

Hospitals and Communities Improving Health Across Chicago and Cook County

COMMUNITY HEALTH NEEDS ASSESSMENT FOCUS GROUP REPORT 2019

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Background and Methods

Between August 2018 and February 2019, the Illinois Public Health Institute (IPHI) worked with Alliance for Health Equity partners to hold a total of 57 focus groups with priority populations such as veterans, individuals living with mental illness, communities of color, older adults, caregivers, teens and young adults, LGBTQ+ community members, adults and teens experiencing homelessness, families with children, faith communities, adults with disabilities, and children and adults living with chronic conditions such as diabetes and asthma. The focus groups included 31 focus groups conducted by IPHI and 21 Learning Map Sessions led by West Side United and Rush University Medical Center with notetaking by IPHI. Figure 1 lists the focus group and Learning Map Session host organizations.

ABJ Services	Greater Galilee Baptist Church
Affinity Community Services	Habilitative Systems
After School Matters (2 groups)	Hanul Family Alliance
Alivio Medical Center	Housing Forward - Tenant's Club Meeting
AMITA Saints Mary and Elizabeth Medical Center	Kedvale New Mount Zion M.B. Church
Asian Human Services Family Health Center	Maine Community Youth Assistance Foundation
Breakthrough	NAMI Chicago family members
BUILD, Inc.	NAMI Chicago individuals with lived experience
By the Hand	New Moms (2 groups)
Chicago Public Library - Austin-Irving Park	New Morning Star MB Church (2 groups)
Chicago Public Library - Edgebrook Branch	Northwest Side Housing Center
Chicago Public Library - Jefferson Park Branch	Oak Park River Forest Food Pantry
Chicago Public Library - Oriole Park Branch	Oakley Square Apartments (3 groups)
Chicago Youth Programs	PLOWS Council on Aging
CJE SeniorLife	Restoration Ministries
Coalition of Hope	Rich Township VFW Post 311
CristoRey High School	Saint Stephen AME
Deborah's Place	Solutions for Care
El Valor	Southwest Organizing Project (2 groups)
Enlace Chicago	Teen Living Program
Evanston General Assistance (2 groups)	Temple of Faith MB Church
Friedman Place	Theace Goldsberry Community House (2 groups, parents and youth)
Frisbie Senior Center	TCA Health, Inc.
Garfield Park Community Council	Timothy Community Corporation
Gary Comer Youth Center	UCAN (2 groups, community residents and youth)

Figure 1. List of Focus Group and Learning Map Session Host Organizations

Community leader and provider focus groups

Faith Leaders, countywide
Immigrant service providers
South Shore Hospital community service providers
Swedish Covenant Hospital community service providers
MacNeal Hospital health care providers

Community input from all 57 focus groups and learning map sessions, was combined and included in the assessment. Focus group questions asked participants about the underlying root causes of health issues that they see in their communities and specific strategies for addressing those health needs. IPHI developed the focus group questions using resources from existing CHNA toolkits and peer-reviewed studies, in consultation

with the CHNA committee and colleagues at partner health departments. Each focus group was hosted by a hospital or community organization. Each focus group was approximately 60-90 minutes long with an average of 8-12 participants. Each focus group included a facilitator that moderated the focus group and a notetaker who audio-recorded the session while typing notes and observations on a laptop. Recordings were stored securely on a server at IPHI and not shared due to the use of first names during focus groups. No names were included in any version of the written notes and any other potentially identifying details were redacted from the notes. The full-length audio-recordings were reviewed, and codes/sub-codes were created. Themes and contrasting thoughts or opinions were highlighted. The software Dedoose 8.1.8 was used to identify and analyze cross-group codes.

Focus group questions varied depending on the topic of interest or priority population. The guides were divided into three major sections (Figure 2).

Figure 2. Overall structure of focus group guides

(Section 1) All focus groups were asked the following questions

- What community do you live in or represent?
- · What makes you proud about your community/what do you like most about your community?
- What does a community need to be healthy?
- · What are the top health needs of your community?

(Section 2) Questions varied by group but contained the following themes

- How easy or hard is it to access healthcare? Mental health care or substance use disorder treatment?
 - Barriers and positive experiences

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- What types of programs and services are available for children in your community?
- Have you encountered any barriers when trying to access programs or services for your children? Other family members?

(Section 3) Strategies and solutions – All focus groups were asked the following questions

- What are some possible solutions to the problems that have been mentioned?
- How can hospitals, health departments, and community organizations work together to address some of the problems that have been mentioned?
- What role do you see people in your community playing in the solutions you mentioned?
- How can we make sure that your voice is heard when decisions are made that affect your community?
- What would be the best ways for us to communicate with communities about the progress we are making?

All focus groups were asked the closing question in a round-robin style: "What is the number one issue that you would like to see **addressed to improve health in your community?**"

Learning map sessions were led by trained facilitators on staff at West Side United and Rush University Medical Center, with notetaking by IPHI staff. West Side United, Rush, and IPHI worked together to identify specific questions that were incorporated into the learning map session protocol that generated data that aligned with the CHNA focus groups, as shown in Figure 3. Figure 3. Assessment questions included in learning map sessions

Learning map sessions incorporated several key focus group questions including:

- What are you most proud of when you think about the West Side?
- Where have you experienced or observed challenges in our community?
 - How have these barriers affected our community?
 - How can institutions and community organizations partner with the community on solutions to these barriers?
- What are the biggest priorities to address healthy food access and consumption in your community area?
- What strategies are needed to improve physical wellness, healthcare access, and mental health on the West Side?
- What specific health conditions or health issues are the biggest priority?

Overarching Themes

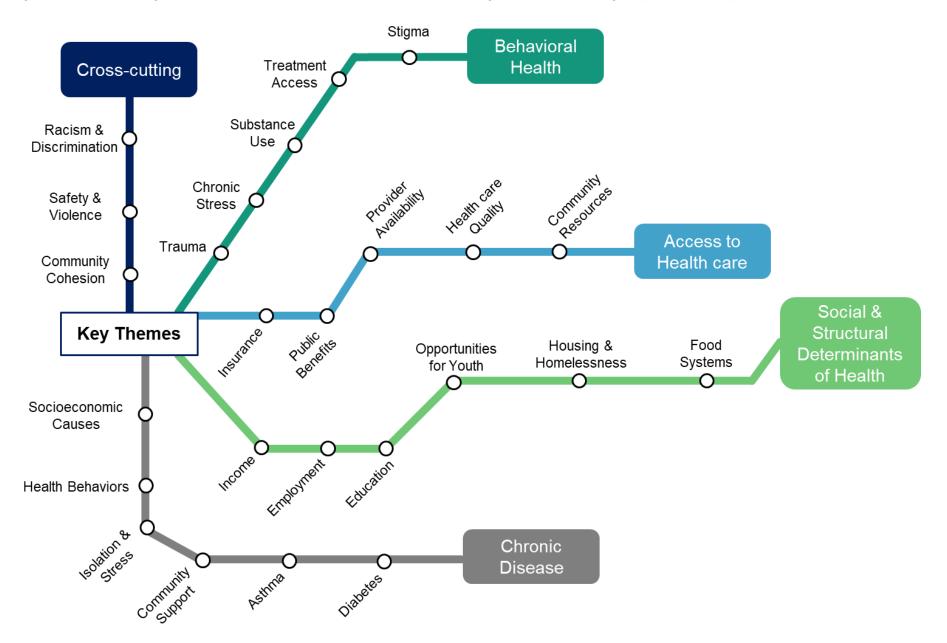
Through analysis of the focus group and learning map session input four major themes were identified:

- mental health and substance use disorders (behavioral health);
- access to health care and community resources;
- social and structural determinants of health; and
- chronic disease (Figure 4).

In addition to the four major themes, there were three cross-cutting themes that were discussed in numerous contexts among participants:

- racism;
- community safety; and
- community cohesion (Figure 4).

Figure 4. Overarching themes and sub-themes identified from focus group and learning map session input.



Cross-Cutting Themes

Racism, community safety, and community cohesion were three major themes discussed in numerous contexts among participants. Racism and violence within communities were identified as underlying causes of socioeconomic and health-related disparities while community cohesion was frequently described as one of the greatest strengths within communities.

Racism

Issues related to racism permeated many of the focus group conversations. Historical structural racism was linked to past and current patterns of segregation and differential access to resources such as quality schools, affordable safe housing, and healthcare. Communities of color, particularly those in the South and West regions of the county, described how a lack of investment in their communities has led to ongoing economic blight including high rates of unemployment, high rates of poverty, limited retail and business investment, deterioration of housing stock, reduced funding for schools, and deterioration of the overall built environment. For communities on the West Side of Chicago, gentrification and displacement of largely immigrant communities of color have been ongoing concerns. Previous research and the lived experience of communities has long ago established the profound effects that these socio-economic conditions have on health including high rates of chronic disease, diminished life expectancy, and increased incidence of behavioral health conditions. In addition, exposure to interpersonal and structural racism can be traumatizing for individuals and communities further contributing to health inequities. Focus groups participants emphasized that racism and discrimination in all forms must be addressed if any effort to improve health equity is to be successful.

Direct Quotes from Community Residents

- "It feels like this structural racism is impacting everything. I mean whether we're talking about the meetings we can attend, whether we're talking about the properties we can buy because of redlining, whether we're talking about being able to afford insurance. It really permeates everything from economics to education to even the way that we think." (Garfield Park Community Council LMS)
- "The city is so segregated. Police cars sit outside County. At Illinois Masonic no one even bothers me" (NAMI Chicago Individuals)

Community safety

Within focus group discussions, community violence was described as being both a cause and outcome of socioeconomic and health inequities. For example:

- community violence and the perception of a community having high rates of violence discourages business investment;
- limited employment and educational opportunities for youth were linked to higher rates of violence, substance use disorders, and mental illness in communities;
- affordable housing is concentrated in unsafe communities and safe communities are not affordable;
- homeless adults and youth sometimes resort to illegal activities for survival and justice involvement further complicates their ability to get back on their feet; and
- safety concerns restrict community access to recreational programs, parks, and safe spaces for exercise.

The causes and impacts of community violence are discussed throughout subsequent sections.

Community Cohesion

Community cohesion also known as social cohesion refers to the strength of relationships and a sense of solidarity among members of a community (Kawachi & Berkman, 2000). Community cohesion is considered an important social determinant of health (Kawachi & Berkman, 2000). Multiple focus groups mentioned that a shared sense of connection between community members was one of their community's greatest strengths and assets. Several other groups described community cohesion as an essential component of a healthy community. It was emphasized that the knowledge and collective power of communities is often an untapped

resource that should be solicited, cultivated, and leveraged in order to develop effective solutions to improve the health and wellbeing of residents.

Direct Quotes from Community Residents

Questions: What are you most proud of in your community? What are you most proud of when you think about the West Side?

- "The quietness and our neighbors, the neighbors we have, we look out for." (Austin-Irving Park CPL)
- "Everybody feels part of a community and gets along with each other." (NAMI Chicago Family)
- "I'm from Atlanta, but like the sense of community on the West Side." (Breakthrough LMS)

Question: What does a community need to be healthy?

- "A healthy community is where we can work out and eat healthy and also to strive to become united as a community politics, religion a healthy community builds a spiritual type community where you are united with everybody where they care for you and you care for them" (Friedman Place)
- "Consideration for those that you share your community with and be considerate of their wants and needs. If everyone did that, a community would be a least livable." (Friedman Place)
- "Cooperation from individuals living there and participation. They need to participate in the education system, the judicial system, get involved, make themselves available." (VFW Post 311)

Question: How can hospital, health departments, and community organizations work together with communities to address some of the problems that have been mentioned?

- "Institutions and community organizations need to come into the community, listen, be present and hear what residents are talking about." (Oakley Square Apartments LMS)
- "They won't listen to us; we don't have the formal education. But we have knowledge and understanding and a way of looking at things. I may not be able to use a computer, but we have something they need wisdom." (Habilitative System LMS)

Access to Healthcare

Access to healthcare is generally defined as the "the timely use of personal health services to achieve the best health outcomes" (Institute of Medicine, 1993). Healthy People 2020 describes the three steps required for an individual to access healthcare services:

- gaining entry into the healthcare system;
- accessing a location where needed healthcare services are provided; and
- finding a health care provider whom the patient trusts and can communicate with (U.S. Department of Health and Human Services, 2019).

Access is a complex and multifaceted concept that includes dimensions of proximity; affordability; availability, convenience, accommodation, and reliability; quality and acceptability; openness, culturally responsiveness, appropriateness and approachability.

Community members cited several factors that impede their ability to access the healthcare system. Entry into the healthcare system is usually gained through healthcare coverage which includes private and public insurance benefits (U.S. Department of Health and Human Services, 2019). Sixteen groups described barriers that prevent individuals in their communities from obtaining healthcare coverage. The most commonly mentioned barriers included:

- the complexity of obtaining and keeping public benefit coverage;
- policy changes that have led to severe delays in the distribution of medical cards from the state;
- fear within immigrant communities that obtaining benefits will impact their ability to acquire citizenship status;
- the high cost of some private insurance plans;
- a lack of knowledge about available insurance and benefit options; and
- diminishing access to services that assist individuals with obtaining coverage.

- "Recertification every year. You have to jump through hoops to get benefits. You go down to public aid or Social Security and you're there all day." (NAMI Chicago Individuals)
- "[Referring to public aid office] It ridiculous and they are there to help. I waited 1 hour 15 mins on hold, and someone hung up on me. Even when you go to the public aid office it is ridiculous." (Solutions for Care)
- "My mom is in-between jobs and my parents are on Medicare. I'm a millennial and I'm still having a hard time signing my parents up. I'm pre-med with college degrees and google it and still can't understand it." (NAMI Chicago – Family)
- "For my dad, he is very diabetic. He has a catheter. We have to go to ER 3-4 times a month. Before he knew about Medicare, he was paying out of pocket. So, he delayed seeing a doctor and it damaged his kidneys." (NAMI Chicago – Family)
- "Administration has put so much fear into communities. Immigrants are afraid of getting things they need like medical cards because they are afraid of getting deported." (AHS Family Health Center)
- "So many people are unaware of their benefits and it makes it difficult to make medical decisions if you are not aware." (CJE Senior Life)
- "Most of us don't have health insurance. You can't get a mammogram or go to the doctor for checkups. If we had health insurance we would go more often, not just when we are sick." (Oakley Square Apartments LMS)
- "You need access to people that can help us get access to care." (NAMI Chicago Family)

Participants stated that lacking healthcare coverage can lead to multiple issues that are linked to poor health outcomes including an inability to access preventative services, worsening of health conditions due to delayed care, an increased need for emergency care, and substantial personal debt.

Participants who had obtained healthcare coverage and were satisfied with that coverage often reported that it gave them improved access to providers and enabled them to access needed medications that they would not be able to afford otherwise. However, the majority of groups that discussed healthcare access and healthcare coverage gave examples of difficulties that they have encountered when trying to access a location where needed healthcare services are provided.

Direct Quote from Community Resident

• I have asthma, seizures, high blood pressure, all that medicine costs - if I didn't have the insurance I have. And I have IlliniCare, so I get a lot of good discounts." (Austin-Irving Park CPL)

Six of the focus groups that discussed access to healthcare described a lack of transportation to services and healthcare appointments as a significant barrier. Participants identified older adults and individuals living with disabilities as having the greatest need for transportation assistance when accessing healthcare. Existing medical transportation services were commonly described as inadequate, inefficient, and unreliable. Several community members cited instances where transportation services failed to arrive or were so delayed that it led to the cancellation of appointments. A staff member at a residential facility recalled multiple cases where their residents have been stranded at doctor's offices or medical facilities because transportation services failed to pick them up following an appointment. In extreme cases, the inability of a community member to find reliable transportation to appointments has led to the cancellation of their ongoing care such as weekly physical therapy appointments.

Direct Quotes from Community Residents

- "I was going to physical therapy and the transportation company blew me off a few times and so my physical therapy got canceled." (Housing Forward)
- "Many times, paratransit that is booked or medical cars don't show up or come really late and make us late to our appointments." (Freidman Place)

Provider availability is another factor impacting community member's ability to access healthcare. Two major themes related to provider availability were identified: the limited availability of providers accepting public benefits and overall provider shortages. Eight focus groups contained participants that had experienced difficulty finding providers that accept their insurance or public benefits. In addition, they reported long wait times or the need to travel extended distances to receive care from providers that accepted their healthcare coverage. Low-income participants in a Suburban Cook County focus group described wait times greater than two months to see a primary care provider that accepted public benefits. Veterans and former military cited wait times for VA services that were 3-4 times longer than if they went to a private clinic.

Direct Quotes from Community Residents

- "I had a friend who fell sick and she couldn't get an appointment for two months and couldn't pay bill without insurance and she couldn't take care of kids." (Asian Human Services Family Health Center)
- "My primary care physician was a two and half month wait to get an appointment to get into there. It was for pressing matters. I needed some x-rays, an MRI, a prostate exam, but it is such a process just to get in there." (Housing Forward)
- "The VA is slow to respond. The wait time is 3-4 times longer than if you went to private clinic." (VFW Post 31)

Individuals living with mental illness and individuals living with a disability highlighted the need for logistical support with scheduling appointments and transportation to healthcare services. It was mentioned that increased support with these aspects would greatly improve the ability of these groups to maintain appointments and follow treatment recommendations.

Direct Quotes from Community Residents

- "Patients need to have access to healthcare financially, geographically, and logistically." (NAMI Chicago – Family)
- "It is stressful for me to handle everything I have going on. I have memory problems, I forget things. It is stressful to maintain the apartment and to be physically challenged. Bills even though I'm not paying for them, I have to bring them here, so it can be sent off. Trying to get doctor's appointments organized and situated." (Housing Forward)

The nation's current demand for physicians continues to grow faster than supply (Association of American Medical Colleges, 2018). If current trends continue, the total physician shortfall is expected to be between 42,600 and 121,300 physicians by 2030 (Association of American Medical Colleges, 2018). In addition, major cities are expected to continue seeing the most severe shortages (Association of American Medical Colleges, 2018). These overall trends were clearly evidenced in the responses of focus group participants. Participants with both private and public benefits reported difficultly finding providers covered under their plans particularly specialists. Behavioral health professionals, particularly those serving children, young adults, and older adults, were highlighted as being the most difficult to access.

Provider shortages not only impact access to locations where services are provided, but they also hinder the ability of community members to find physicians that they know and trust. Community members described how frequent changes to the providers that are covered under their healthcare plans has required some people to switch from their long-term trusted providers to new ones. Participants that mentioned having to switch their care from a trusted provider always described the experience as negative and many thought that switching providers led to a decrease in the quality of their care. For individuals receiving behavioral health care, the effect was even more pronounced. Individuals living with mental illness and their families stressed the importance of being able to establish a relationship with the right provider and several stated that not being able to continue their care with a trusted physician or therapist impeded their recovery. LGBTQ+ community members highlighted how difficult it is to find providers that are knowledgeable about the specific needs and health concerns of LGBTQ+ individuals and described numerous stigmatizing events with non-LGBTQ+ friendly providers. This not only impeded their ability to access appropriate care but made it difficult for them to trust and establish relationships with new providers.

- "I had same doctor for 16 years and I love her, but one of the worst things I had to do was give up my personal physician. It is something that I miss a lot, not that the doctors here aren't good." (CJE Senior Life)
- "For my sister, with changes in insurance, if she finds a psychiatrist or therapist and the insurance changes, she has to start all over with someone new. It is difficult, especially when you find someone you trust." (NAMI Chicago Family)

Healthcare Quality

Healthcare quality can vary greatly between communities due to several factors including the geographic proximity of a spectrum of emergency or urgent care services, percentage of the population receiving public benefits, funding for community-based services, education and training levels of healthcare staff, and localized provider shortages. Race and ethnicity also play a critical role in the quality of healthcare that patients receive.

Previous studies have established that racial and ethnic disparities in healthcare are in part a result of differential access to care and differing socioeconomic conditions. However, previous research has also established that when these differences are accounted for, race and ethnicity remain significant predictors of the quality of healthcare received (Institute of Medicine (US) Committee on Understanding and Eliminating Racial and Ethnic Disparities in Health Care, 2003). For example,

- In an equal-access military healthcare system in California, African American and whites had similar postoperative outcomes. However, when compared to the civilian healthcare system within the state, racial disparities in outcomes were evident, especially among those without private insurance (Schoenfeld et al., 2017).
- A study of patient weight, race, and provider communication quality found that overweight/obese African American patients and healthy weight Hispanic patients experienced disparities in provider communication quality (Wong, Gudzune, & Bleich, 2015).
- In a study of providers, physicians were more likely to rate their African American patients as less educated, less intelligent, more likely to abuse drugs and alcohol, and less likely to adhere to treatment regimens (van Ryn & Burke, 2000). The differences in perceptions persisted even after controlling for confounding variables (van Ryn & Burke, 2000).

Perceptions of discrimination in healthcare have been associated with several outcomes among patients of color including decreased use of preventative healthcare, delayed use of prescription medication and medical tests, and worse chronic disease management and outcomes (Hausmann, Jeong, Bost, & Ibrahim, 2008; Trivedi & Ayanian, 2006; Van Houtven et al., 2005). In addition, research has shown that persistent exposure to racism is traumatic for individuals and that trauma is an underlying root cause of many negative health outcomes.

Focus group participants that belonged to communities of color frequently described themselves as receiving lower quality healthcare compared to whites. Some of the examples of disparities in quality included poor provider communication including a lack of shared decision making; physician failure to provide surgical alternatives; negative remarks from physicians about a patient's ability to comply with recommendations even when they are making progress; and delays in treatment for acute illnesses. Multiple participants indicated that their previous experiences with providers made them reluctant to seek needed medical care, less likely to use preventative services, less likely to have a primary care provider, and much less likely to trust different providers in the future. It was recommended that providers not only be taught cultural competency and how to overcome racial bias, but that they be required to interact with different racial and ethnic groups as part of their medical training and residential rotations. They highlighted the need for prior experience working with communities of color particularly among physicians that wish to focus their work in these communities. It is important to note that negative experiences were reported by participants living across the city and county and were mentioned in a large variety of clinical settings including emergency care, inpatient care, specialty care, and primary care.

- "Healthcare doesn't depend on your level of insurance; they make assumptions when you are black and walk in the door." (Affinity Community Services)
- "I want to see the same services at County as Rush and Northwestern, the same medical benefit." (Oakley Square Apartments LMS)
- "I don't think we are treated the same." (VFW Post 311)
- "My grandmother had a stroke and we took her to Little Company of Mary because we noticed seizures. They told us that she just had low blood sugar and that she was fine. My grandmother had another seizure and the nurse saw it and then they started treating seizures. It took a white person seeing it for them to believe us. She had a UTI [Urinary Tract Infection] that we didn't know about. They were giving her apple juice and were going to send her home." (Affinity Community Services)
- "With my grandma, she tried to go to the hospital, and she didn't have papers, so they didn't help her out like they were supposed to. She didn't get medicine or treatment; they just gave her pills to calm the pain down." (Restoration Ministries)
- "I went to doctor two weeks ago, and they weighed me. I lost ten pounds. The doctor said something to me that was not encouraging like 'I bet that was just water weight.' Just a little word of encouragement, keeps me motivated. It would have helped if the doctor had celebrated a little accomplishment." (Timothy Community Corporation)
- "There is a consistent lack of concern or lack of a standard for certain care for certain groups of people. I don't have a GP and I don't feel bad about it. Either you leave defeated or ready to sue." (Affinity Community Services)
- "Doctors need community-based and culturally relevant rotations." (NAMI Chicago Individuals)

Older adults and their caregivers reported several issues related to poor quality care. Caregivers described how older adults experiencing cognitive decline are often medicated and sedated instead of being given proactive treatments such as stimulating activities, games, and exercises. Older adults themselves stated that doctors prescribe additional medications for health concerns with little consideration for side-affects and interactions instead of looking at the patient's records to develop alternative treatments. Participants emphasized the need to develop alternative options to traditional models of care and for providers to think outside the box in terms of disease management strategies.

Direct Quotes from Community Residents

- "Hospitals don't have people to take care of Alzheimer patients especially if they are walkers, you have to stay with them. The solution unfortunately is giving them meds and sedating them and putting them in a secure room." (Solutions for Care)
- "There has to be certain therapies for people with cognitive decline. My mom's eyesight is fading, and she is hallucinating. All of these things have to be proactively combatted with exercises, games." (Solutions for Care)
- "One of the projects we talk about is having providers think outside the box to come up with some solutions." (PLOWS Council on Aging)
- "Example I always give Two of the biggest conditions are lack of sleep and pain. Almost everyone has pain and it is not always resolvable. If someone goes to the nurse and has pain and the nurse gave them meds already, they say come back. We need to think about other options to distract people or food-based solutions." (PLOWS Council on Aging)

Individuals who are visually or hearing impaired reported that they were not given the same level of care as other patients. Multiple individuals reported being ignored by medical staff and that medical staff often did not try to communicate with them. They stated that medical staff need to be trained on how to communicate with people who have disabilities and need to be trained on how to treat them with the same respect they show other patients.

- "Medical providers do not communicate with me." (Friedman Place)
- "Staff are cool and distant from you; they really don't know what to do with you." (Friedman Place)
- "How would they handle a sighted person in the ER? Would they just dismiss them?" (Friedman Place)

Participants with disabilities highlighted that they thought the issue of poor-quality care and negative provider interactions happens in both hospitals and among private providers but felt that there is less oversight for private providers. Multiple community members reported not being given medical paperwork in advance of appointments with private providers even when requested and stated that most offices don't offer braille or large print options. In addition, they stated that it is often difficult to get onsite assistance from staff with paperwork. They recommended sensitivity training for providers and more exposure to individuals living with disabilities during residencies and other forms of medical education.

Individuals living with mental illness were another population that reported that they received lower quality care than other patients. Multiple participants disclosed that they are typically dismissed when they see a provider for a health concern not related to their mental illness. They reported that this made it difficult and stressful for them to access appropriate medical services when needed. Again, provider training and more exposure to individuals living with mental illness were recommended solutions.

Direct Quotes from Community Residents

- "It took me years to go to a medical professional that would look past my mental illness diagnosis." (NAMI Chicago - Individuals)
- "Unless it is visible, I don't go to the doctor because they will write it off and say that it is just in my head." (NAMI Chicago Individuals)
- "I've had mental health issues from birth. When I was going through physical health issues, doctors wrote off my physical health issues as soon as they saw the history in my chart." (NAMI Chicago -Individuals)

LGBTQ+ community members described ways in which medical care is generally tailored towards cisgendered heterosexuals. They recounted experiences of being ignored, pathologized, mis-gendered, and shamed by healthcare professionals. As previously mentioned, these experiences made it difficult for many of them to seek care when needed. They emphasized the need for provider training to be sensitive to the needs of the different populations that they serve to ensure that all patients receive the same quality care. They also recommended increasing the number of LGBTQ+ friendly-providers and raising awareness about existing LGBTQ+ friendly providers and services.

Direct Quotes from Community Residents

- "Healthcare is not looking to provide services to the LGBTQ community in a way that they are providing services to well-to-do, cis-gendered, heterosexual whites." (Affinity Community Services)
- "We have fear when we are going to institutions where we should expect services." (Affinity Community Services)

Access to community resources

Community resources have an indirect effect on health by shaping the availability and convenience of health resources and shaping habits that support healthy behaviors (Health and Places Initiative, 2014). Community resources can encompass a wide variety of services such as food pantries, farmers markets, libraries, employment programs, housing services, community-based healthcare clinics, utilities assistance, after-school programs and much more.

Nearly all the focus groups discussed the importance of community services. The community services that were most commonly mentioned included:

• housing services;

- food services;
- employment services;
- adult education services;
- parks and recreation opportunities;
- children's programs;
- older adult programs;
- support programs for chronic diseases like diabetes; and
- adult exercise and healthy eating programs.

Specific resources identified by communities are discussed in more detail in subsequent sections.

Direct Quote from Community Resident

• "A healthy community is one that helps people in need get access to services and resources so everybody in the community can prosper." (PLOWS Council on Aging)

Community residents in many groups recommended using a variety of communication strategies such as strategically placed community flyers, TV ads, and social media to raise awareness about existing resources. Multiple groups indicated that knowledge and information about resources varies widely between communities and that special consideration should be given to limited-English speaking communities. It was also recommended that successful programs be expanded into communities where they are not yet available.

Direct Quote from Community Resident

- "Resources are kept a secret. Technically all these non-profits need is people, if they advertise more, then more people come." (Teen Living Program)
- "Outreach to non-English speaking families in the community. Lack of outreach leads to them sometimes being under-resourced." (Oriole Park CPL)
- "There are a lot of programs and initiatives, but people don't know about them or decide not to participate." (AMITA Saints Mary and Elizabeth Medical Center LMS)

Behavioral Health

Mental illness and substance use disorders are two of the largest sources of disability and premature mortality worldwide (World Health Organization, 2013). A major study in 2006 of eight states found that, on average, individuals with major mental illness die 14 to 32 years earlier than the general population (Colton & Manderscheid, 2006; Druss, Zhao, Von Esenwein, Morrato, & Marcus, 2011). By comparison, loss of years among heavy smokers is 8-10 years (Prabhat et al., 2013). Additional studies have found that increased mortality varies by diagnosis but occurs for all behavioral health conditions.

In addition to premature mortality risks, research has established that the risk of co-morbid chronic disease is high among those with mental illness and substance use disorders (Chesney, Goodwin, & Fazel, 2014; Compton, Daumit, & Druss, 2006; Druss et al., 2011; (National Institute on Drug Abuse, 2018). For example:

- for those who have a had a heart attack, experiencing depression increased their risk for cardiacrelated death three-fold;
- those with diabetes have double the risk for depression;
- people with a mental illness are twice as likely to smoke cigarettes;
- people with mental illness are 50% more likely to be obese; and
- individuals experiencing addition often have one or more associated health issues such as cardiovascular disease, stroke, cancer, HIV/AIDS, Hepatitis B and C, and lung disease.

Approximately 16% of Illinois residents are living with a mental illness which equates to more than 1.5 million residents statewide (Mental Health America, 2018). In Illinois, approximately 8% reported having a substance use disorder in the past year (Mental Health America, 2018).

Twenty-two focus groups discussed how behavioral health impacted the health of their communities. The major themes that emerged from the discussion included:

- the prevalence of chronic stress among youth and adults in communities;
- a lack of education among youth, adults, and public servants about mental illness and substance use disorders;
- difficulties accessing behavioral health treatment resulting from provider shortages, minimal community-based resources, stigma, poor healthcare coverage, financial cost, and policy issues;
- the consequences of untreated conditions; and
- the impacts of abuse and other forms of trauma on behavioral health.

Stigma

Several studies have shown that stigma can have a profound effect on health. This occurs because stigmatizing attitudes of the public can lead to discrimination against those with mental illness and substance use disorders. For example, the public is:

- less likely to hire someone who is labeled as mentally ill or as having a substance use disorder;
- less likely to lease apartments to individuals with lived experience;
- less likely to provide access to safe housing;
- more likely to falsely press charges for violent crimes against someone with lived experience; and
- more likely to socially exclude individuals with lived experience (P. Corrigan, 2004; P. W. Corrigan, 2000; P. W. Corrigan, Druss, & Perlick, 2014; Holmes & River, 1998).

At an institutional level, social stigma leads to legislation and funding decisions that decrease the availability of services and impede access to treatment (Henderson, Evans-Lacko, & Thornicroft, 2013). Public stigma also influences how individuals interact with the criminal justice system (P. Corrigan, 2004). Individuals experiencing mental health crisis are more likely to be arrested and people with mental illness tend to spend more time incarcerated than those without mental illness (Steadman, McCarty, & Morrissey, 1989). Intolerance of offenders has led to harsher laws and created barriers to effective treatment planning for offenders with mental illness (Lamb & Weinberger, 1998).

Self-stigma can lead to diminished self-esteem, self-efficacy, and confidence in one's future (P. Corrigan, 2004; Holmes & River, 1998). Numerous studies have shown that self-stigma leads to significantly decreased treatment-seeking and a decrease in people's ability to complete or continue treatment (P. Corrigan, 2004; P. W. Corrigan et al., 2014; Holmes & River, 1998; Wahl, 1999).

In fall 2017, the Alliance for Health Equity conducted four focus groups with individuals who have lived experience of mental illness or substance use disorders to understand some of the ways that communities in Cook County experience behavioral health stigma. When asked about examples of stigma that they have experienced, focus group participants indicated that they had experienced stigma in a variety of settings across their lifespans. Some of the most common examples of stigma included childhood bullying; discrimination in the workplace due to employment gaps or the need for supportive employment; social exclusion; not being allowed to direct one's own medical care; difficulties receiving appropriate emergency medical services; a lack of support because of non-physical disabilities; a lack of support from family and friends; and the use of mental illness against individuals during court proceedings. In addition, multiple participants mentioned that the expectation of violence from individuals in crisis has led to many negative encounters with law enforcement including an escalation in the use of force.

A prevailing theme across all four of the lived experience focus groups was that self-stigma greatly diminished their self-esteem, confidence in their abilities, feelings of inclusion, and hopes for recovery. However, multiple individuals from each group mentioned that once self-stigma was overcome, it improved their recovery process, increased their social inclusion, allowed them more advocacy opportunities, made them feel empowered, and allowed them to be more empathetic towards others with lived experience.

Recommendations from the 2017 focus groups for changing public and provider perceptions about behavioral health included a mix of interpersonal/intrapersonal and systems level strategies (Figures 5-6).

Figure 5. 2017 Focus group recommendations for changing public perceptions about mental illness and substance use disorders.

Recommendations for Changing Public Perceptions

Interpersonal/Intrapersonal Level strategies

- Build the collective power of individuals with lived experience
- Disclosure and telling stories of recovery
- Awareness activities such as marches
- Expand the public's understanding of disability
- Holding meetings to inform community leaders and educate them about local community resources
- Better advertising of affordable services and resources

Systems Level strategies

- Advocate for more resources from the state government
- Police reform and corrections reform
- Make mental health a healthcare and policy priority, it is often put on the back burner
- · Change payer systems and policies
- Enact policies that require the same level of care regardless of income and coverage
- They should handle mental illness and substance use disorders like they handled the AIDS crisis
- Create more employment opportunities including opportunities for supportive employment

Figure 6. 2017 Focus group recommendations for changing provider perceptions about mental illness and substance use disorders and improving provider interactions.

Recommendations for reducing stigma among providers and improving provider interactions Interpersonal/Intrapersonal Level

- Implement trauma-informed practices*
- Provider education about recovery
- Provider education about the potential for increased productivity and employment
- Re-evaluate how providers collect histories for MI/SUDs
- Create policies that give providers the resources, time, and skills needed to build relationships with clients
- Incentivize providers to improve patient outcomes

Systems Level

- Implement trauma-informed practices*
- Address provider refusals to accept Medicaid
- Increase oversight of private treatment facilities
- Increase oversight of nursing and assisted living facilities
- Disability reform
- Create policies that give providers the resources, time, and skills needed to build relationships with clients
- Incentivize providers to improve patient outcomes

*Previous research has shown that trauma is nearly a universal experience of individuals with mental illness or substance use disorders. Focus group participants emphasized the importance of trauma informed practices.

Chronic Stress and Trauma

Numerous studies have shown that chronic stress can impact brain structure and cause inflammation of the immune system. Diseases that have been linked to chronic stress and inflammation include cardiovascular disease, diabetes, cancer, autoimmune disorders, and mental illnesses such as depression and anxiety disorders (Mariotti, 2015). In addition, stress is a well-known risk factor for the development of substance use disorders and addiction relapses (Sinha, 2008). Participants from thirteen focus groups mentioned causes of stress in their daily lives and its effects. Several different sources of stress were highlighted including:

- chronic illness management for yourself or a loved one;
- homelessness and housing instability;
- repeated exposure to traumatic events or situations;
- financial challenges; and
- academic pressures.

Focus group participants linked chronic stress to several different health effects. Community members reported that stress impacted their ability to cope with chronic illnesses such as diabetes and could disrupt their ability to engage in behaviors such as healthy eating and exercise. Parents caring for children with asthma and caregivers for older adults both reported that the stress of caring for a family member had negative impacts on their mental and physical well-being. Youth living with asthma reported that stress was a trigger for their asthma attacks. Individuals living with mental illness or a substance use disorder from two different focus groups mentioned that stress negatively impacts their recovery process. Participants from three focus groups directly linked chronic stress to the development of substance use disorders.

- "Mental health is one of the most important things that we talked about today. Stress and anxiety when not treated, can lead to a lot of other issues." (Maine Community Youth Assistance Foundation)
- "For folks that are trying to make it through multiple stressful events, they can collapse if they don't have stress management and coping services available to them." (Evanston General Assistance)

Trauma

Trauma is defined as "an event, series of events, or set of circumstances that is experienced by an individual as physically or emotionally harmful or life threatening and that has lasting adverse effects on the individual's functioning and mental, physical, social, emotional, or spiritual well-being. (SAMHSA 2018)" Traumatic events can include but are not limited to abuse, childhood neglect, having a family member with a mental illness or substance use disorder, exposure to violence, and sudden separation from a loved one (SAMSHA 2018). Individuals of any socioeconomic status can experience trauma, however, individuals living in poverty often live in communities with high rates of violence, have relatives who have been incarcerated, and experience ongoing structural racism and discrimination which all have impacts on health (SAMSHA 2018). These impacts are most pronounced when trauma is experienced in childhood. Adverse Childhood Experiences (ACEs) have been linked to higher risks for physical inactivity, obesity, smoking, poor self-rated health, multiple sexual partners, sexually transmitted infections, alcoholism, substance use disorders, depression, and suicide attempts in adulthood (Felitti et al., 1998). In addition, as the number of ACEs that an individual experiences has been linked to their level of risk for conditions such as cardiovascular disease, cancers, AIDS, chronic obstructive pulmonary disease, skeletal fractures, and liver disease (Felitti et al., 1998).

Focus group participants described multiple situations that have led to trauma among community members including:

- child abuse,
- domestic violence,
- living in high crime neighborhoods,
- continual discrimination against marginalized racial and ethnic groups,
- homelessness,
- experiences as a refugee or immigrant, and
- military service.

Direct Quote from Community Resident

• "Everyone in the city is suffering from some level of trauma due to fear." (Affinity Community Services)

The impact of these types of trauma were wide reaching. Examples of the impacts of trauma in communities are listed in Figure 7.

Figure 7. Examples of trauma impacts in the communities of focus group participants

- Most homeless youth participants reported traumatic events such as abuse as precipitating events to them becoming homeless.
- Within the LGBTQ+ community domestic violence is largely underreported and unaddressed. This has had profound negative impacts on the mental health of some community members.
- Service providers have reported an increase in school difficulties, mental health concerns, and physical ailments among children of immigrants and refugees due to the current political climate. Children have reported being afraid that they will be separated from their families and concerns about the well-being of family members remaining in their countries of origin.
- African American and Hispanic/Latinx community members living in low income, high crime areas reported greater difficulties managing their chronic illnesses, poor mental health, and poor overall physical health as a direct result of continuing trauma.
- Youth and adult participants from multiple groups stated that substance use was a common coping mechanism for dealing with trauma among their peers.

The majority of recommended strategies and solutions for addressing trauma in communities were focused on early intervention and adequate support. The need to address major gaps in behavioral health services was emphasized particularly for populations such homeless youth and adults, children and youth, communities of color, and individuals exposed to violence.

Access to behavioral health treatment

Due to the Affordable Care Act, the Unites States continues to see declines in the number of uninsured individuals. However, over 24 million adults living with mental illness in the United States are going untreated (Mental Health America, 2018). In addition, 59% of youth in Illinois with major depression are untreated (Mental Health America, 2018). In Illinois alone, the percentage of untreated adults living with mental illness is 54% (Mental Health America, 2018). Individuals who are seeking treatment but not receiving needed services are facing several barriers including:

- no insurance or lack of coverage for services;
- provider shortages;
- a lack of available treatment types (inpatient treatment, individual therapy, intensive community services);
- the disconnect between primary care systems and behavioral health systems; and
- insufficient finances to cover costs including copays, uncovered treatment types, or when providers do not take insurance (Mental Health America, 2018).

The percentage of adults with unmet treatment needs in Illinois is estimated to be 22% (Mental Health America, 2018).

Barriers discussed by focus group participants closely matched the national and statewide trends. Participants from eight focus groups described a lack of public and private insurance coverage of behavioral health services. Some participants mentioned travelling 20 miles or more and occasionally out of state to get services particularly for children living with conditions such as autism and intellectual disabilities. School-based services such as counseling were described as lacking by both parents and high-school aged participants. Multiple groups gave examples of how closures of clinics and overall provider shortages have led to an increase in the use emergency departments for crisis care. Jails and shelters are additional places where individuals with unmet behavioral health needs are frequently placed. These issues were highlighted as being universal across the city and county, but most severe on the South Side of Chicago and in the South Suburbs. The lack of services to prevent crisis or care for individuals in crisis was highlighted as a direct cause of negative interactions between individuals living with mental illness and law enforcement.

Participants from the VFW Post 311 focus group highlighted that they are rarely screened for behavioral health conditions by their primary care providers. They found the lack of screening particularly problematic due to the high rates of trauma in some of their communities and among certain populations such as African American men, women, and veterans. Participants thought that provider screening might help connect some individuals

to services since they would be unlikely to seek out these services on their own. However, some communitybased service providers that participated in other focus groups expressed hesitancy to screen clients because of a lack of available referral services.

Direct Quote from Community Resident

- "We need to make sure that we have infrastructure in place before we offer services for people. For example, when you get health insurance you need to make sure that providers take their insurance. We can refer a lot of people but there is nowhere to send them. Access to clinics is not available and there are a lot of mental health institutions that are shutting down." (AHS Family Health Center)
- "More mental health facilities people can afford. A lot of the mental health facilities closed down, and they put people in jail." (New Morning Star LMS)
- "There isn't much mental health care on the West Side. You have to go to Oak Park or downtown." (BUILD LMS)
- "The wait times to get in to see a psychologist are way too long, and it is very expensive." (Enlace LMS)
- "My daughter was hospitalized twice over two short periods and they recommended that we send her out to a program. It was a recommendation to send her to a 20-30K program that isn't covered by insurance. Person who did exit interview said 'good luck with that one. You could take out a loan to pay for it." (NAMI Chicago Families)

Three focus groups mentioned the need for additional substance use disorder treatment programs for youth and adults including peer programs that connect individuals in recovery with sponsors, mentors, and other types of peer providers. Homelessness, mental illness, stress, and trauma were identified as both root causes and direct outcomes of substance use disorders. Participants highlighted the importance to address these issues when trying to engage individuals in treatment or trying to retain individuals in treatment.

Overall behavioral health strategies and solutions frequently mentioned by focus group participants included:

- knowing how to help individuals in crisis;
- what to do in case of someone experiencing an overdose;
- increasing community-based options for treatment;
- behavioral health screening in primary care settings and greater connection between primary and behavioral health systems;
- acceleration of efforts to train law enforcement officers in Crisis Intervention Training; and
- increasing awareness and access to behavioral health services among school aged children.

Social Determinants of Health

Research has long established that socioeconomic inequities are key drivers of health outcomes. For example:

- children born to mothers without a high school education are twice as likely to die before their first birthday than children born to mothers who are college graduates;
- the percentage of individuals reporting poor health increases with decreasing levels of income and education;
- low-income individuals are more likely to have a chronic disease; and
- low-income individuals have higher rates of diabetes and coronary heart disease (Robert Wood Johnson Foundation, 2008).

Socioeconomic inequities were mentioned by several focus groups. Inequities in community economic investment and development, employment opportunities, transportation resources, quality affordable housing, education opportunities, and food access were highlighted particularly by groups held on the West and South sides of the city and county. In addition, groups held on the North side of the city and county highlighted disparities in resource distribution with the North region having the most access to economic opportunities and community resources.

- "It is very one sided. The North side has so many resources and even better transportation." (NAMI Chicago Individuals)
- "I moved from the South side and predominately black communities. There's a lack of affordable decent housing, lack of nutritious food - everywhere except the Northside." (NAMI Chicago – Individuals)
- "On the West Side there isn't much funding to create better opportunities like schools and jobs." (Breakthrough LMS)

Participants explained that the lack of business investment and economic resources in the West and South were due to underlying factors such as long-term divestment in certain communities, the loss of locally owned businesses, limited educational resources, low levels of home ownership, and minimal employment opportunities.

Employment Opportunities

A lack of employment opportunities was one of the most frequently discussed issues among focus group participants. Again, participants living in the West and South regions of the county described having the least number of quality job opportunities and employment resources. However certain populations such as those living with mental illness, young adults, homeless individuals, and formerly incarcerated were highlighted as having significant barriers to employment regardless of their geographic location. Within certain communities, jobs are available, but they are described as part-time, temporary, and/or low-paying.

Direct Quotes from Community Residents

- "People from the community should be involved in the building up and supporting businesses that reflect the community." (New Moms)
- "We don't have anywhere in our community to go to that has restaurants with tablecloths and waitresses." (VFW-311)
- "People come in from other neighborhoods and open stores and go back to their nice neighborhoods. No black businesses in our neighborhood." (Greater Galilee LMS)
- "I have to go out of my neighborhood to do anything. I don't shop in my neighborhood. I don't eat in my neighborhood." (Greater Galilee LMS)
- "They forgot about this place. There are broken down houses, burned houses, abandoned houses, ugly streets, litter, littered parks." (Restoration Ministries Youth)

Individuals living with mental illness mentioned the difficulty of transitioning from receiving public assistance to full-time work. Participants explained that the transition to work would ideally be gradual for individuals in recovery, but that they are often forced to forgo all financial support from public benefits to attempt full-time positions. This can create significant stress and impede progress for some individuals. They indicated that there is a significant need for more transitional jobs and workplace support for individuals transitioning back into the workforce during recovery from mental illness.

Direct Quote from Community Resident

"As a CRSS [Certified Recovery Support Specialist], I realized that in order for me to get certified, I
would have to volunteer or work. I'm on social security and on disability. I can't use training that I have
to help people like myself. I would be penalized by the state and federal agencies [for working]. Not
only would it affect my income, it would affect my housing, my ability to get food - why would I work as
a CRSS and get penalized for it? It puts stress on those who are seeking help and those who can help
them. It doesn't make sense for my recovery or those I try to serve." (NAMI – Individuals)

Cook County has some of the highest disparities in youth employment in the nation. In 2016, the employment rate among African Americans aged 20-24 was 47%, the lowest in the nation, and the rate for whites in the same age group was 73%, one of the highest in the nation (Svajlenka, 2016). During focus groups, multiple youth of color described instances where they felt that their racial or ethnic background prevented them from

obtaining employment. Overall, focus group participants attributed low rates of employment among youth to inequities in education quality, a lack of mentoring and tutoring programs for youth, the need for additional after-school programs and internships, employment discrimination against youth of color, limited opportunities to develop trade skills, limited alternatives to college, and a lack of knowledge or information about available employment resources. Participants highlighted that certain groups of youth, such as those who did not complete their education or have a history of justice involvement face staggering barriers to obtaining employment and getting back on their feet and that many youth development programs do not address these issues. Participants recommended increasing the number of programs that are tailored to youth facing these challenges. Multiple groups linked the lack of opportunities for youth in some communities to issues such as higher rates of community violence, increases in substance use and mental illness, and generational poverty.

Direct Quotes from Community Residents

- "There are a lot of jobs out here, but we are not qualified. We don't have the education." (Teen Living Program)
- "I've been to multiple temp agencies and there is a racial tension on the job. Certain ones like black people and others don't." (Teen Living Program)
- "There is nothing to do since I have a record there is nothing to do." (UCAN LMS)
- [Referring to youth] "It would be good to have extracurricular and after school or weekend activities where they can shadow someone in a trade." (NAMI Family)
- "For employment, they are trying to develop programs. You have to hear it by word of mouth." (Evanston General Assistance)

Youth and adults who are experiencing housing instability or homelessness described many of the same barriers to employment as other groups. However, they explained that individuals experiencing housing instability are often experiencing other problems such as mental illness, substance use disorders, or poor physical health that compound the difficulty of finding stable quality employment.

Direct Quote from Community Resident

• "Some get caught in limbo. People show up when they are struggling with substance use disorders and they get kicked out on the street and kicked out of the shelter and services." (Housing Forward)

Education

Education was another widely discussed topic among focus group participants with approximately 19 different groups mentioning the importance of quality education opportunities. The major education-related concerns expressed by focus groups included:

- school closures and diminishing education opportunities on the West and South Sides of Chicago;
- poor quality schools particularly on the South Side of Chicago and in the South Suburbs;
- limited or non-existent resources for learning trades;
- a lack of support programs such as quality, low-cost tutoring; and
- limited adult education programs.

Youth in the South Suburbs described their schools as being outdated, dilapidated, and dirty. They also described extremely limited curriculum opportunities, unengaged instructors, poor quality books and materials, and severely limited options for after-school activities. Several students mentioned that they felt their education is not going to adequately prepare them for college or entering the workforce. Students on the South side of Chicago mentioned that school closures have led to more student dropouts. Multiple adult participants across Chicago mentioned serious concerns about the quality of Chicago schools. Participants identified education as an underlying root cause of unemployment. Additionally, they linked education issues to many of the same problems caused by unemployment such as higher rates of community violence, increases in health issues such as substance use disorders and mental illness, and generational poverty.

- "I know a lot of people that have been dropping out. It is probably because they are tired of school, sometimes the teachers, our school supplies." (Restoration Ministries)
- "Soon we will be adults in this community, so they need to give us the education, teachers, and better schools we need because that will advocate for a better Harvey in the future." (Restoration Ministries)
- "They don't give us much to explore so we can find out what we enjoy so we know what we want to do when we grow up and when we go to college." (Restoration Ministries)
- "Engage youth, start with the education system. As black children, we have poor education." (After School Matters LMS).
- "I've been watching schools go down in Chicago over time. Schools in Chicago appall me." (Oriole Park CPL)
- "Education is the biggest challenge I don't think the quality of education in our communities is very good." (Enlace LMS)
- "Reopening the trade school, they are making it more difficult to get into trade school. We need to make it so that once you finish high school then go into trade apprenticeship." (Breakthrough LMS)
- "Lots of young people are not able to get jobs because schools are under-resourced, and they are not prepared for jobs." (AMITA Saints Mary and Elizabeth Medical Center LMS)

Housing

Homelessness and housing instability are associated with high rates of mortality and morbidity (Kushel, Gupta, Gee, & Haas, 2006). Housing instability does not have a standard definition and encompasses several issues including difficulty paying rent, overcrowding, frequent moves, living with relatives, and cost-burdened housing (Frederick, Chwalek, Hughes, Karabanow, & Kidd, 2014; Kushel et al., 2006). Housing was frequently discussed by focus group participants. Major themes that rose to the top of discussions included:

- segregation prevents communities from having diverse economics, racial/ethnic groups, and resources;
- gentrification pushes low-income families out of communities;
- safe, quality housing is often not affordable and affordable housing is often not safe or good quality;
- older adults are still struggling to recover from the housing crisis; and
- oversight of landlords and homeowners is lacking in many communities.

Cook County has one of the most segregated populations in the nation. Ongoing racial and economic segregation affects public school performance, community safety, economic investment, job opportunities, workforce development, access to healthcare, and more (Metropolitan Planning Council, 2018). Focus group participants highlighted that segregation results in poor quality housing being concentrated in communities of color with high rates of violence and poverty. Crowded housing with multiple families living in a single residence is also concentrated in these communities. Gentrification was often identified by participants on the West and North sides of Chicago and Suburban Cook County as one of the primary forces behind decreasing income and racial/ethnic diversity in communities. Focus group participants that lived in neighborhoods that were more diverse in terms of racial/ethnic and income composition typically had more positive feedback on the quality of their housing and the safety of their communities. In addition, they almost always reported that the diversity was one of their community's greatest assets. However, many of these same participants often reported that cost of housing in their communities was high.

- "I feel like in Chicago where it's affordable; it's not safe. Where it is safe; it's overpriced." (New Moms FG)
- "The houses are decently affordable, but the taxes are high. The safety of the house has to be sacrificed to afford it." (Edgebrook CPL)
- "I feel like they're trying to take everything from us and move us out of places like Wicker Park and West Town." (Breakthrough LMS)
- "If you're not in a certain income bracket you are being squeezed out." (Oakley Square Apts LMS)
- "The biggest challenge is displacement of those with lower resources, we're being forced out. The landlord will remodel an apartment and then start charging \$2000 in rent" (El Valor LMS)
- "More affordable housing in Evanston. They are trying to push minorities out, because the rent is entirely too high." (Evanston General Assistance)
- "It's not just violence it's the lack of money in the area. If people had money, there would be less violence." (Breakthrough LMS)

Housing Conditions

Focus group participants described varying housing conditions based on the communities they lived in. Some of the housing quality issues mentioned included dilapidated and crumbling structures, incomplete units, plumbing problems, and pest infestations. Renters described how these issues can be left unaddressed by landlords and property owners for extended periods of time or indefinitely. Some homeowners described these issues within their own homes but stated that they lacked the financial resources to address them. The health problems that were most often associated with these housing quality problems included exposure to mold, asthma, and stress. Children were identified as being at a higher risk for health problems associated with poor quality housing. Participants from two groups mentioned that immigrant communities were more likely to be taken advantage of by landlords. They explained that some immigrant communities are reluctant to report housing problems and negligent property owners because they fear losing their housing or housing benefits or because they are undocumented. Another population struggling with housing conditions is older adults. Focus group participants explained that as homeowners age, maintenance of their houses can become difficult. Without outside assistance, this can lead to the rapid deterioration of their housing conditions.

Direct Quotes from Community Residents

- "I work full time and have side jobs. I have a basement apartment that floods and there is probably mold and I can't afford to move." (NAMI individuals)
- "My ceiling fell in a few weeks ago and the landlords didn't repair it." (Evanston General Assistance)
- "The rent is being raised and the places are also incomplete. Some houses have high prices but no completed kitchens. You kind of take it how it is." (Northwest Side Housing Center)
- "My daughter is dealing with bad housing conditions in the South [Side] Mice, Roaches not an
 optimal environment for kids." (Housing Forward)

Homelessness

As previously mentioned, homelessness and housing instability can have significant impacts on morbidity and mortality. Adults and youth who are experiencing homelessness and housing instability reported several health problems that were a direct result including hypothermia, frost bite, severe weight fluctuations, gangrene, poor sleeping habits, and severe stress. They also reported that minor health problems often became serious due to homelessness or housing instability. Behavioral health conditions such as mental illness and substance use disorders were identified as both a cause of homelessness and the direct result of homelessness or housing instability. One parent stated that the housing instability and frequent moves that they experienced with their children made it difficult for their kids to remain engaged in school and to socialize and make friends with other children.

- "When I started having housing problems and had to be homeless, I had a little cut in my foot, and it got infected and it got damaged." (Housing Forward)
- "I was homeless in 2014 and it was so cold my health got really bad pneumonia, frost bite on toes everything gets complicated when you are homeless." (Housing Forward)
- "I also had a cold when it was -3 because there was nowhere to go. Was sick, had a fever. I still have to be outside because I'm homeless." (Teen Living Program)
- "Alternatives to drinking, people drink a lot out of boredom. When you are homeless, you don't have anything else to do." (Housing Forward)
- "We smoke weed all the time because we are stressed and don't know what to do. We can escape reality." (Teen Living Program)
- "Once it gets long term, then you get people living on the street and they've got so many problems we can't solve." (Jefferson Park CPL)

Homeless shelters and housing services were difficult to access for some community members. Homeless youth reported that shelters are particularly dangerous for teens and young adults and that they often resorted to staying on the streets or breaking into abandoned houses as an alternative. Multiple homeless teenage youth under age 18 reported being turned away from shelters in favor of families with children. They explained that they felt it was often due to them being young men of color. Youth emphasized the need for more youth-specific services and homeless resources. Adult participants mentioned that it is often more difficult to get housing support if you have a mental illness, substance use disorder, or are not disabled. These groups and service providers in the South Suburbs highlighted a need for more low-barrier shelters and services across the city and county.

Direct Quotes from Community Residents

- "Not having the right shelter to go to. There are a lot of bad shelters where people do things you don't want to be involved in." (Teen Living Program)
- "If you don't make it into shelter in time. There's lots of abandoned houses around the shelters." (Teen Living Program)
- "Have more people that work in the field that understand what we have going on. With some of us being homeless, we don't have people to talk to." (Teen Living Program)
- "Some get caught in limbo. People show up when they are struggling with substance use disorders and they get kicked out on the street and kicked out of the shelter and services." (Housing Forward)
- "If someone has disabilities it is easier to get housing. My referral went through faster." (Housing Forward)

Focus group participants reported that older adults are struggling with housing instability and homelessness as well. In the suburbs, participants explained that many older adults still had not recovered from the housing crisis and were dealing with issues such as mortgages that were higher than their home's value as well as decreased home values that resulted in lost equity.

Direct Quote from Community Resident

• "Seniors end up homeless or in housing they can't afford. We have a lot of clients that haven't recovered from the housing crisis and they're under water. For them to sell and move is nearly impossible because anything they would put towards living somewhere else is gone, the equity is gone." (PLOWS)

Food Systems

Access to healthy foods is another important factor needed to support a healthy lifestyle. Participants across the city and county reported difficulty accessing healthy foods. Participants on the West and South Sides of the city and county reported a high proportion of fast food restaurants and limited access to grocery stores selling healthier options. Low-income participants on the North Sides of the city and county reported that there were

several grocery stores available but that they often could not afford to shop at them. Older adults are another population than can have trouble with routine grocery shopping and accessing healthy food. Meals on Wheels was described as a major community asset, but the need for grocery store delivery services that are affordable was highlighted. Community members living with chronic diseases such as diabetes explained that living in communities with less access to healthy food options and more access to fast food made it more difficult to manage their conditions.

Both youth and adults from multiple communities reported that having a healthy diet can be difficult for several other reasons as well including:

- youth often find healthy foods unappealing particularly if they have had limited exposure to them;
- the cost of healthy foods was frequently described as a barrier, but there was often disagreement among groups on this issue;
- food pantries do not always provide healthy options;
- fast foods are more convenient particularly for working parents with children; and
- many lack the knowledge of how to prepare healthy meals.

Additional community assets mentioned by participants included food pantries offering fresh fruits and vegetables, the Supplemental Nutrition Assistance Program (SNAP), community gardens, and educational programs about managing chronic illness through diet. Some barriers to accessing these community assets include limited hours and locations, cuts to SNAP programs, fear that enrolling in SNAP might have an effect on immigration status, and general knowledge or information about resources.

Direct Quotes from Community Residents

- "It is easy to purchase fresh fruits and vegetables in our community. We have three nearby grocery stores. Fixed income or low-income people might have issues affording the food." (Oriole Park CPL)
- "I work out a lot but I'm not always good with food. It is expensive to eat healthy food, but it is more expensive to be sick. It scares me because unhealthy food is there. You eat things just because you want to eat late at night." (Timothy Community Corporation)
- "To eat healthy, you need to eat organic and that's expensive, that's why there's a lot of corner stores and fast foods." (By the Hand LMS)
- "Build more stores like Whole Foods, Cermack, and Mariano's on the low ends instead of places like Popeyes." (Gary Comer Youth Center)
- "Cost McDonalds is much cheaper than Pete's in Oak Park for vegetables, why is it that greasy foods are so much cheaper? Then they want to talk about obesity, yeah look what's in our community." (After School Matters LMS)
- "Healthy food tends to have less flavor than non-healthy food and my taste buds prefer flavor." (Gary Comer Youth Center)
- "One of my concerns is that I have diabetes and so does my daughter. Sometimes when I get home, I make food and sometimes I just grab chicken. I hear some people meal prep. I leave home at 6am and get home at 6 or 7pm, it is hard for me." (Timothy Community Corporation)
- "I think we need more supermarkets because not everyone has a car. Then maybe kids will learn about fruits and vegetables and learn how to eat" (New Morning Star LMS)

Chronic Diseases

Focus group participants across the city and county described several issues related to chronic disease and chronic disease management. The major themes that were mentioned by participants included:

- social determinants of health such as poverty, limited access to healthy foods, exposure to violence, and housing conditions are both underlying root causes of chronic disease and are barriers to the management of chronic disease;
- education about preventing chronic disease, risk factors, and when to seek medical help is lacking in communities;
- chronic illness such as asthma can be isolating for youth, parents, and adults;

- taking care of a child with a life-threatening chronic illness can often cause severe chronic stress; and
- community groups that share information about resources and support each other with adjusting to healthier lifestyles would be extremely helpful to communities.

The 2016 CHNA established asthma and diabetes as priority health conditions for several communities throughout the county. As a result, several hospital and health department partners have coalesced around these issues. In addition, development, progression, and outcomes for these two diseases are strongly tied to the social determinants of health and have large equity-related gaps between communities. There were multiple focus groups that were comprised of individuals living with these conditions to further our understanding of the causes of the disparities related to these conditions as well as to gain insight into additional community-level strategies and solutions that could be used to address them.

Asthma

Although asthma occurs in all racial and ethnic groups, low-income and communities of color share a disproportionate burden of asthma morbidity and mortality (Forno & Celedón, 2012). Previous research indicates that issues such as poverty, limited access to healthcare, exposure to violence, chronic stress, overcrowded housing, deteriorating infrastructure, poor housing conditions, and higher rates of air pollution all contribute to the increased burden of asthma morbidity and mortality in certain communities (Williams, Sternthal, & Wright, 2009).

Youth and adult focus group participants indicated that there were a number of environmental and behavioral factors that could trigger their asthma including:

- common allergens such as dust, pollen, paint, pets, perfumes, cleaning supplies, air fresheners, and second or third-hand smoke;
- housing-related factors such as carpet, drapes, air-conditioning, heat, humidity, pest infestations, and mold;
- weather changes from hot to cold or vice versa; and
- behavioral factors such as physical activity.

Parents of younger children were more likely to report that their children always carried their rescue medication than older youth or adults themselves. In addition, younger children were more likely to be receiving controller medication. Despite these factors, nearly all parents of young children with asthma reported several repeated visits to the emergency department for severe asthma attacks. Some additional challenges faced by parents of the youngest children included the difficulty of properly administering medication to a young child, their child's fear of the doctor, and the difficulty of restricting activities of a young child with severe asthma. Many parents found that caring for their children's asthma significantly restricted their ability to sleep, engage in healthy behaviors, and engage in basic self-care activities. Parents also conveyed that they often stressed about the health of their children both when they are at home and when they are at school.

- "I can't keep count of how many times I go to the ER with my child." (Theace Goldsberry Community House)
- "Whatever they give them in the hospital, they perk right up, it's so frustrating. You're trying so hard to figure it out at home, for 12 hours, and then it just works right away at the hospital." (Theace Goldsberry Community House)
- "I always take my child to the ER. As he gets older, it's has gotten more severe, and he is agitated. He asks questions about when he can stop taking medications." (Theace Goldsberry Community House)
- "My child takes a lot of medication. At night he gets frustrated and says, "here we go again." He takes sleep apnea medication plus 2-3 medications for asthma." (Theace Goldsberry Community House)
- "My nephew has a lot of energy; he is breathing hard, but you can't tell him to sit down." (Theace Goldsberry Community House)
- "The children will be running and jumping around despite me telling them to calm down. When I give my son the medicine with steroids, he can't sit still. He has problems in school because he can't focus. The medicine helps his asthma, but it makes him too energetic." (Theace Goldsberry Community House)
- "I'm running on no sleep because my child can't sleep at night. Then the hospital gives him medication to knock him right out – and then I have to carry him off the bus. He's 69 pounds. Give me the medication so I can give it to him at home, so I can get a break. Let me take a shower and straighten stuff up. You can't take a break, it's your child, you do what you have to do." (Theace Goldsberry Community House)

Parents stated that they found educational courses about asthma triggers and how to avoid them to be extremely helpful. They also stated the importance of working with family members and school staff to have emergency plans in place in case of a severe asthma episode. Other parents recommended learning life-saving techniques such as CPR. Most emphasized the importance of expanding educational programs and planning strategies to all parents of children living with asthma. In addition, more comprehensive care options may be needed for some patients to avoid poorly controlled asthma and frequent visits to the emergency department.

Many of the youth participants living with severe asthma reported that their symptoms severely restricted their day-to-day activities even if they were receiving treatment. Asthma of any severity level has the potential to be life-threatening (National Heart, Lung, and Blood Institute, 2007). In general, youth with less severe asthma symptoms reported fewer restrictions to their day-to-day activities but commonly reported that they frequently did not carry their rescue medication with them because they felt their risk was lower. However, at least one of these students reported being transported from school to the emergency department via ambulance because she had a severe asthma attack at school and did not have her rescue inhaler.

Direct Quotes from Community Residents

- "Sometimes it makes me feel like I have a disability. I wanted to go into the army, but I couldn't because I have asthma. It makes me feel bad, dang why I got asthma." (Theace Goldsberry Community House)
- "I hate when my lungs close. I cannot do what I want to do." (Theace Goldsberry Community House)
- "I don't do things that I can't do because I don't want it to get worse. I used to play basketball, but my asthma started coming back. I can't do what I did last year." (Theace Goldsberry Community House)
- "I don't' take my asthma pump to school because I don't have bad asthma." (Theace Goldsberry Community House)
- "If I go out somewhere, I don't always have it with me. It's not the first thing that comes to mind. It just slips my mind." (Theace Goldsberry Community House)
- "I left my asthma pump at home they had to call an ambulance for me at school." (Theace Goldsberry Community House)

Diabetes

Like asthma, diabetes morbidity and mortality disproportionately affect low-income communities of color. Several focus groups mentioned diabetes as a major health concern in their communities and two focus group was composed entirely of adults living with diabetes. Adults living with diabetes all agreed that they understood the importance of healthy diet and physical activity in controlling their conditions, but they mentioned several barriers that made it difficult to engage in healthy behaviors:

- chronic stress in everyday life makes it difficult to manage diabetes;
- limited access to grocery stores and easy access to fast food can make it difficult to choose healthy food options, particularly for individuals and parents who are busy and work long hours;
- the affordability of healthy foods;
- physical activity routines can be difficult to begin by yourself;
- not everyone knows how to prepare healthy meals;
- resistance from non-diabetic family members, other household members, and friends to changes in diet; and
- lack of knowledge about community resources that may help with disease management.

Direct Quotes from Community Residents

- "We have food deserts in Chicago, and you go a long way before you find healthy food, but you find fast food like burger king." (Timothy Community Corporation)
- "One of my concerns is that I have diabetes and so does my daughter. Sometimes when I get home, I make food and sometimes I just grab chicken. I hear some people meal prep. I leave home at 6 am and get home at 6 or 7pm, it is hard for me." (Timothy Community Corporation)
- "A lot of people don't like working out by yourself. They feel they are not doing it right, so they stop doing it." (Timothy Community Corporation)

Participants recommended creating support groups for individuals living with diabetes so that they can share information about resources and support each other with lifestyle changes. Several participants mentioned that creating workout groups for individuals with diabetes that accommodate different schedules would help motivate them to exercise more frequently. However, these groups need to be tailored to different levels of fitness and be inclusive of individuals living with disabilities. Programs that teach skills related to meal planning, healthy food choices, and preparing healthy meals were found to be extremely helpful and it was recommended that these programs be expanded. Social media posts and videos about meal prepping, recipes, exercise, and managing diabetes were highlighted as a great opportunity for educating the community. Supporting home gardens and community gardens was described as an excellent way to improve access to fresh fruits and vegetables and increase physical activity. Food pantries were also cited as another important community resource for improving access to fresh fruits and vegetables.

Direct Quotes from Community Residents

- "Need to establish a weekly meal plan. For example, on Sunday write down the meals you want to eat and work in time to work out. It's a matter of making a meal plan and exercise plan for the week so you don't get bored. Research the food you want to eat." (Timothy Community Corporation)
- "I started a garden and put everything in a bucket. Fresh fruit and herbs." (Timothy Community Corporation)
- "We've been able to control it with food. It is expensive. We found a food pantry at Saint Elizabeth's. They had arugula, grapes, apples, tomatoes. They had some good stuff, really fresh food - it was good food. Every fourth Saturday that's where we get food." (Timothy Community Corporation)
- "I have discussions with people who struggle with diabetes and we discuss recipes. I also use Pinterest and they have a lot of good ideas - recipes, meal plans." (Timothy Community Corporation)
- "I do look on social media and look at the recipes and I do experiment." (Timothy Community Corporation)
- "Social media, there are a lot of groups on social media how to eat healthy, how to work out." (Timothy Community Corporation)

Conclusions

The major topics discussed in each focus group and Learning Map Sessions are summarized in Figures 8-9. Communities throughout Chicago and Suburban Cook County are facing a number of inequities that are decreasing overall health and wellbeing. Behavioral health including mental illness and substance use disorders rose as the top health concern identified by focus group participants. The critical role that the social and structural determinants of health, racism, discrimination, and trauma play in influencing health outcomes within communities cannot be overlooked and must be addressed for future interventions to be successful. In addition, the strength, knowledge, and grassroots efforts existing in communities are a critical asset that should be leveraged when developing effective plans to address the health needs identified by participants.

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Figure 8. Summary of major topics discussed in focus groups

	Access to community resources	Access to healthcare	Asthma	Child and adolescent health	Chronic disease and health behaviors	Community cohesion	Disability and inclusion	Discrimination and racism	Economics and unemployment	Education	Environment - Natural and Built	Faith and spirituality	Food systems	Formerly incarcerated	Housing and homelessness	Immigrant health	Mental illness and substance use disorders	Older adult and caregiver health	Policy	Veteran's health	Violence and community safety	Solutions	Behavior change solutions	Behavioral health solutions	Civic engagement solutions	Funding solutions	Healthcare access solutions	Partnership solutions	Policy solutions	Program solutions	Role of communities in solutions
ABJ Services	- ¥	• ¥	● ¥	Ċ	ن •	ŭ	ā	ā	Щ	ш	• ■	Fa	Ъ	Fc	Ĭ	2	€	ō	Å	ž	ž	• SC	• •	Bé	Ö	цц	Ĭ	P	<u> </u>	e Pr	u de la constante de la consta
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Alinity Community Services	-	•	•		•	•		-	-	-			•				•	-			•	•		-		┝┻┤			–		•
Asian Human Services Family Health Center	•	•	-	•	•	•		•			•	•	•			•	•		•		•	•			<u> </u>	──	•	•			
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Chicago Public Library - Jefferson Park Branch	•	•		•	•	•	-		•	•	•	•	•		•	•	•	•	•			•		•	Ē	┝─┦	┢──┤	\vdash	•	•	•
Chicago Public Library - Oriole Park Branch	•	•		•	•	-			•	•	•	-	•		•	•	•	•	•		•	•		-	•	++			-	-	-
Chicago Youth Programs	•	•	•								•		-		-		•	-	-		_	•				++					
CJE SeniorLife	•	•				•	•	•		•						•		•				•				•	•	•	•	•	
Evanston General Assistance	•	•		•	•		•		•		•		•	•	•	•	•	•	•		•	•		•	•	1 1	•	•	•	•	•
Friedman Place	•	•			•	•	•	•			•		•						•		•	•			•		•	•	•		
Frisbie Senior Center	•	•									٠		•				•	•				•			•					٠	•
Gary Comer Youth Center	•			٠	•	•			•		•		•		•		•		•		•	•	•		•						•
Hanul Family Alliance	•	•			٠								•				•	•				•				•		•			
Housing Forward - Tenant's Club Meeting	•	•	•	•		•	•	•	•	•	•	•	•		•		•		•		•	•			•		•	•		•	•
Maine Community Youth Assistance Foundation	•	•		•	•	•				•	٠						•				•	•					•				•
NAMI Chicago Family Members	•	•		•	•	•			•	•			•		•		•	•	•		•	•		•	ļ'	•	•		•	•	• •
NAMI Chicago Individuals	•	•		•	•	•		•	•		•	•	•		•	•	•		•		•	•		•	•		•		•	•	
New Moms	•	•		•					•	•	•		•		•		•				•	•			ļ'		•	•	•	•	•
Northwest Side Housing Center	•	•	•	•	•				•	•	•		•		•		•	•			•	•			ٰ ا	<u> </u>		<u> </u>	•	<u> </u>	
Oak Park River Forest Food Pantry	•	•		•	•	•	•			•	•		•				•	•			•	•			•		•	•		\square	•
PLOWS Council on Aging	•	•				•		•	•	•	•		•		•		•	•	•			•		•	•	•	•		•	\square	• •
Restoration Ministries	•	•		•	•					•	•		•			•	•		•		•				'	<u> </u>	<u> </u>	<u> </u>	<u> </u>	<u> </u>	
Rich Township VFW Post 311	•	•		•	•	•		٠	•	•					•		•		•	•		•			•	•	•	•	•	<u> </u>	•
Solutions for Care	•	•	-		<u> </u>	•					•	•						•	•		•	•			<u> </u>	•	•	•	<u> </u>	•	• •
Southwest Organizing Project	•	•		•	•	-			•		•		•		•	•	•	•	-		•	•			•	•	⊢ _′	•		└── '	•
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Theace Goldsberry Community House Parents	•	•	•	•							•						•					•			'	──	•	└── ′	—	•	
Theace Goldsberry Community House Youth	•	•	•		•												•					•		•	'	_┘	\vdash			•	•
Timothy Community Corporation, TCA Health Inc		•	L	L	•	•	L		L		L	•	•				•					•			'		•	•	L		•

Figure 9. Summary of major topics discussed in Learning Map Sessions

	Access to community resources	Access to healthcare	Child and adolescent health	Chronic disease and health behaviors	Community cohesion	Discrimination and racism	Economics and unemployment	Education	Environment - Natural and Built	Faith and spirituality	Food systems	Housing and homelessness	Mental illness and substance use disorders	Older adult and caregiver health	Violence and community safety	Solutions	Civic engagement solutions	Partnership solutions	Program Solutions	Role of communities in solutions	Communication and community voice
After School Matters (2 Groups)	•	•				•	•	•	•		•	•	•		•	•				•	
Alivio Medical Center		•	•	•							•		•		•	•				•	•
AMITA Saints Mary and Elizabeth Medical Center						•	•	•			•	•			•				•		
Breakthrough	•				•		•	•				•	•		•	•	•			•	•
BUILD, Inc.		•					•	•			•		•		•						
By the Hand		•		•		•	•	•			•		•		•						
Coalition of Hope	•	•					•	•		•	•	•	•			•	•	•		•	•
CristoRey High School			•					•													
El Valor				•	•	•		•	•		•	•	•		•	•	•				•
Enlace Chicago		•	•			•		•			•	•	•		•	•		•	•	•	
Deborah's Place	•			•	•		•		•				•			•					
Garfield Park Community Council	•	•		•		•	•	•			•	•	•			•		•		•	•
Greater Galilee Baptist Church	•			•			•	•	•		•	•	•		•	•		•		•	
Habilitative Systems		•	•	•			•		•		•		•	•	•	•				۲	
New Moms (Learning Map Session)	•			•		•	•	•	•		•	•			•	•		•		•	•
New Morning Star MB Church (2 groups)	•	•		•	•	•	•	•	•		•	•	•		•	•				•	•
Oakley Square Apartments (3 groups)	•	•	•	•			•	•	•		•	•	•	•	•	•		•		•	
Saint Stephen AME	•					•	•	•			•		•		•	•				•	
Temple of Faith MB Church				•	•		•	•	•		•	•				•		•			
UCAN (Community Residents)	•	•	•	•	•		•	•	•		•	•	•		•	•					
UCAN (Youth)	•		•	•		•	•	•			•	•	•		•	•					•

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