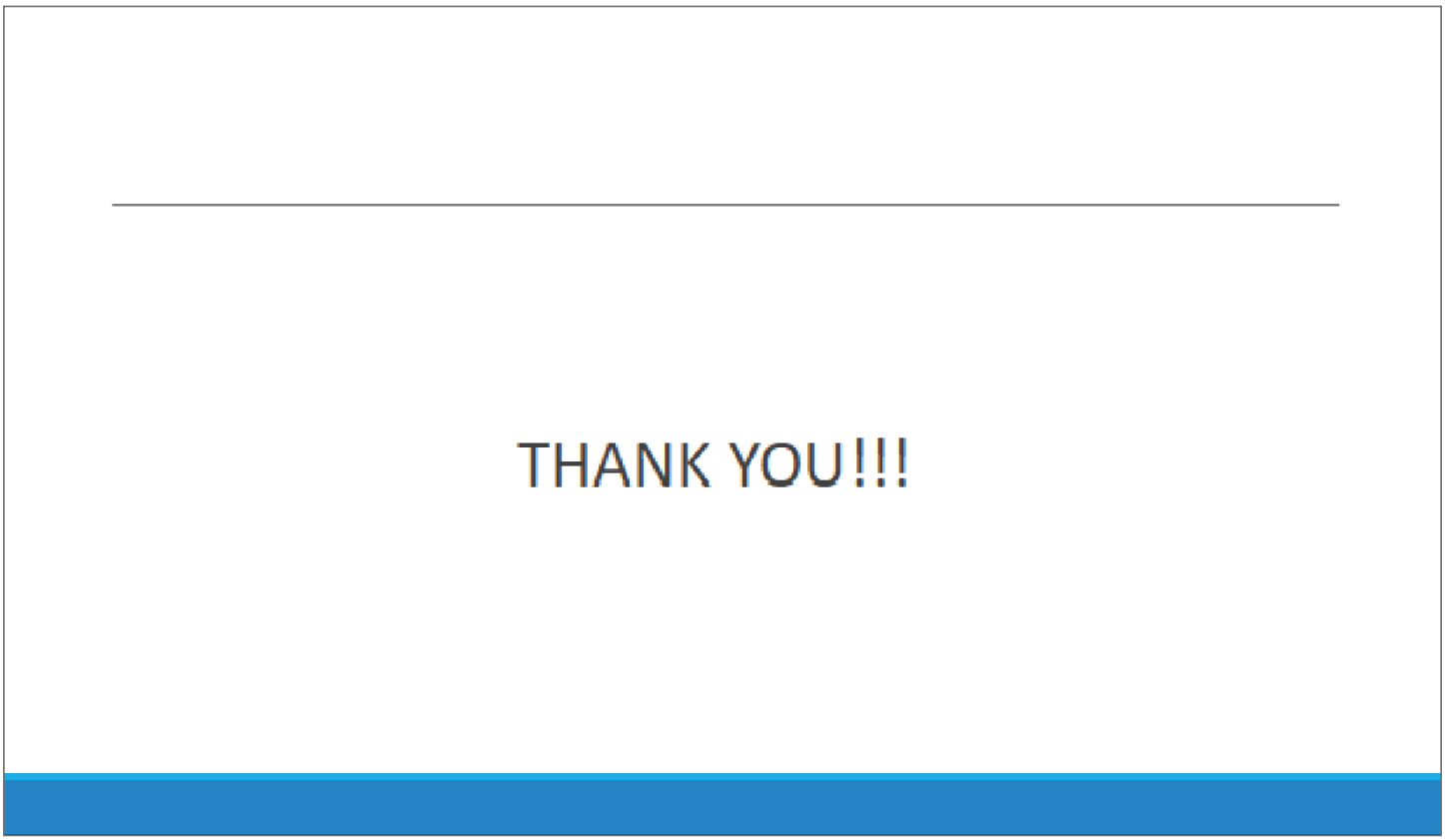
Electronic
- Zoom
- Social media: FB, IG –posting details + flyers on org. page
- Email (listservs)
- Focus groups
- Text messages
- Phone calls (ROBO calls)

Traditional Media
- Television (news)
- Print (newspapers, magazines, etc.)
- Radio

Face-to Face
- Community round tables
- Focus groups
- Presentations + talks
- Door-to-door outreach

Leverage reach of public officials + community organizations
- Disseminate information through faith-based organizations, state government officials, aldermen, hospitals, and other local community orgs.

Flyers: posting them around communities in public areas


THANK YOU!!!