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SCHOOL OF SOCIAL WORK

# Children's Mental Health Initiative 3.0 Evaluation: Implementation Year Two Site Visit Report

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# Table of Contents

# 1. Introduction and Background

## 1.1 Overview of the Children's Mental Health Initiative 3.0

In 2021, the Illinois Children's Healthcare Foundation (ILCHF) awarded implementation grants to five Illinois communities to build children's mental health systems of care (SOC). These grantees were the third cohort of communities to be provided funding under the Children's Mental Health Initiative (CMHI) funding umbrella and are therefore referred to throughout this report as the CMHI 3.0 cohort. ILCHF uses the definition of SOCs developed by Stroul, Blau, and Friedman (2010): "a spectrum of effective, community-based services and supports for children and youth with or at risk for mental health or other challenges and their families, that is organized into a coordinated network, builds meaningful partnerships with families and youth, and addresses their cultural and linguistic needs, in order to help them to function better at home, in school, in the community, and throughout life."[1] Children and youth with or at risk of mental health disorders and their families need supports and services from many different child- and family-serving agencies. Often, such supports and services are provided in a fragmented fashion. By creating partnerships and integration among agencies and organizations, systems of care can better coordinate those services and supports to meet the ever-changing needs of children and families, with the idea of improving outcomes.[2]

Each of the CMHI 3.0 grantees had applied for ILCHF funding under the previous funding cycle in 2018. Although they were not selected for funding for the CMHI 2.0 cohort, they were invited to reapply during the next funding period in 2019. All five sites received funding for a four-year period from January 2021 through December 2024. Unlike the 2.0 cohort, which received funding for a one-year planning period, there was no designated planning period for the CMHI 3.0 grantees. It was anticipated that the sites would be able to utilize the local infrastructures that were developed to apply for the previous CMHI funding to begin the SOC planning and implementation process more readily. The funding proposals required each site to specify a well-defined set of goals, an organizational structure, a financial model, and a plan for sustainability. Although ILCHF expects that funded projects will be unique to each community, it required implementation plans to be consistent with the Child and Adolescent Service System Principles (CASSP) outlined by Stroul, Blau, and Friedman (2010):[3]

[1] Stroul, B.A., Blau, G.M., & Friedman, R.M. (2010). *Updating the System of Care Concept and Philosophy.* Washington, DC: National Technical Assistance Center for Children's Mental Health, Georgetown University Center for Child and Human Development.
[2] Illinois Children's Healthcare Foundation. (2019). *Children's Mental Health Initiative 3.0 Targeted Invitation for Applications.* Oak Brook, IL: Author.
[3] Stroul, et al. (2010), ibid.

1. Family driven and youth guided, with the strengths and needs of the child and family determining the type and mix of services and supports provided.
2. Community-based, with the locus of services as well as system management resting within a supportive, adaptive infrastructure of structures, processes, and relationships at the community level.
3. Culturally and linguistically competent, with agencies, programs, and services that reflect the cultural, racial, ethnic, and linguistic differences of the populations they serve to facilitate access to and utilization of appropriate services and supports and to eliminate disparities in care.

ILCHF also required that CMHI 3.0 sites impact 11 outcomes related to effective service systems and child and family well-being:

1. Early identification of children and youth for whom there is concern about possible mental health disorders.
2. Increased capacity in the service system to provide families with evidence-based clinical interventions.
3. Increased parent/caregiver/youth 'peer' provided services and leadership in the local system of care.
4. Effective local use of outcomes measurement data to inform operations and changes in the system, including sharing data between service provider systems.
5. Understanding the costs of service provision.
6. Increased service integration among service providers in the community.
7. Development of a well-prepared mental health workforce.
8. Improvement in life domain functioning for children with and at-risk of serious emotional disturbance; including school participation and academic success variables.
9. Strengthened parenting practices and caregiver-child relationships.
10. Reduction in caregiver related stress for parents/primary caregivers of children with mental health disorders; reduction in parental depression.
11. Reduction in unmet basic needs of families participating in the mental health service system.

Finally, CMHI 3.0 sites are required to commit to having 25% consumer (youth, parent, caregiver) representation in their community implementation teams.

## 1.2 Overview of the CMHI 3.0 Evaluation

The Children and Family Research Center (CFRC) at the University of Illinois at Urbana-Champaign has partnered with ILCHF to design and conduct a comprehensive evaluation of the CMHI 3.0 at each of the five sites. The evaluation has several components, some of which are adapted from those utilized in the national evaluation of the Children's Mental Health Initiative (CMHI).[4] The components of the CMHI 3.0 evaluation include:

- An *implementation study* to document the processes that are used to implement systems of care in the five communities. The sustainability of the system of care implementation efforts will be assessed toward the end of the evaluation period.
- A *system of care fidelity assessment* to examine whether the five communities implement services in accordance with the system of care principles outlined by CASSP.
- A *descriptive study of the children and families* served by the systems of care in the five ILCHF-funded communities. In the descriptive study, information is gathered at intake about the demographic characteristics, living arrangements, child and family risk factors, presenting problems and clinical diagnoses, functional status, and mental health service histories of the children served in the systems of care in the five communities.
- A *descriptive services study* to describe the types of services used by families, their patterns of service use, and their satisfaction with services.
- A *longitudinal outcome study* to assess change over time among the children, youth, and families participating in systems of care services in the five communities. Information on a variety of outcomes will be collected from caregivers at intake and at regular intervals for 24 months following intake. In addition, information on system-level outcomes will be gathered from a variety of stakeholders in the annual stakeholder survey.
- A *cost analysis* to assess the costs associated with system of care services.

## 1.3 The CMHI 3.0 Implementation Evaluation

The purpose of the implementation evaluation is to describe the activities that are undertaken to implement children's mental health systems of care in each of the five sites over the 4-year implementation period. A combination of qualitative and quantitative data collection methods will be used for the implementation evaluation. Qualitative data are collected during site visits in each of the five CMHI 3.0 communities. During these site visits, CFRC conducts focus groups with service providers, parents/caregivers, youth, community planning teams, and other key stakeholder groups. Site visits also include individual interviews with project directors and other staff/stakeholders with essential knowledge about the implementation of systems of care in the five sites and a review of documents such as strategic plans and implementation progress reports. The goal of the site visit data collection is to provide more in-depth descriptions of the

[4] ICF Macro. (2011). *The Comprehensive Community Mental Health Services for Children and Their Families Program Evaluation Findings – Annual Report to Congress.* Washington, DC: Center for Mental Health Services, Substance Abuse and Mental Health Services Administration, U.S. Department of Health and Human Services.

activities and processes that are being employed in each site to implement the goals of each system of care, as well as to document successful strategies for and barriers to implementation. In addition to the qualitative data that are collected during the site visits, quantitative data on implementation will be gathered through an annual stakeholder survey that contains questions related to implementation activities and their effectiveness in producing change in the systems of care in the communities.

This report provides information from the site visits conducted in each of the five sites during the second year of implementation. The report provides information to address the following topics and questions:

1. During the interim year before the sites received funding for the CMHI 3.0, did they continue to engage in system of care planning and implementation activities, and if so, what did this look like?

2. What are participants' understandings of their sites' major goals and activities aimed at changing or improving the children's mental health system of care?

3. What progress has been made in implementing children's mental health systems of care during the first two years of implementation?

4. What are participants' perceptions of how parents and youth have been involved in SOC implementation efforts?

5. How did participants describe the implementation infrastructure and processes that guided and supported implementation?

6. What were participants' perceptions of barriers to implementation?

# 2. Methods

## 2.1 Site Visit Participant Recruitment

The evaluation team contacted the project directors in each of the five sites to obtain a list of community stakeholders and parents who were involved in the system of care implementation in their site. These individuals were sent email invitations to participate in a focus group or interview. These recruitment emails described the purpose of the focus groups and included an informed consent form so that participants could review the information prior to the meeting. Parents and youth[5] were offered a $50 Amazon gift card as an incentive for participation in the focus groups. Table 1 shows the number of community stakeholders, project staff, parents, and youth who participated in the focus groups or interviews at each site.

Table 1. Number of Participants by Site

| | Building Relationships - Generationally Effective Systems | | St. Clair County Youth Coalition | | Youth Empowerment Services | | Youth Mental Health System of Care | | Greater Peoria Area Youth Mental Health Initiative | |
|---|---|---|---|---|---|---|---|---|---|---|
| | Invited | Participated | Invited | Participated | Invited | Participated | Invited | Participated | Invited | Participated |
| Parents | 8 | 1 | 6 | 3 | 0 | 0 | 15 | 4 | 4 | 2 |
| Youth | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |
| Project Staff | 8 | 6 | 2 | 2 | 2 | 2 | 4 | 4 | 3 | 3 |
| Community Stakeholders | 30 | 4 | 9 | 5 | 17 | 6 | 18 | 7 | 11 | 4 |
| Total | 46 | 11 | 17 | 10 | 19 | 8 | 37 | 15 | 18 | 9 |

## 2.2 Data Collection Procedures

All data collection procedures were reviewed and approved by the Institutional Review Board at the University of Illinois at Urbana-Champaign. Prior to each site visit, the research team reviewed existing documents related to the system of care in each of the sites, including the initial implementation grant applications and 6-month implementation progress reports required by the funding agency.

Participants for the study were recruited from each site using a purposive method targeting key stakeholders in each system of care. Project Directors from each site provided the research team with a list of individuals to include in the recruitment for the site visits, based on their involvement and ability to report on SOC implementation to date. The team contacted stakeholders on the list via email to offer the opportunity to participate in either a focus group (professionals and service providers, youth, and parents) or an interview (project staff) to provide their perspectives. The option for Spanish materials and data collection procedures was made available. Stakeholders then self-selected for participation.

[5] All youth were over 18 and could therefore provide informed consent.

The focus group and interview protocols were developed by the research team to assess a range of topics related to system of care implementation. The semi-structured questions that were asked are included in Appendices A, B, and C. The focus groups and interviews took one to two hours to complete. They were all conducted virtually using Zoom videoconferencing by researchers from the Children and Family Research Center during the period of October 2022 – January 2023. All interviews and focus groups were recorded and transcribed for analysis. Informed consent was verbally obtained for each focus group and interview prior to starting the recording and participants were provided with a copy of the consent form in advance.

## 2.3 Data Analysis Procedures

Team members checked each transcript for accuracy, removed identifying information, and uploaded transcripts to qualitative analysis software ATLAS.ti (version 23), grouping the transcripts by site. Team members coded each transcript using a priori codes that were created to correspond to each of the research questions. Sections of the transcripts could be coded with more than one code; for example, one quote could be coded as both an activity and parent involvement.

The team then generated code reports from ATLAS.ti for the purpose of second-level coding for subthemes. The code reports were analyzed for appropriateness of the coding and for patterns that emerged within each category that would offer additional nuance and insight. Once these subthemes were established, we organized the findings around participant quotations that illustrated each theme. The first round of coding utilized a shared set of a priori codes while analysis within each of those codes occurred through an emergent process for each site's data. This allowed for data to be understood within the original research questions as well as for subthemes to grow from each site. After conducting analyses and identifying findings for individual sites, the research team sent drafts of each site's report to their project directors and asked them to inform us of any inaccuracies. The team discussed the findings across all five sites to determine similarities, differences, and implications related to the research questions.

It should be noted that efforts were made when possible to protect the confidentiality of individuals and organizations in the report

## 3. Results – Building Relationships - Generationally Effective Systems (BRIDGES)

Building Relationships - Generationally Effective Systems (BRIDGES) is a system of care developed by Rush University Medical Center (Rush) and its partners on Chicago's West Side. According to the 2020 U.S. Census, Cook County has a population of 5,275,541. The largest city in the county is Chicago, which has a population of 2,746,388. In 2021, the median household income in Cook County was $72,092. 13.8% of people the county live below the poverty level, which is higher than the state average of 12.1%. Additionally, 18.5% of children(18 years and below) in the county live in poverty.[6] In terms of race and ethnicity in the county, 42% of the population are White (non-Hispanic), 22.9% are Black or African American (non-Hispanic), 12.4% are White (Hispanic), 9.3% are Other (Hispanic), 7.4% are Asian (non-Hispanic), and 2.9% are multiracial (Hispanic), 2.1% are multiracial (non-Hispanic), and 1.0% have another racial-ethnic designation.[7]

The SOC is contextualized by and responsive to documented needs in the community. Rush's 2022 Community Health Needs Report and Action Plan[8] highlights some of the social and health-related challenges in the service area. Life expectancy for people living in East Garfield Park, a West Side community that is 85% Black is 66 years compared to 80 years in an affluent, primarily white community just 4.5 miles east. As indicated by the Hardship Index Map included in the report, communities that are primarily Black and Hispanic/Latino fall in the moderate or high categories. Additionally, in communities that are primarily Black, the percentage of mothers who receive "good" prenatal care is lower than the overall rate of 65% for the City of Chicago.

Rush University System for Health is an academic health system located in Chicago with a mission of improving the health of individuals and diverse communities via the integration of patient care, education, research knowledge, and community partnerships. Rush places emphasis on identifying and addressing barriers to health and promoting health equity. Rush, in partnership with COFI (Community Organizing and Family Issues), a community-based organization that works to build capacity, leadership, and voice for low-income parents, are the grantees, with Rush serving as administrative authority for the grant.

As stated in their grant application, the goal of BRIDGES is the development of a sustainable multi-generational system of care for children ages 0-5 years and their caregivers. Another focus of the proposal was that the SOC serve caregivers experiencing trauma-related distress using a family-centered, trauma-informed approach. According to the proposal, Rush, COFI, and community partners planned to implement a public health model with the aim of identifying children in the target age range and their caregivers who are trauma-impacted and/or are

[6] Census profile for Cook County, IL: https://data.census.gov/profile/Cook_County,_Illinois?g=050XX00US17031
[7] Cook County DataUSA: https://datausa.io/profile/geo/cook-county-il
[8] https://www.rush.edu/sites/default/files/chna-chip-2022.pdf

experiencing mental health concerns, and to coordinate and facilitate early access to care. Highlighted strategies included home visiting programs, use of pediatric integrated behavioral health screening and early identification, addressing social determinants of health, centralization of operations, enhanced collaboration, and engagement of parents in service design and evaluation.

Staff employed by Rush and funded by the grant include the full-time Project Director as outlined in the grant application. Others on Leadership Team are also funded at levels of 5-10% FTE by the grant and parents and community partners with formal agreements receive remuneration for time spent working on implementation of the SOC. As agency leader for BRIDGES, the first Project Director devotes 20% effort supported in-kind by Rush entailing "co-leading the Community Planning Team in up to 10 meetings over the course of the planning grant year, and engaging BRIDGES partners and related community health partner initiatives through sustained participation, development and collaboration in planning meetings as appropriate" according to the site proposal. As planned, Rush recruited a second project director to operate BRIDGES within the division of Community Behavioral Health, devoting 100% effort to BRIDGES operations including planning and coordinating meetings, engaging health partners, communicating with partners, and coordinating implementation.

A total of 13 individuals participated in the site visits including both people defined as project directors employed by Rush and one parent from COFI. The remaining participants were either Rush staff or community-based providers. Disciplines and service types represented included social work, pediatric medicine, psychology, and family support organizations.

## 3.1 Pre-grant Activities

Rush submitted an unsuccessful application for the Illinois Children's Health Foundation's CMHI 2.0 initiative, and later applied for and received funding as part of the CMHI 3.0 cohort. Site visit participants were asked about the activities undertaken during the interim year between receiving feedback for the unfunded 2.0 application and reapplying for the 3.0 cohort. Questions were aimed at how feedback from the first proposal was integrated and how that interim year was utilized for SOC planning.

Stakeholders described the impact of feedback from ILCHF for revisions made for the 3.0 application:

> *…the foundation felt that the first proposal was like too already baked. It was a very much a Rush-focused proposal. And there wasn't a lot of input from families. And so the Rush team that was working on that really took that to heart, and tried to figure out how they could sort of pull back, and be open to input from actual consumers, as you might say, or the people who were likely to be in the population being served. And then, I think, the other big piece was trying to understand more the idea of a system of care, and that all these different people could be brought together to serve this age group.*

*And so, there was a lot more effort to sort of de-center Rush and focus more on the system itself.*

During the interim year, there were intentional efforts toward community outreach, family involvement in planning, and co-creation of a new proposal. Relationship-building, listening, and mindful attention to an emergent process of goal setting were at the center of those efforts. Additionally, COFI (Community Organizing for Family Issues) became a more significant partner in the work; participating parents are members of this organization, which has chapters in various locations in Illinois to empower participants to create positive change. The partnership is relatively new, and the parents do not necessarily represent children accessing mental health services currently, but they do represent the caregiver and community perspective. These efforts were perceived as having a positive impact for the network of agencies and individuals who participated in the visioning process:

*We created not only some deeper partnerships with those agencies, but a monthly standing meeting where we're able to connect and talk about referrals that have been made, specifically from Rush to some of these home visiting agencies. I think we really worked on the Rush side, on developing those partnerships that would later go on to be a huge foundation of the 3.0 application for BRIDGES.*

The process led to a shift to co-apply for funding with COFI rather than as Rush University Medical Center alone. A project leader shared:

*And one of our partners said, why aren't we co-applying with COFI? And it was like the biggest ah-ha moment, right? And so silly that we didn't just all collectively say like oh, and now this time, let's apply with COFI, right…And the leadership of COFI all really laid the groundwork for what that application was all about.*

A capstone of the collaborative visioning efforts was "Design Day" where community members and early childhood providers came together to envision the future design of their system of care:

*During Design Day, we had a couple of our parents participate…and that really fueled the energy back in terms of COFI with our parents, and their kind of commitment to this work. And so, it was a pretty successful event in terms of bringing in community members to brainstorm and vision together. And I think that was pretty powerful for our parents… some really great questions… were posed to the group like, what's going to happen 20 years from now if we do nothing different than what we're doing today? And so, what do what we want in 20 years instead of what we have now, and then how do we get there? …. And there was a real diversity of people in the room. And I feel like the folks that wrote the first grant really went into that day listening to figure out how to revamp what they were proposing in the next proposal.*

## 3.2 System of Care Goals

Site visit participants were asked about the goals and values that underlie the BRIDGES SOC implementation. Goals included employing an intergenerational trauma-informed approach; grounding provider training and service in the relational perspective; meaningful family inclusion and leadership; increased access to services/reduction of barriers to access; consistent and coordinated early intervention; addressing social determinants of health; and creating system-wide culture shift toward these aims.

> *Our goal for BRIDGES is to help families with young children zero to five. So pregnant and parenting families, that is our focus. Specifically, those who have experienced trauma, our goal is to help them heal from trauma by connecting them to services that they might need, connecting them to social support services, peer-to-peer support services, and overall, helping to identify and remove the barriers to care.*

One focus is the application of a trauma-informed framework and evidence-based strategies for reducing the impact of trauma. One participant stated, "*I think one of the goals is to establish a trauma-informed system of care for families on the West Side, that really starts prenatally, even from before conception through early childhood.*" Another participant elaborated on this goal, also noting the evidence-based practice goal:

> *We want to, identify those pregnant and parenting individuals in our communities who themselves have experienced childhood trauma. And then link them to the supports that could help support building healthy and strong relationships. So, aka evidence-based home visiting and doula services…we actually do have evidence that evidence-based home visiting disrupts the intergenerational cycle of trauma and violence.*

BRIDGES partners share a broader lens on family and child well-being that recognizes the importance of social determinants of health and:

> *…the need to address the life expectancy gap that we see in our city and, and many segregated cities like ours have a similar life expectancy gap. The need to address the social and structural determinants of health in order to reduce that gap. And when we had some leadership buy-in to say yes, you know, pediatrics and maternal child health should be part of this effort.*

Participants also spoke widely of using a trauma-informed framework with an intergenerational emphasis:

> *Children are in a larger environment and to interrupt the influence of trauma across generations, there has to be equal attention to the fact – the parent's needs as well as the infant and child's needs.*

Another important goal articulated by a community partner was the reduction of barriers and enhancement of access to needed services:

> *And then I think also like really thinking about ways to overcome barriers for families, I know that that's a lot of our involvement. Being able to work direct service with the families through home visiting programs, we're able to provide a lot of that insight on the barriers to service and things like that. So, I know that that's a big goal of BRIDGES is to also be able to understand what some of those barriers are, and how we can work systematically as a team and as a community to overcome some of that.*

The foremost value for developing the system of care was the relational approach, both in providing service (the mother-child dyad, importance of secure attachment) and building the system (between professionals, partners, families, communities). Values inherent to a trauma-informed model are also consistent with a relational approach, for example safety, collaboration, and shared voice. Professionals elaborated on the relational approach:

> *…we articulated those two elements, support and understanding, as being values that drive healthy relationships as well. Secure attachment is the other big one. Which is, again, a really big part of the concept of relational health is that healthy mental health is grounded in strong relationships. Which means secure attachment to one another.*
>
> *How are we going to bring back the trust and, in the components of the system, is a really big and hard question. But it starts with relationships. And so, we really have to double down on these relationships we have with each other and our Community Planning Team and with our families. COFI, that has with their communities. Our communities. And we really, we do believe that if we uphold strong relationships with each other, that it can then be reflected in the system of care that we're hoping to strengthen and support.*

Another community partner also discussed the connection between the trauma-informed approach and a relational model:

> *The other level or layer there is that whatever we decide to strengthen, support or implement must be trauma-informed. And the larger definition that we're really going for in trauma informed is it has to be grounded in strong and healthy relationships. …having strong infant, early childhood, maternal, paternal, and family mental health is possible only through strong relationships with each other. And so, anything that we support, strengthen or implement has to be grounded in the approach of relational health, which is by definition trauma-informed.*

The creation of an SOC that is family-centered was also discussed as a key goal:

> *… there's a few very important anchors. One is family centeredness, which means the family is of the center of anything that we think is appropriate to support in the system*

*of care or strengthen in the system of care. … we have to reflect on and understand whether or not a family can benefit in a way that is meeting their needs.*

Overall, participants communicated a shared emphasis on family-centeredness and bottom-up system-building which in turn begins to create a context in which there can really be shared power, authenticity, and the construction of shared experience.

## 3.3 Activities and Progress Toward Goals

Participants were asked to discuss activities they have engaged in meet their goals. We also consulted a PowerPoint presentation that BRIDGES developed to present its 2022 activities.[9] Efforts toward networking and resource sharing have been important to the system-building elements of implementation. Additional activities have involved development and delivery of direct services for the target population, professional training for providers, and COFI training for professionals and parents.

**Community networking and resource sharing.** Related to the goal of increasing access to services and reducing to barriers to access; one of the barriers interviewees talked about was simply being unaware of all the relevant services and resources in the community. The resource sharing and networking that was described highlights news and information for and from both parents and professionals; one project director explained how monthly SOC community planning team meetings have provided a useful forum:

*I would say that's been a big accomplishment of that meeting is expanding the network in the system and making us all more aware of all of these great services that exist to support the families that we work with. We do that, we also almost always, this is a new thing this year, we always have a spotlight from the parents, so we all get to keep up to date with what parents are doing in their communities to further the work.*

To promote networking, the BRIDGES CPT monthly meeting regularly features what they call the CPT Spotlight. This highlights a new or little-known program or service that benefits families with children age 0 to 5 in their service area. Staff from the spotlighted program have time on the agenda to describe their service and solicit referrals from larger, more established programs on the CPT. BRIDGES' hope is that other programs will become familiar with the little known program and refer their families to it. Two examples of programs in the CPT Spotlight in the past year were a home visiting program and a pro bono speech and audiology program.

**Direct services.** Several examples of direct services were discussed. These include Survivor Moms Companion; the Smooth Way Home NICU project; and patient navigation services. Survivors Mom Companion is an established one-on-one intervention implemented in multiple locations across the country (see survivormoms.org). It trains professionals to work with

[9] BRIDGES. (2022) *BRIDGES: Building Relationships Generationally Effective Systems.* Presentation. Chicago, Rush University Medical Center.

trauma-impacted pregnant and parenting women. BRIDGES is the first project to implement it by training COFI parents to provide the intervention, reflecting the COFI value or providing peer support. One project director described:

> *I think from that, one of our other successes has been really trying to address barriers to care through the integration of community member and professional voice. From that we have developed programs like Survivor Mom's Companion, which is a peer-to-peer support program that we now offer across our entire System of Care.*

Focus group participants offered additional insight on the intervention, highlighting its connection to SOC goals of trauma-informed care and enhanced service access:

> *Survivor Moms is not a traditional mental health intervention. These are interventions we chose specifically because we wanted a more universal approach to healing and care than the traditional mental health system approach…*
>
> *Survivor Mom's Companion is one, that's our peer-to-peer service. It's a psychoeducation intervention for pregnant people who have symptoms of PTSD, and it is delivered peer to peer. The meetings* [of COFI parents trained to provide the intervention] *that they have every week are not just, hey parents, how are you doing? Do you need any support with your clients that you're working with? They are also, how is the program working? Do you have any suggestions for how to make it work better?*

One of the COFI parents trained to implement Survivor Moms provided a helpful description based on her experience:

> *I'm also in Survivor Moms. That's under the umbrella of BRIDGES. So that's like another pilot that's helping mothers that are pregnant or had a baby, when they're pregnant and trauma…we teach them to cope, to how to deal with it. That's kind of women's health. So, like something will trigger them. And so, we're teaching them different modules.*

BRIDGES reported that it trained 19 individuals in SMC in 2022, including four COFI parent leaders. The program has provided the intervention to two mothers, with one completing the entire program. BRIDGES had been developing plans to provide Survivor Mom in conjunction with a home visiting program at Marillac St. Vincent Family Services, but they have not been able to recruit mothers for the intervention; in part, their plans have been disrupted by staff turnover at Marillac.

Smooth Way Home is an intervention to help families whose child is in the Neonatal Intensive Care Unit, to assist them with the transition from NICU to home through the support of infant mental health specialists. According to the progress report available during data collection, Smooth Way Home specialists have helped 29 families in the hospital and during their transition home.

BRIDGES also supports services provided by a patient navigator, who helps assess the social needs of pregnant and parenting families, discuss available and relevant family support services in the community, and provide referrals to the SOC when indicated. The patient navigator is housed at Rush but BRIDGES support has expanded her ability to receive referrals from community partner agencies. The BRIDGES navigator uses both a web-based resource platform (NowPow) to send closed loop referrals to partner home visiting agencies (and other social need supports), as well as email \when needed. As of the end of 2022, the BRIDGES navigator received 79 referrals and served 37 families.

**Training and professional development.** Through education and training, BRIDGES is equipping professionals with different knowledge as well as building support for their SOC values, and in turn, a commitment to partnering in service delivery and system change. A priority has been providing Circle of Security, an evidence-based training that supports early childhood professionals in viewing a child's needs through a relational, trauma-informed lens (https://www.circleofsecurityinternational.com/). BRIDGES has used ILCHF funding to pay the costs of enrolling participants in COS for over 60 trainees. BRIDGES has also provided Circle of Security training to home visitors from community partner agencies and four COFI parents. One project director talked about the importance of training to bring about the system-level changes they hope to see:

> *We don't necessarily need to reinvent the wheel when it comes to what's available, but instead train the existing workforce in models that are going to be much more relationship oriented. Then make sure we know about each other and that we're linked, and that we're able to seamlessly refer families back and forth without them falling through the cracks.*

The success of the trainings so far and the fit with BRIDGES' goals and values has made Circle of Security a key element of SOC implementation as a pathway for centering a relational paradigm:

> *In terms of workforce training, our plan has become to use Circle of Security as our training model and to disseminate that to our partner agencies and within Rush. To have a bigger net of providers who are trained in this very specific, relationally-focused framework for thinking about child behavior. That is a strategic plan that came from this goal of developing a workforce that is more focused on relationships, as opposed to individual child behavior.*

True to BRIDGES' value for family participation and shared power, both professionals and COFI parents have received the Circle of Security training:

> *Somebody brought up Circle of Security, hey, this is this thing that I've done and have training and it's really great. I think it fits these values and goals that we have, so we all got trained in it. That was something that we did during our planning year, just to okay, how do we feel about it? Do we like it? Do we not like it? How does it feel for us as a*

*leadership team? We did like it we did feel like it fit with our values. Then we started offering it to people in our community planning team, to see if they also felt that way, that it was consistent with our values and our goals. We got really good feedback about it, and now feeling that we have the buy-in from COFI, we've had a couple COFI parents go through the Circle of Security training. We've had two, three of our home visiting partner agencies have staff go through the training, and then our whole leadership team has been through it. We now have buy-in from all of those different groups at the table.*

Another experience that many participants talked about was participation in COFI training, a three-tiered training model that unfolds over the course of months and provides tools, strategies and supports for parents (or in this case, professionals as well) to become more empowered to impact their own lives and communities. One person shared that:

*Our entire leadership team also went through that first COFI training, the — family and team training. One, because we wanted to get to know the model a little bit and have experience with it. But I think two, it's a personal development and professional development tool as well so we've all gone through that.*

Another participant also discussed the "COFI Way" training and how it is an effective foundation across the roles that people may play in the SOC:

*So much of it is listening and talking. Essentially just listening and talking until we're able to get to a mutually kind of agreeable standpoint…The leadership team all took the COFI Way training…which is if you are an organization or institution who wants to work with parent leaders, take our orientation to the COFI Way, so that you can better learn how to work with parents. So all of us went through that training in two sets…The COFI Way is all about who you know, when you have a goal that you have set for yourself …you have built an understanding of who is your web of support, who can help you with your goal, who might be a hindrance to your goal, and who is you know, who is sort of essential to your advancing that.. how is it that you can work with your web of support in order to achieve and advance your goals?*

## 3.4 Implementation Structures and Processes

Another area discussed in site visit interviews and focus groups related to the structures and processes that have been developed in support of SOC implementation.

**Organizational structures.** A wide range of disciplines are represented among BRIDGES members and stakeholders who participate at different levels and in varied ways. The Leadership Team is the core set of individuals from Rush and COFI including pediatricians, psychologists, family support specialists, and social workers. The wider Community Planning Team includes pediatricians, mental health professionals, psychologists, social workers, home visitors, doulas, patient navigators, Early Intervention service coordinators, and other professionals, initiatives and policy specialists serving the early childhood system spanning

prenatal to age 5. COFI parents also hold their own meetings and work with the other teams. Participating partners serve the relevant geographic area in Chicago and have an early childhood/early intervention focus. Participants further discussed the process of gathering SOC members and creating the structures through which implementation will occur:

> *I think that everyone, all of our people who are our leadership team, have such strength, like strong relationships in the community. COFI, again, super instrumental. We couldn't do anything without them.*

As reflected below, the strength of existing and newly forged relationships among Rush, COFI, early childhood providers and the community have been instrumental to implementation:

> *…relationships that people have built…in their current positions in prior projects and prior activities. I think that's what's helped us bring all kinds of different voices to the table.*

The Leadership Team serves a number of functions, according to site visit participants. A few key elements are described:

> *The role…of the Leadership Team is not in any way to control what's coming out of the Community Planning Team meetings, but it is to, number one, plan for sustainability. And, number two, think systemically. So we're thinking about how does everything coming out of the Community Planning Team impact the system as a whole, as we're making changes to how we are all working together, if that makes sense to move forward with this target of interrupting multi-generational trauma within families with young children.*

Other individuals described elements of how the Leadership Team functions as a smaller group than the Community Planning Team. The teams follow an iterative process in which the Leadership Team receives input from the CPT and COFI and then comes back to the latter group with new developments. The quotes below provide further explanation of the iterative process, including description of the smaller "debriefing" meetings that then feed ideas back to the Community Planning Team. These interconnected and relatively nonhierarchical groups engage in a back-and-forth process that meets the participation needs and capacities of diverse people. The structures described were designed in part to facilitate and support parent involvement:

> *Every time we have a CPT meeting, we have a debrief meeting the following week. Where we meet with a couple people from the leadership team, at least one or two parents who attend that meeting as well as some COFI staff members who are not part of the leadership team. During that debriefing meeting, we will take the time to collate the information that comes from the meeting. Let's say we had a sit down where we talked about the waiting list thing, we try to take notes during those meetings. The debrief meeting is a space to come back together and say, what did you hear? We'll make sure we got it all. That group really spends time thinking about okay, what are the*

*programmatic implications of this conversation that we've had? We'll spend some time thinking about what might be some good ideas that came from that meeting, and it's that conversation that I will then take to the leadership meeting and say, here are some things that we've distilled from the CPT meeting, what do you think about this? What do you think about that? That way, the parent voice is not just involved in the initial brainstorming process, but also the program development process as well. Then what will typically happen is, the leadership team we might think through an idea or come up with something, think through all the budgeting concerns and that kind of stuff or something like that. Well, then we'll tend to bounce it back to the CPT or a smaller group of parents and get some feedback before we proceed with anything. That way the leadership team is not the final say, we really want the CPT to be participating in every aspect, from brainstorming, to design, to implementation.*

Another individual further described the function of the Leadership Team, emphasizing gathering information from multiple sources and also planning for sustainability:

*The Leadership Team is really responsible for "Okay, we've got all this input from all these different stakeholders including parents, how do we want to steer the ship from here?" Where are we going from here? We're really trying to take all of the information that we're getting from the community and from our partners and making decisions about implementation during those meetings. Another big focus of those meetings has to do with systems sustainability.*

All active members of the Community Planning Team receive financial compensation for their work on the BRIDGES SOC implementation:

*We have a formal contract with them. Everybody who we have, letters of support from, we also have a formal contract with. Because we do support their participation in the CPT as well, using grant funds too, for their expertise and contributions. We also support our trainers, our Circle of Security trainers. We also support mental health specialists for our Smooth Way Home Program. That's a program currently in the Rush NICU helping families transition from the NICU to home.*

Participants also mentioned subcommittees that relate to the development of specific interventions or tasks (e.g., Survivor Moms). For example, several people mentioned a new subcommittee focused on preparing for policy and legislative advocacy work.

**Leadership.** Participants were asked to talk about leadership in the implementation of BRIDGES. They mentioned intentionally decentralized leadership structure and processes that create and support parent leadership. The role of parents as leaders will be discussed in more detail in Section 3.5 below. Participants talked about the importance of relationship-building for leadership. One focus group participant reflected:

> *…agencies remain really committed to the project, and … I attribute that to two things. One, [project director] has an incredible capacity for partnership building, and I mean develops relationships with people at these agencies. She's friendly with them, she has touchpoints with them outside of these meetings where she just is sending people information, or just remembering that they have events coming up and saying, "Hey, is there any way that we can join you in this effort?" I mean, she just really spent all this time building these relationships with these agencies that are really secure.*

The strength of a leader in building relationships is incredibly relevant in a system being built on a relational model of services for families.

**Communication.** Another question in both focus groups and interviews was about methods and adequacy of communication as part of SOC implementation. E-mail, virtual conferencing platforms and social media were mentioned as ways that BRIDGES-related information is communicated. For instance:

> [Leadership Team member] *routinely sends out what we call Bridges Blasts. And those are e-mail blasts to our CPT that are typically filled with different resources from each other…It typically goes out maybe once a month, or once or twice a month sometimes. We've created Bridges Bulletins, which are a quarterly bulletin of what the, what Bridges is up to. We have a website now as well, and so that is for both partners and parents.*

Another Community Planning Team member talked about perceptions of SOC communication and its role in maintaining her connection to implementation:

> *And I think as someone who doesn't go to those meetings, I feel like I get pretty regular kind of communication from key members of the BRIDGES team with just updates on like next steps or, you know, here's what we're thinking…they do a really a nice job of sort of keeping folks up to date on where things are.*

Overall, participants appeared to feel that the various types of communication about implementation elements have been adequate and effective. One individual stated, "*I think the frequency of the leadership committee meetings, which is once a month, seems like an appropriate frequency and, and communication has been adequate in my perspective*."

The BRIDGES teams were flexible in their means of communicating with family members; a project director stated:

> *Sometimes I'll just like screenshot somebody and send it to them, text message. And some participants yeah, we just hand them a paper copy, and so it's like every family is different…I remember the COFI parents being like, my car is so full of flyers and paperwork because we're always having stuff right on hand...*

Participants described some other activities related to communication within the SOC and among its stakeholders:

> *I guess even with our own Leadership Team, it's all virtual meetings. Because we're coming in from COFI and Commons and Rush and different departments within Rush, so. We did have a retreat, like a leadership team retreat earlier this year, that was in-person, hosted by COFI. And then we have our two Healing Together family fairs, and that was all, that was in-person as well. So, events like that where we can come together and communicate in person are, everybody's just over the moon, you know?*

**Decision-making.** Participants were asked about decision-making processes in BRIDGES SOC implementation. BRIDGES' mindfulness about representation and diversity has brought together many different perspectives, which may bring benefits as well as challenges to decision-making. One project director noted:

> *People [*are*] coming from different backgrounds. So, I think that everyone offers their expertise and their thoughts on how to approach a problem, or an issue, or a barrier. Honestly, I can't think of many disagreements that there have been, but there are different voices at the table. And so, I think it's helpful to have those voices and to work off each other's strengths to come to an agreement. I think COFI is really helpful in that they have a very strong voice…And so when the Rush folks or the other leadership team, if they have "clinician provider blinders" on, they will speak up and say, "Hey, like, wait a minute, like, let's look at the whole picture" or offer their voice. And that is super appreciated by everyone at the table.*

One project director delved a bit deeper into how decision-making roles and processes are rooted in BRIDGES collaborative goals and processes:

> *Any time we're going to choose something to be part of our system of care, it has to meet [our] values…the Community Planning Team are part of saying yes to something, because we won't really say yes to something if it doesn't meet those values*…[The] *leadership team really does the operational decisions, if you will. So, things like moving forward with a certain training…That kind of decision is something that we didn't have to take the whole decision back to the community planning team….I make decisions alongside the leadership team, but really, I do a lot of the decision making around like, do we have the budget support for this?…But the leadership team, we do our best not to serve as gatekeepers for projects that might arise from the community planning team. I don't really see that as our function.*

While this quote indicates that there are decisions made as part of the project director's role, it also demonstrates that those decisions are couched within a larger SOC culture guided by shared values. Another individual discussed the fact that more diverse teams with shared power and voice may take longer to make decisions:

*From my perspective, the Leadership Team collectively makes decisions. Sometimes…if there's something that we want feedback on, we typically would go to the Community Planning Team, and just kind of explore something together, or the parents, and get their input…And I think it takes a little bit longer, sometimes, because we do want to be intentional around getting people's perspectives. But it lives in the Leadership Team, in terms of here's the decisions that we have to make, and deciding on who we're asking, and where we're getting feedback before we move forward.*

**Use of data.** Participants were asked to discuss ways that data are utilized in SOC implementation and decision-making. One participant highlighted how BRIDGES is learning from data collected by COFI in a door-to-door mental health survey. As described by a project director, they have been able to read and reflect on the quotes provided from the survey and to take those perspectives into account as they plan:

*…during debrief and planning meetings, we're bringing those qualitative pieces from the CPT to inform how we're going to shape the direction we're moving in, with the system of care. One other example of qualitative data was when COFI recently did their statewide door to door mental health survey, and so they presented…their data from that meeting. And what that consisted of was the three main themes that emerged from their door-to-door survey*.

Additional data is being collected to evaluate the service interventions being implemented through the SOC:

*For Circle of Security training, we're doing an evaluation of that training. And that is, it's kind of like a pre and post evaluation. So, people who go through this Circle of Security training are shown a series of videos and given questions about the behaviors they're seeing in those videos, and reflections on them and things like that. And then at the end of the training, they're given the same set of videos. And I think maybe even the same questions…And then for Smooth Way Home, we actually have evaluation of the families who are participating in Smooth Way Home. And they were using two different scales, I think to evaluate parents who've been through that.*

Data is also collected through their Patient Navigator about how many families have been referred to and served by BRIDGES. BRIDGES also maintains data about the number of people trained in Circle of Security.

*We do track how many families have entered the BRIDGES system through our patient navigator at Rush. [Project directors] meet monthly with home visiting agencies to kind of discuss how many families have been referred by the BRIDGES system, and make sure that they are, in fact connected to the services that they need. We keep track of how many families have been served by us or by Survivor Moms' Companion, how many providers and clinicians, and now parents, have been trained in Circle of Security.*

**Other supports**. The BRIDGES SOC has made deliberate efforts to ensure that implementation teams and organizational partners reflect the cultural diversity of the neighborhoods they serve. In describing the nature of diversity in BRIDGES, one project director stated:

> *Number one it of course means diversity by experience…so for parent experience and making sure that there are parents at the table who have a diversity of experience, whether it means educational or neighborhood level, linguistically, or are parents or grandparents, right? Like that, all of that diversity among parent representation is important. And I think that we just leaned on COFI to tell us, right? Who are the parents who have a diversity of experience within our West Side communities? And those are the parents that they brought to the table.*

A focus group participant noted that attention to diversity happens within individual partner agencies which supports, in turn, inclusion efforts of the SOC:

> *I think each of the organizations pays attention to diversity, and therefore, the people involved. For the neighborhoods that we're serving represent that diversity, it's extremely diverse. And we haven't had to make a special effort because we were not diverse, because it's diverse from the start.*

In-vivo bilingual translation during meetings as well the availability of Spanish and English materials such as meeting agendas were used to support parent involvement and seek cultural competence. Several participants described those efforts:

> *It's not just the translation, it's that we are attentive to people from different backgrounds. So, you know, I think probably most of the people on the call do speak English, but the leadership team felt it was important to recognize that English was not the primary language of all participating.*

This commitment to linguistic competence has not been without challenges, as highlighted below:

> *It's not that we have to have…bilingual meetings, although we did try that early on and it felt very cumbersome and we kind of dropped it. But we do make sure all of our printed materials, flyers, anything, our meeting agenda, our meeting minutes, of all of the written material is in both English and Spanish.*

## 3.5 Parent Involvement and Leadership

Site visit participants were asked about how parents were involved in the SOC implementation. The Design Day discussed above is an example of how BRIDGES has built support, values, goals, and relationships inclusive of family stakeholders from the pre-grant stage forward. One site visit participant described the consistently high level of engagement that parents have in their implementation efforts:

*We have really good commitment I think particularly from COFI who makes up, I mean those parents are six to seven of that 30 every time we meet, and then COFI staff make up at least three to five additional folks. I mean they are a big part of the meeting, which is by design. We just have really great commitment from them as well as our home visiting partners and we're able to consistently keep our attendance pretty high, which is I think been really helpful for us.*

The partnership with COFI has been integral to the successful efforts of BRIDGES to integrate parent voice into the SOC implementation process. One participant describes how having COFI co-lead the project has allowed them to put parent voice at the forefront of all their planning efforts:

*I think what's unusual about this system of care compared to others, is that we've really – having COFI in a co-leadership role has also meant that we're putting parent voice and peer to peer central to what we do in a way that's different than traditional mental health services. And so, we're not in a mental health clinician to family relationship. We're in a how do we create a holding space for families in our communities that could be led by parents, but don't have to be led by clinicians. So, we have a different consideration that's part of that. It has really helped to be out of the box, thinking around the traditional mental health system, and having a parent leadership co-lead to really push on.*

Two participants described how the COFI training has helped develop parent leadership skills so that they have an equal voice at the table:

*BRIDGES has not…recruited a cohort of parents to take through these phases of training. We haven't done that. So, we haven't said we're going to bring in a group of parents, and train them to be leaders to change the system of care for children, zero to five. COFI does that work…the work of COFI is developing parent leaders, and those parent leaders go on to make whatever kinds of change they want to make in the world...We haven't brought in a bunch of people to say, hey, we want to change the zero to five system. We're going to bring in these leaders and take them through these levels of training.*

*[Parents] that we have participating right now at the Community Planning Team are in various levels of leadership, but almost all of them have been around for some time, and so have had the benefit of going through all three phases [of the COFI training], and then also having experience sitting with legislators or talking to the media and telling their story. And so, the idea is that, that word "movement" is that there's more parents out there. It's not just the seven or eight that are a part of this, right, that there's a lot more parents out there who maybe perhaps don't view themselves as leaders, but have a lot of insights into how the system is working or not working for them. And the more leadership we build, the louder that voice will be in terms of coming up with solutions.*

Involving parents in system change efforts requires careful thought about how to support them before and during team meetings. This includes mentoring them before the meeting and then debriefing with them after the meeting to ensure that they felt heard and respected:

> *There's an intentional effort to make sure that the parent voices are mentored before the CPT meetings, and that they're not overwritten by professionals at the meeting, or not an intentional desire of the leadership, and on the part of COFI's partnership that is made sure that parents' voices are not drowned out, so that they're equal footing at the table. And that we're always keeping them central to what we do. And then they also have a debriefing afterwards to sort of say was – did everything you want to get voiced get voiced? Are there other ways we can continue to support that? If they didn't, you know, really to make sure that there's always a mentored approach to it because professionals have a different set of resources to support that conversation sometimes than, um, residents and parents themselves.*

BRIDGES implementation has involved efforts to craft structures and processes that enable and support parent involvement. Another participant mentioned the debriefing meetings that occur after the Community Planning Team meetings. These debriefing meetings are smaller and parent-led, providing a safe place to discuss what happened in the CPT:

> *And it's been intended to have space for debriefing, reflecting, sharing, and brainstorming, and envisioning together just as a parent group. It is sometimes used to further explain some things that went on in the community planning team. I think, although after all this time that we've been together, the parents are pretty comfortable on those calls with a larger group. But it wasn't always that case. You know, like, we had to really make sure. And these are parents who have quite a bit of leadership work under their belt. But there's a lot of acronyms, and there's a lot of industry talk that sometimes can get tough to keep up with, even for us. And so, it's, I think, been helpful for the parents to know they have their own space, and they can help drive what we're focusing on, or maybe provide feedback back to the Leadership Team.*

Meetings are structured in such a way that parent voice is highlighted and emphasized:

> *I think one of our other main accomplishments is the integration of parent voice into the building of programs and services on the West Side. We do that very deliberately by making sure they have at least 30 minutes on our agenda, every time we meet so that partners are hearing directly from parents what the work is that they're doing and what the needs are that they have. Then the last thing that we do, typically at every meeting is we'll have some kind of a deep dive discussion into some barrier or challenge that's facing families trying to connect with services on the West Side.*

The relational approach underlies the BRIDGES SOC has also facilitated parent involvement:

> *Our process was pretty organic by design, I also think keeping it organic and more conversational. Using person to person relational way of developing these things, is what's also helped keep our parents engaged because it's not too overly structured or something that feels inauthentic to them. This is how they're used to solving problems in their own lives, and with their own families and communities, talking it out. That's a lot of what we do, is talk it out.*

Efforts have been made to schedule and conduct meetings in a way that will most facilitate participation for the most people, but especially parents. Site visit participants highlighted some of those:

> *We actually time our meetings for family so that school aged children. So, for example, we don't generally have a nine o'clock meeting, you usually don't start till about 10, till the kids are at school so we kind of accommodate one another in [that way]. I would say, it's not always seamless but it's pretty good.*

> *Yeah, I recognize a lot of folks have probably struggled with parent engagement because people need evening and weekend time slots to be able to participate for whatever reason. I think because our parents a lot of the work that they do is through COFI, and then they have this time that is able to be earmarked for these types of things. As long as we avoid, pickup and drop off times for school, we tend to be good for getting parents to be able to participate.*

Parents are financially compensated for the time that they spend working on implementation efforts for the BRIDGES SOC.

## 3.7 Barriers to Implementation

**Workforce shortage, staff turnover, and waitlists.** Across the state and nation, there is a shortage of mental health providers. SOC partners discussed the impact of this shortage on workload and the capacity of agencies and professionals:

> *Well, certainly some of our agencies have experienced staff turnover. It's not to say that we haven't seen new faces come in and out in the community planning team, but we still have representation from the agency…one of our partners, they stand out as the faces of who attends our community planning team meeting have certainly changed and I do think they struggle with staff turnover at an agency level.*

> *For example, our partner COFI did actually a statewide survey where they asked community members about the barriers that they face to receiving mental health treatment. One of the things that came out of that discussion was [the understanding of a] really long waitlist for services, which is something we were aware of but it's always*

*good to just continually get that feedback from parents. We spent a bunch of time brainstorming how do we address this issue recognizing that we can't just make staff appear out of thin air but is there something we can offer people while they wait. For example, like a peer-to-service, or even just education to take with them and start to work with their young child even before they're able to get into the door to see the mental health professional.*

# 4. Results – Greater Peoria Area Youth Mental Health Initiative

The Greater Peoria Area Youth Mental Health Initiative (GPAYMHI) is a system of care that serves Peoria, Tazewell, and Woodford counties in Central Illinois. According to the 2020 U.S. Census, Peoria County has a population of 181,830. The largest city in the county is Peoria. In 2021, the median household income in Peoria County was $55,949. Almost 17% (16.9%) of people in the county live below the poverty level, which is higher than the state average of 12.1%. Additionally, a higher percentage (21.2%) of children (18 years and below) in the county live in poverty.[10] In terms of race and ethnicity in Peoria County, 69.2% of the population is White (non-Hispanic), 17.7% is Black or African American (non-Hispanic), 4.2% is Asian (non-Hispanic), 3.6% identify as multiracial (non-Hispanic), 2.8% is White (non-Hispanic), and 1.3% is Other (non-Hispanic).[11]

Tazewell County has a population of 131,343. In 2021, the median household income in Peoria County was $63,621. Nine percent (9.3%) of people in the county live below the poverty level, which is lower than the state average of 12.1%. Additionally, 10.4% of children (18 years and below) in the county live in poverty.[12] In terms of race and ethnicity in Tazewell County, 93.7% of the population is White (non-Hispanic), 1.5% identify as multiracial (non-Hispanic), 1.2% is Black or African American (non-Hispanic), 1.7% is White (non-Hispanic), and 1.0% is Asian (non-Hispanic).[13]

Woodford County has a population of 38,467. In 2021, the median household income in Woodford County was $76,483. Six percent (6.2%) of people in the county live below the poverty level, which is lower than the state average of 12.1%. Additionally, 5.6% of children (18 years and below) in the county live in poverty.[14] In terms of race and ethnicity in Woodford County, 95.4% of the population is White (non-Hispanic), and 1.2% identify as multiracial (non-Hispanic).[15]

The lead agency for the GPAYMHI is the Methodist Medical Center. At the time of the site visit, Methodist Medical Center of Illinois was then a part of UnityPoint Health (UPH) - Central Illinois, a non-profit regional tertiary health care facility serving 19 counties in central Illinois. UPH provides a comprehensive continuum of behavioral and physical health care and preventive services delivered in inpatient, outpatient, physician offices, clinical settings, school sites, emergency care, and post-acute care venues. In 2019, UnityPoint Health solidified a partnership with two community mental health centers in the Peoria region, the Human Service Center and Tazwood Center for Wellness, and formed UnityPlace. UnityPoint Health – Central

[10] Census profile for Peoria County, IL: https://data.census.gov/profile/Peoria_County,_Illinois?g=050XX00US17143
[11] Peoria County DataUSA: https://datausa.io/profile/geo/peoria-county- yoil
[12] Census profile for Tazewell County, IL: https://data.census.gov/profile/Tazewell_County,_Illinois?g=050XX00US17179
[13] Tazewell County DataUSA: https://datausa.io/profile/geo/tazewell-county-il
[14] Census profile for Woodford County, IL: https://data.census.gov/profile/Woodford_County,_Illinois?g=050XX00US17203
[15] Woodford County DataUSA: https://datausa.io/profile/geo/woodford-county-il

Illinois (UPHCI) affiliates include Methodist, Proctor, and Pekin Hospitals, and the UnityPlace and UnityPoint Clinics. Together, the entities that comprised UnityPlace served a catchment area that encompasses seven counties in central Illinois providing a spectrum of behavioral health services in hospital and community settings.[16]

Initially, project staff employed by UPH included a project director, a data manager, and .25 FTE administrative staff. UPH made an in-kind contribution of leadership staff (.1 FTE each) including its Director of Outpatient Behavioral Health Services and the Director of Inpatient Behavioral Health Services. UPH lost the data manager and did not have a project director for the GPAYMHI for six months, from late March through August 2022. During this period, paid dedicated staff was reconfigured to include a full-time project director and 2 FTE community liaison positions.

GPAYMHI's grant application envisioned a planning year and included a multitude of goals, strategies, and activities. They included:

- ensuring understanding of system of care and the wraparound model across all community organizations,
- developing a coordinated standardized intake process for youth and families in which there is no wrong front door,
- developing a structure for a coordinated network and improved care integration,
- establishing a data sharing system that communicates to all of an individual's providers,
- establishing ways to measure the impact of services and systemic changes on lives of children and families,
- marketing the project in the community to raise awareness and encourage consumer engagement,
- prioritizing sustainability in all planning, expanding programs designed to strengthen parenting practice and caregiver-child relationships,
- expanding Peoria Public School's data collection system that identifies students with adverse childhood experience,
- working with the UnityPoint pediatric service to facilitate screening and referrals for services,
- identifying unmet needs of families participating in the mental health services system,
- identifying gaps in services that address caregiver stress and depression for parents/primary caregivers of children with mental health disorders,
- identifying areas where additional capacity is needed to provide families with evidence-based clinical interventions,
- building a regional peer support system and examining ways to empower youth,
- providing analysis of project costs and benefits and a sustainability plan, and
- leveraging relationships with regional academic institutions to improve specific workforce competencies and recommend potential academic changes to support continued education opportunities on child mental health issues.

[16] Several months after site visit interviews and focus groups, Carle Health replaced UnityPoint Health.

During the site visit, individual interviews were conducted with the project staff from GPAYMHI, and focus groups were completed with community stakeholders and parents who participated in system of care planning and implementation initiatives.

## 4.1 Pre-Grant Activity

In the year between their first and second grant application, the people and organizations from the three counties who had been involved in preparing the first application were involved and collaborated on another cross-organizational endeavor called the Partnership for Health Community. This partnership had a subcommittee on mental health and substance use which was co-chaired by an individual who was active in developing the GPAYMHI applications for the children's mental health system of care. As one participant described it, the idea of a children's mental health system of care continued to live through this partnership.

> *There was another huge initiative happening at the same time…called the Partnership for Healthy Community, and that is the three county health departments' plan. That…cycle, they came together and collaborated around the development of this partnership, and they brought in all the decision-makers in the Tri County area…So, I think the only thing that I can see happening between [the two CMHI grant applications]…is continuous conversation about…what [children's mental health] system of care means [and] how it can help…In other words…there was planning, but it was not coordinated planning.*

Another interviewee recalled the following regarding their involvement in the Partnership for Healthy Community during this period.

> *Yeah, [*the idea of a system of care for children's mental health*] kept coming up in all of the meetings. Every time we'd turn around, everybody would say…'We have so many things going on, there needs to be coordination of it'…and the issue was nobody was stepping into that role, whether it was [*because they were*] not sure [*of*] how to do it, whether it was lack of funding, whether it was [*a question of*] who should be responsible for something like that, et cetera.*

## 4.2 System of Care Goals

The interviews and focus groups explored participant perceptions of the goals of the GPAYMHI. Document review also revealed information about goals. When asked about processes originally used to develop shared goals, site visit participants recalled that goals were developed after working through a values clarification process in which between 10 and 12 organizational partners participated.

When asked to detail the content of shared goals, participants could not recall or gave a range of responses which were often non-specific. The variety and lack of specificity of responses

suggests there has not been a strong understanding of shared goals. One interviewee, with the project since its inception, could not recall the shared goals during the interview.

> Interviewer: *Do you remember what … the goals were that people agreed to?*
> Interviewee: *I don't off the top of my head, honestly. … I have the documents, but I don't remember offhand*.

Another interviewee understood the shared goals to consist of making the effort to create a children's mental health system of care sustainable.

> *Obviously, we want to make sure that this effort is sustainable… We're great at getting it going, but then after it's going, … what happens when people switch roles and retire.*

Participants in two different focus groups identified shared goals in terms of percentages of parents and service providers implementing "system of care practices," using "system of care services," experiencing improved behavioral health, as well as achieving a 5% growth in the behavioral health workforce "engaging in the system of care" (e.g., "*by 2024, there will be a 10 percent increase of parents and service providers utilizing effective system of care practices"*). Consistent with the ambiguity about goals was a lack of clarity about what the system of care practices in the goal statements were. When asked what the system of care practices were, a respondent answered, "*Deciding…what practices or procedures were going to be put in place, we never really got to that."*

During the site visit, participants explained that they decided to reexamine their goals because of the lack of clarity, the six-month hiatus with no project director, the hiring of the new project director, and the expanded number of stakeholders who had recently joined the project.

> [Shared goals] *are being reviewed because…we lost some momentum and…our partners are like, 'Hey, let's kind of hold until we have a reset with a new project director.' There was* [also*] feedback we received that there were some partners…feeling…lack of clarity around our direction.*
>
> [The new director has] *brought on so many brand-new partners that we really have to be at that baseline again of what are we trying to accomplish and why do you matter and who am I? So we're really kind of back at – I think we're a lot further than we would be at the starting line because we've already developed all that, but we have to get everybody else to that baseline, and I think that's what this last meeting was…We … have too many new people…[*who*] don't…know maybe why they're in that meeting quite yet.*
>
> *I don't foresee a lot of significant changes…by any means, but we will be reconvening in January [*2023*] after…reinitiating…meetings with partners and…individuals involved in the system of care...Then…we're hoping to really hone in during the meeting and focus on…what the goals were previously…[and ask] 'Does everybody still agree to them?'*

Minutes from the all-partners meeting in January 2023 contain the goals the full group decided on at that meeting:[17]

- Short term goals
  - Resume partnerships/implementation team monthly meetings
  - Enrollment of youth and families into SOC within the community by February of 2023
  - Partners on IRIS can begin referring to appropriate agencies
  - Create a comprehensive resource directory 4/30/23
- Long Term Goals
  - 2024: one service provider from each organizational category will be implementing SOC procedures
  - 2024: one service provider from each organizational category will be implementing policies

## 4.3 Activities and Progress Toward Goals

Site visit participants shared that GPAYMHI activities have included hiring staff, training staff and participants, conducting outreach to parents and youth, working on data collection and use, and developing a common intake and referral system. The new project director also engaged in extensive one-on-one outreach with stakeholders, recruited new participants, facilitated monthly meetings for all GPAYMHI participants, and drafted a mental health directory.

A professional in the three-county partnership who had expertise in system of care building provided training to all staff and, early on, to all participants in the GPAYMHI:

> *I did the initial training with the group that came together when we first got the grant…a three-session overview training of what is system of care and the steps to develop a plan.*

Another activity was outreach to parents and youth. Participants explained that the first director reached out to churches.

> *There was a reach out. [*The first project director] *did…a good job with this. We talked about natural supports for the families, and…he reached out to a lot of our churches and groups that might be connected.*

The second project director reached out to Community Organizing and Family Issues (COFI), a non-profit organization in Chicago that trains and organizes parents to participate in public decision-making processes and has worked with other CMHI sites. She also reached out to staff of youth-serving organizations.

[17] Greater Peoria Area Youth Mental Health Initiative. (2023, January). SOC 2.0 January meeting minutes.

Interviewees also described activities related to data collection and use and development of a common intake and referral system.

> *One of the teams has been working…to identify the data…our community really needs to be looking at… [We] worked on a common intake form and towards what kind of referral system are we going to utilize in our community…We did identify IRIS and are going through final approval stages with UnityPoint Health…to be able to utilize it.*

The Integrated Referral & Intake System (IRIS) is a web-based intake and referral system, developed by the University of Kansas Center for Public Partnerships and Research, that primarily enables service providers to make, receive, track, and respond to referrals. The decision to implement IRIS was made prior to the hiring of the second director. The new director explained that implementing IRIS has become a key activity for the GPAYMHI. "*The way we're connecting and coordinating our efforts is through IRIS*." The GPAYMHI developed a common intake form for those who cannot use IRIS.

Several participants described the new project director's extensive outreach and one-on-one communication with old and new participants to help them understand what a system of care for children's mental health is and the role their organization or they, as parents or youth, could play in building it.

> *I think she's really trying to…get the foundation for 2023…She's…been working to…meet the partners and get ingrained into…different groups…that already exist. She's been in almost every single meeting I've attended, which is amazing.*
>
> *I have never seen anyone reach out like that in my life.*
>
> *She has gone around and met every agency plus in the community since she came on board.*

The new project director has so far expanded the number of organizational partners from 12 to 30. She has been leading monthly meetings of the full group of partners and leading them through a process of reviewing previously established goals and making decisions on goals, meeting procedures, partner responsibilities, mission statement, work groups, vision statement, outcome measures, and internal methods of communication.

> [At] *our most recent meeting…the current director…was asking the whole group, 'Let's agree upon our goals. From here, let's talk about our priorities. And from there, let's then structure…subcommittees…and people can choose* [the subcommittee] *they want to be a part of.'*

The new project director drafted a mental health directory for the Greater Peoria area that was sent to participants for review. In addition, the current project director reports attempting to

secure data from member organizations and working with UnityPoint data to identify gaps in services in the three-county area.

## 4.4 Implementation Structures and Processes

The ability of a community to implement SOC or any other large initiative depends in part on supportive structures and processes, including leadership, internal communication, decision-making processes, and data collection and use. Site visit participants were asked about each of these processes and the structures they created to advance their work.

**Organizational structure.** Project staff are employed by the lead agency, UnityPoint Health (UPH). Originally, project staff included a 1.0 FTE project director and a 1.0 FTE data manager who were supervised by the Director of Outpatient Behavioral Health Services. The project did not have any paid staff for six months after the first project director left the position. Current project staffing includes a 1.0 FTE project director and 2.0 FTE community liaison positions which are staffed by three employees. The project director is supervised by the UPH Manager of Outpatient Behavioral Health Services who reports to the Director of Outpatient Behavioral Health Services. The data manager position was eliminated.

The new project director describes her role as including management of both GPAYMHI and the Integrated Referral & Intake System (IRIS): "*My position is not only project director, but I'm also a director and systems manager for our IRIS program."* Staff described the new community liaison positions as having responsibility for interaction with partner organizations and families with children needing mental health services, including speaking with staff of partner organizations to understand their needs, trouble-shooting partners' experience with IRIS, engaging in outreach to families, referring families to needed services, and ensuring that agencies follow-through on families referred to them.

> [The community liaisons are to] *focus…on direct contact with organizations…and families*…[with families they are to] *make referrals, help to build…*[their] *trust of our system.*
>
> *Our community liaisons…do community outreach…*[and] *family navigation…help our families, [and] make sure that…providers are following through…holding them accountable…community engagement…going to partners, asking how we support them, helping partners troubleshoot things in IRIS and getting them connected to other resources…and…helping families navigate when they're being referred…doing check-ins with families and saying like, "Hey, are you getting the services that you're needing, are you doing all these things?"* [They will work on behalf of] *any child…receiving mental health services and…in the referral system for IRIS.*

Within the project, there is one group of partners that is referred to by several different names, including "leadership team," "steering committee," "community implementation team," and "the system of care." The new project director expanded the number of organizational

participants that are members of this group with the goal of including all local organizations that might encounter children and youth in need of mental health services.

> *We didn't have the cross-section as much previously…We looked at…no wrong doors. So, we had done…a flowchart [of] where kids with certain issues might be connecting in. We wanted to…[include] schools…justice…health…child welfare.*

> *We have partners who are mobile youth counselors from…the school district to probation officers...Our goal is…to make sure…every sector is hit. We are attempting to develop a no wrong door methodology where families can enter through the education system, the juvenile justice system, their primary care physicians. We're also trying to incorporate a lot of natural support so that if they go to their faith-based organizations or if they're going to a community resource center that they're also able to access mental health services through different entry points around our community.*

The new project director also developed responsibilities for members of this group. Minutes of the January 2023 meeting state that members are required to attend at least 8 monthly meetings per year in person or virtually, launch IRIS or use the common paper intake form, participate in the UIUC evaluation, and actively provide input to the group.
Participants explained that this full group was meeting monthly until the first director left, and then did not convene between March and November 2022. They explained that decisions under the first director tended to be made by an informal group of four people with whom the project director often spoke, and now the function of this larger group under the second project director is to make all decisions.

> *At this point in time, there is no small, little group that meets and then brings everything back to us...*[The project director] *brings things to us as a larger group, we can make decisions there, and then we take it out to our own respective agencies and get whatever responses are needed. Eventually, in 2023, in January…workgroups will be starting up.*

After a nine-month hiatus in which there were no project meetings, the current project director has convened monthly meetings of this large group since November 2022. These meetings are held with the option of attending either in-person or virtually. The project director, who facilitates this meeting, uses a software designed to keep virtual participants actively engaged and contributing to discussions. The individuals who are a part of this group are described as including individuals in management roles, direct service, and parents. An interviewee described the quality and content of these meetings.

> *Our meetings are…consensus based. [There are] very open-ended questions…Everybody's given a chance to [provide] input…The director is guiding but not in any way, shape, or form a dictator.*

Work groups were initially formed under the first project director, but interviewees indicate they met infrequently or not at all.

> *We had all of our outcomes listed, goals and outcomes, and then out of that we decided what our teams should be, and we came with support and services, which would do prevention, early intervention, and wraparound. We looked at sustainability, we looked at service coordination, we looked at public awareness education, and we looked at a data workgroup, and then the last was a workforce workgroup. So we ended up coming up with like six different workgroups for this plan…But really the only workgroup that ever met, maybe two, was data, and they met once or twice…and then we had – I think there was services … that met once to look at service mapping.*

An organizational participant explained what the function of work groups will be going forward, stating "*Strategies will be developed by the workgroups."*

**Leadership.** The GPAYMHI struggled with long periods in which they did not have a project director. The first project director started four months after the foundation grant was made available and left the position 11 months later. Six months elapsed before a second project director was hired. We asked participants who they saw as GPAYMHI leaders, of what their leadership consisted, and how their leaders are supported.

All participants saw the current project director as the primary leader, and some believed there were additional leaders. Several identified the Central Illinois coordinator of IRIS as a leader. Several cited the participant who had provided trainings to staff and participants as a leader. Several viewed the UnityPoint Director of Outpatient Behavioral Health Services as a GPAYMHI leader. One interviewee stated that the whole implementation team should be viewed as leaders.

Interviewees saw the current project director as having strong leadership skills, a genuine commitment to the work, and strong relevant substantive knowledge.

> [The current project director] *has a passion and drive for [this initiative]…[and] a pretty clear vision of the outcome, what we're doing, and what we're looking for.*

Several organizational participants praised her extensive one-on-one conversations with members, her responsiveness to their concerns and questions, and the way in which she helps members with understanding what a children's mental health system of care is and how they as individuals or organizations can help to build it.

> *When [*the current project director*] onboarded, she said, 'Let me know if there are any confusions or things that you want to see at a meeting', and I said, 'Yes, I want to see where I fit in. Why am I here and what does it matter if we're at the table?' … I think she's doing a really good job of asking individuals…what they need or where they may have some confusion…and bringing [explanation]…to the next group meeting…Even*

> *though I've been involved in this from day one, I still had a lot of confusion…It was…so easily solved [*at*] the next committee meeting, which may have cleared up…confusion for our newer partners that were joining.*
>
> [The project director] *has taken it upon herself to meet with almost everyone individually who had been part of this, to get a good feel for their participation, their goals, how they fit into this, so she would have a great understanding…moving forward on what to do.*

Participants also praised the current project directors' external communication.

> [I] *serve on other…community initiatives, three others, and I'll go to a meeting and there's [the project director]. She's wanting to make sure she gets involved with everything else that's going on, so that we can fully integrate all these initiatives to produce the best results. She's a rock star.*

An interviewee described the project director's leadership style as facilitative.

> *We're working on* [developing shared goals]. *it was talked about at the last meeting, and she had some suggestions…She's not the type of leader that says, 'Here are the goals. This is what we're going to do.' She puts things out there, 'Let's discuss,' gets feedback*.

Another interviewee noted how the new project director's meeting facilitation is proactively inclusive.

> *I so appreciated the way that she indicated in the meeting…she wanted…other people's voices around the table...[*she made it clear that*] we need to hear from other people. That, to me, was a tremendous step of communicating a message to people in regards to respect and* [the] *importance* [of] *everyone there.*

Those who saw the IRIS coordinator for Central Illinois as a leader explained that they did so because she trained the project director on how to coordinate IRIS for delivery of services and to obtain data useful to the community and helped bring other organizations into the GPAYMHI. Those who saw the participant who had provided trainings to other participants and staff as a leader explained that they did because of her expertise in children's mental health systems of care, because she provided training in system of care planning and implementation to participants and staff, and because she had given a great deal of support and direction to the first project director. Another organizational participant regarded her as a leader because she is "well connected…keeps us going…has passion for it…[and is] able to connect people and the dots."

The Director of Outpatient Behavioral Health was seen by an organizational participant as being a leader of GPAYMHI because of her position with the lead agency. The Director of Outpatient Behavioral Health also identified herself as a leader, explaining that her position and longevity

in the community enables her to work effectively with other departments within the large UnityPlace health organization and with external colleagues to advance GPAYMHI's agenda.

> [My position enables me to] *move things forward in UnityPlace, work…with other leaders and ensure we…are creating something that is lasting…What departments can be involved, how…we involve them, and making those connections…Sometimes it's line authority and sometimes it's…working with senior leaders…helping to make those connections… I've worked in our community for my entire career… Over the years, I've…been able to build relationships…that [*allow us]*…to expand our system.*

The current project director expressed concern about over-reliance on the leadership that she, the project director, provides. The project director views engaging and empowering others as part of her job.

> *There was very little understanding of what a system of care…[is]. We did have to take a step back and say…how can we explain this to our community members, how can we make sure that we're letting them know that this is not proprietary on the part of Unity Point. We're…trying to make sure…they know that in order for us to be successful they have to have input, they have to be part of a planning process, they have to be part of IRIS, they have to be part of all of these different components because the grant will run out in 2024, and we need to be able to identify a way to sustain ourselves…How can we make this process worth…keeping even after there's no one quote/unquote leading it or there's no one in my position? How can we as a community continue…even as we have turnover?…So that is one thing that I think will be a really big struggle, is when you have a figurehead – me – it's easy to just assign it to me and then for me to take care of it, for me to do it or whatever…But at the end of the day, this has to be a systems change…It can't just be one person…and now we have a system of care...Let's say…I leave for whatever reason. It can't fall apart. It shouldn't fall apart. That's one thing that I'm…trying to communicate at our next couple of meetings…that the system of care cannot be dependent on a project director, it cannot be dependent on a data person…It has to be an interconnected, collaboration…*[within] *the community. I don't think that was established beforehand, which is why it just kind of stood still when…*[the first project director] *left…*

We also asked participants to speak about the supports that are available to GPAYMHI leaders. Several themes emerged. There has been an internal system of support and supervision within the lead agency, UnityPoint, to support the current project director. In addition, a consultant, who is a member of the GPAYMHI provided training to both project directors. This participant's organization contributed her time to the project and allowed both project directors to request consultation from her.

The Director of Outpatient Behavioral Health reported that the ILCHF program officer provided support to her in her leadership role. The Director of Outpatient Mental Health identified that

some of this consultation stemmed from the initiative of the program officer; and some she herself initiated.

> *I found a lot of great support from the foundation.* [ILCHF program officer] *did some one-on-ones with us to try to help us move things forward…We had some challenges and we had some things that we needed to work on and to improve and really appreciated [*that*] she brought those things forward. And she really did it from a we want you to be successful consultative manner and…gave us some great suggestions…we were able to follow through on.*

The current project director reported that she found *Building Systems of Care, A Primer* by Sheila Pires to be helpful to her in her leadership role, but not sufficient. The Primer "offers a roadmap for those involved in building systems of care … [and] is intended to be useful" (Pires, 2010, p. 4).[18]

> *I…read the entire manual…300 pages…I think it has very clear dos and don'ts…It…gave me a framework…to go on…It's up to you to work within that framework and be innovative…I don't think it's enough, but I'm doing the best with what I've got.*

Several participants expressed that current levels of support for leadership need strengthening. The current project director reflected:

> *I think I was left to figure out a lot on my own… I don't think we have support. Even from our funder…At least halfway through [ILCHF program officer] left, so then we had XXX, who…started the same day I did…So she doesn't have the knowledge, and that's fine because she's also learning, and I'm patient and flexible…I came into UnityPoint and…[my supervisor] was new, I was new, so I was just like, 'I have to figure it out or I'm going to fail.'…We need more mentoring from people who have successfully launched and implemented system of care within their community. I personally would want somebody who has longevity within their system…I want it to be that I can ask them…a lot of questions about the future…Nobody can answer it, especially not from my cohort because we're in the same time, and even the previous cohort, it's also very hard to communicate with them because they're busy with other things…It was very challenging at first, and it still is, but especially at first.*

A parent participant expressed concern that the project director receive support in steering a group of professionals who have been working collaboratively for a very long time and have settled views. The parent also believes that the project director should, in order to get fresh ideas, have more exposure and communication with people with experience building children's mental health systems of care in other environments.

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[18] Pires, Sheila. (2010). *Building systems of care: A primer.* Washington DC: National Technical Assistance Center for Children's Mental Health.

*She's…going up very directly against this group mentality of, "Well, we understand what the system needs to be, and this is just how it needs to be." Versus, "Hey, let's look at the Oregon program. Let's look at the Nebraska program…I worry that she's not having enough access…to people beyond the local community about what this could be. I don't think people think there's a need. And that, to me, is already just so disheartening.*

**Communication.** Participants discussed the ways in which information has been shared among GPAYMHI participants. They often differentiated among the periods in which the first director was in place, the six and a half months between the two project directors, and since the second director has been in place.

Staff located primary responsibility for managing internal communication in the project director position. Participants described internal communications under the first director as minimal. They shared that he sent emails with meeting agendas and documents to be reviewed before meetings but did not share meeting minutes or document progress.

*There's very little that was actually shared*.

*I don't want to speak badly of [*the first project director*], who is very kind, but I think … sometimes with him there probably could have been more e-mails or more up to date [*communication*] than there…[was].*

They further shared that the lack of internal communication and documentation under the first director made the project less resilient to his departure and the transition to a new director more difficult.

*There were things lacking* [under the first director] *and some of the feedback that we had gotten from partners was regarding…needed improvements with communication, clarity around…what are we working towards, what is our plan, those types of things…I think [*we*] lost momentum…due to…communication [*issues*].*

*Unfortunately, the previous director didn't leave any documentation or any minutes of meetings that he had or any of that.*

Interviewees remarked on the reduction in internal communication during the six months between project directors when they received updates to let them know the project would continue and there was a search for a new project director.

*After…[*the first project director*] left…there was an interim who kept everybody updated, 'Hey, this is what we're doing to find a director. We're not going to stop with this initiative…Updates and information…were sent out. We may not have met formally …but she was keeping everyone up to date.*

*I think there was a lull for a while…after…[the first director] left…We did get some information, don't get me wrong, but there was definitely a lull.*

Participants shared that the second project director engages in a far greater quantity of internal communications, to a wider group, using a greater variety of methods:

*She sent out an e-mail when she came on, introducing herself, laying out what she wanted to take on. She even did an "About Me" flyer.*

*She's doing a really good job of asking individuals or entities what they need or where they may have some confusion … making sure that there's that one-on-one communication and keeping in contact with the partners.*

*She has taken it upon herself to meet with almost everyone individually who had been part of this, to get a good feel for their participation, their goals, how they fit into this.*

*[*The second project director*] will communicate in a variety of ways…She sends e-mails …make[*s*] phone calls, [*makes*] videos. She goes to places in person…It's very frequent.*

A parent participant raised concern that several of the professional partners meet outside of GPAYMHI meetings and may be sharing information in ways that are not accessible to partners who are not professionals and not part of these networks. He particularly worried about the impact of these professional networks on family voice.

*Is our group one…*[that] *will let official business happen* [outside] *the official meeting? How much is being done between people who see each other outside of the meeting and doing planning on other pieces?…There* [are] *concerns…because this group* [of people*] probably see each other multiple times a week in different meetings, and if families… don't have the opportunity to do that…as a family voice…How do we set that norm? How do we say – "Okay, when you're in your committee … that committee work happens within that committee…and then you bring it back to the big crowd." But, you know, if you guys are gathering and, you know, three of the five committee members are at another meeting and* [they] *start talking about it, it's not fair…Families can't do this, because we don't see each other outside…meetings. We can't really talk about this stuff and have equal participation.*

**Decision-making.** A formal decision-making process had not yet been developed at the time of the interviews and focus groups. When asked about decision-making, interviewees spoke about the degree to which UnityPoint, the lead agency, would or would not influence decisions.

*We have to make sure that the different organizations, the different entities, the different providers, the different family members in our community are all a part of the decisions for implementation…We've made it very clear, even to our marketing team here, this is not a UnityPoint initiative.*

Many shared a sense that decisions are made by the full group of partners, but there was a lack of clarity on process and whether decisions are made by majority or by consensus.

> *I think we came up with…[*decisions*] at meetings. The [*first director*] kind of led some of us through that…He would put it out to us, and then we actually would come to consensus.*

> *I'm not aware if our decisions go to UnityPoint…once they're made. But we would make decisions during meetings, especially around goals and things, and that's where we'd leave it…I'm not aware if [*the first director*] would take them to UnityPoint or UnityPlace for their approval or not.*

> *If there's a decision that needs to be made, we think it'll be presented to our group in one of our meetings. There will be conversation and discussion about it, a final recommendation will be made. That's what I think is going to happen. That was the process that we talked about*.

> *Thus far, my experience, especially in our last meeting* [under the second project director, is that*] decisions are made in more of an anonymous vote...It's not a leadership team bringing things to a larger group and saying, "Let's have discussion input," and then the leadership team going back and making it. It is the large group having discussion and then the large group overall having input on priorities or goals…I guess, we are still pretty young. So, I'm not sure where we're headed.*

The current project director stated it is her plan to have the full group decide on how decisions will be made.

> *I don't know how the decisions were made before…One of the things that I think is really important is that we decide…as a group…how will we make decisions…I think that's something that we…have to vote on…I want us to decide as a group what is the best way for us to determine decisions moving forward.*

**Data collection and use.** Initially, there was a full-time data manager position, and a data workgroup was formed early on under the first project director. As with other aspects of the implementation process, data collection is starting over under the guidance of the second project director.

> *There were…discussions with [the data manager] about…what we could measure and what that would look like...It just kind of hit a snag when he left*.

The current project director describes they will use IRIS data and data collected from participating providers to identify, for planning purposes, gaps in services, unmet needs, and highly utilized services. She reported requesting data from participating organizations but receiving data from only one of them.

## 4.5 Parent and Youth Involvement and Leadership

Site visit participants were asked to describe how parents and youth have been involved in the GPAYMHI and the degree to which the GPAYMHI has tried to ensure that the parents and youth who are involved reflect the diversity of the area's population. They shared that three or four parents of children with mental health-related needs, but no youth, have been active in the GPAYMHI**.** One of the parents also represents one of the organizations in the GPAYMHI and served as co-chair of one of the workgroups. Two parents were interviewed during the site visit, neither of whom were employed by an organization in the system of care. One of the parents shared:

> *This is what shocks me. Our community [*has*] been involved with systems of care for a number of years now. And that's what I'm sad about, that we're not at that place, after so many years, to really think about engaging these parents and valu[*ing*] what they've gone through.*

Interviewees shared that they intend to engage more parents and to engage youth. One of the roles of the newly established community liaison positions is to "get people with lived experience more involved in the partnership."

> *There was a huge absence of…family members and youth with lived experience…So we knew that needed to be our focus...We…decided that…we need to spend more time focusing on engaging our community and getting them more involved…If their voices aren't at the table, it's not going to work.*

Interviewees said that involving parents and youth had been difficult and identified COVID and a lack of trust between professionals and consumers as barriers.

> *We tried to do a lot of marketing [*for the*] Community Advisory Committee. One of the initial challenges with that was during that time we were in the height of COVID. Our goal was to implement in-person meetings at sites that are viewed as neutral...So [*the first project director*] had been working with our school district in Peoria on being able to utilize space so that it seemed more community oriented...But we weren't able to do [it] at that time because of [the] COVID restrictions…we had. So, the meetings were done virtually, which made it more challenging to…get the incentives right…[*such as*] gift cards and providing food...*
>
> *We were afraid there were trust issues with some folks…There was…a lot of talk about being very much aware of cultural issues and things like that that might be going on, that may lead folks to not be so trusting.*

Participants described past and current efforts to increase the participation of youth and parents in system of care planning and implementation. The efforts they described included outreach to parents through printed materials at some community events and asking provider

partners to distribute printed materials to their clients' parents. The second project director reported seeking advice from COFI about engaging parents. She also reported conducting outreach to youth-serving organizations for youth and targeting youth who are already engaged in service. Current staff reported plans to use a school wellness program that requires youth and parent participation as a source for recruiting parents to participate in the GPAYMHI.

> [The second project director] *has reached out to our alternative school…and to our agencies to see if there are any youth that might want to participate…The regional state superintendent gave a couple of names to [*the second project director*], and she immediately reached out to them and explained what was going on.*
>
> *We didn't have any youth involvement in the past and now we…[*have*] contacts with certified peer counselors where the youth are counseling…other people and doing peer education...We have contacts and partnerships with Goodwill, Center for Healthy Living, and the school district to get more youth potentially involved in our system of care…One of the things that I think is going to be really important is being able to engage youth [*who*] are already attempting to engage in programs.*
>
> *We also have the COVID school wellness initiative grant from the foundation…There is a lot of focus on inclusion of youth and…families to…be drivers of what those services look like…And so, we're trying to make [*a*] connection between [*the two initiatives*]. We have two counselors who are providing service for school districts [*with*]…six or seven schools …[*We may*] encourage parents from those schools to become involved in* [the GPAYMHI*] implementation team, as well.*

Participants described a long-standing debate about whether parents should meet separately in a "Community Advisory Group," join with the large group that meets to discuss and make decisions, or be given both options.

> *Currently, we have three parents…in our process. However, it wasn't really established, or at least from my understanding and the records that I have, that they were part of… governance. There was some resistance before…about [*including them in*] our governance.*
>
> *I have multiple emails that I…sent to the previous director saying we can't… [meet separate*ly*]…We need to have families, we need to have youth…*[at meetings*], and it just never happened. It was kind of pushed off, pushed off, pushed off.*
>
> *Another step…we've implemented* [is*] to have a Community Advisory Committee and… wanting individuals from that to also participate in the implementation team…That Committee was…for individuals with lived experience. [*We*]…have struggled with [*this*]. We would be able to take a dual approach with…offering the opportunity for community members to have a meeting that was just with individuals with lived experience because … sometimes meeting with organization [*professionals*] can feel…intimidating, especially*

> *initially, but then…offering to anybody involved…to be a part of the implementation group as well [*and*]…shooting for that minimum of…25 percent [*parent/youth*] participation…I think we're…trying to steer away from [*the*] Community Advisory [*Committee*]…The goal is to have the organizations and those individuals [*with lived experience*] sitting at the same table and planning and developing together.*

Interviewees shared that there were no supports for parent participants prior to the second project director's tenure. The second project director met with currently involved parents prior to their participation in the all-partners meeting and has been working on the possibility of providing additional supports to parents, such as monetary compensation, meals, childcare, and meeting at times available to youth and parents. The current project director plans to discuss with parent and youth participants what they might need to meaningfully participate and believes facilitating their participation in the project may also include providing supports to professional participants on how to interact appropriately with youth and parents.

> *I want to have an honest conversation with* [parents*] without them having to be intimidated…by directors and executive-level individuals…but rather create…a safe space for them to be able to honestly and openly tell me 'I need you to back me up' or 'I need you to have people hold their questions until the end because then I get confused or I lose my train of thought.' I want to have a…conversation about what their role looks like in our system of care governance and how we can move forward for them.* [I also want to]*…make sure…we are being clear* [with] *our partners about how they should…interact with our families…I don't want* [families] *to be tokenized.*

The two parents we interviewed were initially invited to be a part of the Community Advisory Team by the first project director but did not become involved with the project until the second project director came on board, met with them, and invited them to the meeting of the full group.

> *I was aware of systems of care before it came to the Peoria area…And…[*when*], we got a program here in Peoria…we were so excited about it…We knocked on the door a couple of times...And my wife and I were, like, 'Let us in. We want to be a part of it. Please. Because there's so much in the system that needs to be changed and be[*come more*] family-friendly.'…I don't know if that scared them off…but it was…bumpy for a while … That was probably a year and a half ago…When…the [*project*] director left, and the new [*project director*] came on, we have been engaged almost…100 percent, 'Please come in, help guide us. Please give us your experiences and what [*role*] you would…like to play in subcommittees [and] as any part of…leadership.'*

These parents shared that with the advent of the second project director, they feel heard and respected for their expertise as parents, but do not experience that parents are seen by participating professionals as potential leaders.

*I have felt so invested and feel really, really heard and very much part of the table with the Regional Office of Education Superintendent or with administrators of the OSF [*Saint Francis Medical Center*]…They…do treat us as experts. And I…appreciate that [*this*]…is a lot about the current director.*

*I…only want to talk about…this last couple of months with the new director because that's where I feel like we…started moving forward. Honestly, during this time, I feel we've been seen as equals, our voice carries…[*and has*] similar weight to other professionals and/or community directors or executives…We've been asked to weigh in on the priorities.*

*I think there hasn't been enough…opportunity for [*leadership*], yet, given we're just starting to talk about some of those things. But the felt experience from the current director is very much about [*that*]…[*She*] communicates that she wants families…and youth in leadership. I don't think we're there yet.*

*When and if [*the project director*] is able to…put a family member very observably, recognizably in a leadership position of this initiative, it's going to be an adjustment for this group of professionals because they are used to the same voices, the same people…Their heart's right, and a lot of times they have some great stuff. But…if it's not connected to…family experience…it's not really family led.*

The parents recommended several strategies for recruiting additional parents and supporting their involvement in building the system of care. Their recommendations for recruitment included having participating organizations recruit from their client populations and including a wider public recruitment event. One emphasized the importance of recruiting parents to reflect the diversity of the community.

*So many of these agencies that are sitting at this table…could go internally to [*their*] families and say, "Oh, my gosh, you've been telling us that we're not doing this right. Please, please, please consider, how can we get your voice at this table?"…To coordinate … every agency recruiting from within, to bring at least one parent to the table, I think is a great way to [*recruit parents*]. And [*also*] making…a public…announcement and recruitment event…*

*While [*the project director*] represents and brings a viewpoint from a Hispanic background, and I'm Native American, there's not one African American involved – I'm sorry, there is one, but he's [*a professional representing*] the school district…We don't have representation, and I think…we can't…say we're representing the community, when, in fact, we're not.*

The parents recommended several supports for prospective parent participants, including financial compensation, childcare, a mentor, and full access to information, including the project budget. One of the parents added the view that GPAYMHI professionals will need

education and training on parent experience and equitable inclusion of parents in order to fully integrate parents into planning and implementation processes.

> *There is a majority of this population…[*that*] is struggling, and I think one of the first things is prioritizing…some sort of reimbursement of time, or…"Let's provide some childcare," or "Let's make sure that your needs are being met when you're lending your time and expertise to us for this community event."…It is an extraordinary amount of time and money to…parent a child with mental health needs.*

> *If it's going to be…a family-led initiative, at some point, which is the model…we've got to be at a point that every family member that comes in has a mentor, has someone that they can ask questions* [of] *and be able to have these conversations…a debriefing…And it has to be a part of the pace of this group…We are versed in all that, right, so we're flowing, and we still have a bunch of questions…But for a family member stepping into this without any of that background…*[Also,] *I don't know what our strategic plan is for… spending that money. I don't even know how long we have this. I mean, there's so many different things here that, again, if we are to be included in a leadership position, we should know, fully, some of those points, because that's a big part of how we make decisions about different initiatives or priorities.*

> *My number one…thing is, the attitude of [*professionals who should*] com[*e*] to the table with curiosity, openness, and a lack of ego…The[re should be] education, discussion, and training [regarding] how to look at this project differently…and understanding that working in an area that touches on mental health is not the same as having mental health concerns in your family…We can't be walking around with the mindset…[*parents are*] only coming because they're paid…It's vital that we [*provide*] some DEI training* [to professionals*] in that area [*and build*] understanding of real everyday life and how people who are dealing with this are experiencing the world.*

## 4.6 Barriers to Implementation

We asked site visit participants to identify and discuss barriers they had experienced in implementing their grant and building a system of care. We asked specifically about the impacts of workforce shortages and the COVID pandemic on their progress.

**Workforce shortage.** Interviewees identified that the mental health workforce shortage was a barrier that impeded the progress of implementation. They described that it stretched existing staff, making it challenging for them to take on new initiatives and tasks associated with GPAYMHI.

> *Hands down the work force staffing shortage…in the mental health field…has been a huge barrier for this initiative because there's just – number one, there's just not the work force out there [*that*] has availability [*in their*] schedules…They're spread very thin right now.*

*There's been times when we've identified an agency, but who is going to come to this meeting when you have so many holes to fill?…You don't have the people to do everything. They are just trying to meet the basic demand for mental health, let alone…take on this extra task of being on this group to do this extra work.*

**COVID.** The 3.0 grants began in December 2020, when COVID pandemic protocols were in place. Most interviewees shared that COVID created a barrier to participation in the work of the GPAYMHI, especially in the recruitment of parents, and that it significantly slowed the pace of progress.

*I think* [COVID] *has been a big barrier for engagement and actually being able to move things forward. I think…it's been a giant barrier for families too to be a part of this, people with lived experience…Many families…were already in survival mode if they have severe mental illness going on within the family and they're experiencing difficulties. But when you* [add] *the pandemic…they're even more in survival mode.*

O*ne of the biggest impacts* [of COVID]*…is…we…lack[*ed*] ability to do things in person. Doing things virtually, trying to e-mail people is just not the same. I think we were more successful with our partners and with other organizations because we all had to…transform to* [virtual] *but as far as really trying to engage…community members… we've struggled with that… To try to send people a Teams link to join a meeting…* [is] *really a challenge…We're accustomed to there being a lot of community-based events and things at schools, health fairs, all these different things and those things were not happening, so we didn't have…opportunities to* [communicate] *across our community.*

**Staff vacancies and gaps in leadership.** Interviewees identified that staff vacancies and not having a strong project director were substantial barriers to their progress. Initially, it took the lead agency 4 months to hire the first project director. The full-time data manager left his position just shy of a year's employment. When the first project director also left his position soon afterwards, it was six months before the position was replaced. Interviewees shared that almost nothing was done to move the project forward during the two periods without a project director.

S*taff leaving [was a barrier to building the system of care]…Losing [the data manager] and then losing [the first project director]. I think you lose momentum. You lose…the person you felt was driving the boat.*

*The biggest barrier thus far…has been [the lack of]…consistent…strong leadership…the gap between directors…I'm not really sure about any of the reasons behind the bumpiness of the first director in terms of the process of building the initiative, I would say…not enough strong leadership, which is what [the second project director] is…providing now.*

**Complex and lengthy approval processes of a large health care facility.** The lead agency is a large health care organization with many departments, hierarchies, and restrictions related to patient data. Interviewees shared that the need to gain approval from several departments and protect patient data significantly slowed their progress with hiring staff, obtaining data, and implementing IRIS.

> *It took us…six months to get the staffing taken care of, because [it had] to go through the hospital chain of command*.
>
> *[*To get*] data…we had to go through so many hoops of our legal and compliance and data department because it's a healthcare system.*
>
> S*ome of [UnityPoint] internal processes…can take time and take longer than we would like...So the data sharing agreement, IRIS, [*staff*] turnover…We've had some changes in our compliance department and our legal department.*
>
> *We're…happy…we're with UnityPoint, but also it brings a lot of cons…because a hospital system is much more complex than a smaller nonprofit or a community-based clinic… IRIS was denied [*by*] the hospital…So now we have to go back and forth with Kansas University. They denied it due to IT security because they're going to be sharing patient health information…so it got an F rating…It makes it hard…when so many things…[*require*] waiting.*

# 5. Results – St. Clair County Systems of Care Coordination Project

The St. Clair County Youth SOC serves a region in Southern Illinois. According to the 2020 U.S. Census, St. Clair County has a population of 257,400. The largest city in the county is Belleville and the county also includes East St. Louis. In 2021, the median household income in St. Clair County was $67,530. 12.3% of people in the county live below the poverty level, which is slightly higher than the state average of 12.1%. Additionally, 20.9% of children (18 years and below) in the county live in poverty.[19]

In terms of race and ethnicity in the county, 61% of the population are White (non-Hispanic), 29.7% are Black or African American (non-Hispanic), 3.9% identify as multiracial (non-Hispanic), 2.16% are White (Hispanic), 1.42% are Asian (non-Hispanic), 1.11% are Other (Hispanic), 0.75% are multiracial (Hispanic), 0.403% are Other (non-Hispanic), 0.134% are Black or African American (Hispanic), 0.127% are American Indian or Alaska Native (non-Hispanic), 0.0402% are American Indian or Alaska Native (Hispanic), 0.0195% are Asian (Hispanic), 0.0153% are Native Hawaiian and Other Pacific Islander (non-Hispanic), and 0.00421% are Native Hawaiian and Other Pacific Islander (Hispanic).[20]

Chestnut Health Systems serves as the grantee and lead agency for their SOC project. According to their grant proposal, Chestnut was founded in 1973 and has been continuously accredited by The Joint Commission since 1975. They utilize recovery-oriented care models and provide services in the following core areas: adult substance use disorder treatment, inpatient and outpatient mental health treatment, training and professional development, credit counseling, community-based primary health care, services for veterans, prevention education; crisis response, and supportive housing for low-income individuals and families with addictions or persistent mental illness. Chestnut's children's treatment services include screening and assessment, early intervention, services for children of incarcerated parents, school-based mental health services, medication management, substance use prevention, outpatient and inpatient treatment.

The St. Clair SOC project plan at the time of application was to partner with the Belleville School District 118, St. Clair County's Probation and Parole Office, and St. Clair County's Juvenile Detention Center as sites for assessment and intervention with youth. The stated purpose of the project at its inception was to develop and implement a trauma-informed system of care for school-aged children. Additional aims included addressing children's emotional and physical safety through the SOC, using evidence-based services to support social and emotional skills, focusing on youth with significant mental health needs, integrating mental health and primary care, and implementing a universal screening tool for youth to identify behavioral, emotional and social challenges. The project also planned to increase and utilize parent engagement. The St. Clair County Youth Coalition that was in place prior to the funding from ILCHF formed the

[19] Census profile for St. Clair County, IL: https://data.census.gov/profile/St._Clair_County,_Illinois?g=050XX00US17163
[20] St. Clair County DataUSA: https://datausa.io/profile/geo/st-clair-county-il

foundation for the SOC implementation team. SOC implementation is spearheaded by one project director who is employed by the lead agency Chestnut; the agency-based supervisor provides support for that role and also served as the primary project director for over a year; they were noted in the grant application as being funded at 10% and 20% of salary, respectively. The proposal document also notes that the project team would be comprised of three Clinician Level III positions, a Project Coordinator, a Family Engagement Specialist and a Clinician. A primary function of the SOC to date has been identification of provider needs and filling clinician positions within schools and the juvenile detention center in order to most directly serve youth in need of mental health services.

A total of 10 individuals participated in the site visit including both project directors, four parents, and four community-based professionals who were identified participants in SOC implementation. In line with the vision for the system, these individuals represented the school district and juvenile justice detention center.

## 5.1 Pre-grant Activities

The St. Clair Youth SOC received feedback from their unsuccessful application for CMHI 2.0 funding from the Illinois Children's Health Foundation and reapplied a year later for the 3.0 cohort. In our interviews, we asked participants about the activities undertaken during that year related to development of an SOC. Though not all the site visit participants were able to provide information about the interim year, several shed light on it. A project director talked about seeking broad participation by remaining engaged with other organizations:

> *We attended all of the community meetings…still trying to partner with everybody. "Hey, let's all get on the same page". Same planning phases going forward, instead of everybody just being in their siloes. And so, we challenged people to come to the same meetings, instead of all just having different or separate meetings. Meaning juvenile justice, schools, mental health, DCFS, everybody. So, we were able to create a youth coalition meeting. And that's been I guess going on maybe for like five years, but it's often segmented. And so, I guess over the last year and a half or so, it's that everybody comes to one table now, and it just makes more sense.*

In addition, a project director talked more about their partnership with local schools and their continued efforts in the interim year:

> *We started embedding clinical therapists inside of a school district, 118. Not as many as we have now of course with the grant. But I think we had started already with two. We're up to seven now and trying to hire another… And so, we started our work embedded in the detention center and the juvenile justice system also.*

## 5.2 System of Care Goals

One focus of the site visits was to explore participant perceptions of the aims of the SOC and progress toward those goals to date. Project directors, implementation team members, and community partners provided perspectives on their shared goals as well as progress toward those aims since receiving funding.

**Mental health screening.** The focus of the St. Clair Youth SOC lies largely in the schools and it is hoped that they will continue to build a partnership with the juvenile justice system, both key pathways for mental health access:

> *There is a strategic plan…the overall plan is to create trauma informed systems…We wanted…people in the systems…to be trained to understand or know a little bit more about mental health…And so, behavioral health screeners…we've implemented them in both the juvenile justice system and the entire district 118, just so that they know what youth are struggling with.*

**Professional development and direct service provision.** Training and professional development to support a well-informed clinical workforce is another key aim. Once children have been screened for mental health needs, there is a need to staff in the schools and juvenile justice center with skills to meet their needs. The SOC seeks to utilize grant funding to pay needed service providers in key positions in the community. According to one project director:

> *We had previously developed our…school-based therapy partnership. So, we, at that point, had a handful of therapists in the schools, seeing students that were Medicaid-eligible to get their direct therapy…But with the grant, really that focus was who else are we missing? You know, are there other kids that we are missing? And just more than anything, building a better system, a more robust system of places to be able to refer our kids to once we did identify a need.*

Parents were not able to articulate the SOC goals as clearly as the organizational partners. The parents are members of COFI (Community Organizing and Family Issues), an organization with chapters in various locations in Illinois that empowers participants to impact positive change. The partnership between COFI and the SOC is relatively new, and the parents who participated in the site visit were a little unclear about the specific goals of the SOC implementation:

> *I guess I can only assume that it's to better support families or community to access mental health resources, and I don't know if you're asking me this but I'm just going to say it, it seems like when I hear what they're doing it's very confusing. There's several different systems and how you access things, and I wouldn't try it if I needed it.*

Another parent summed up her understanding of the purpose of the St. Clair Youth SOC saying, *"It's a group of organizations that come together and talk about what's going on in the county around mental health or any of the new stuff or are there new resources."*

## 5.3 Activities and Progress Toward Goals

Participants discussed activities and interventions to date toward meeting SOC goals. Much of the work of the St. Clair SOC so far has centered on implementing an enhanced screening and referral process, in support of the goal of reaching every child who needs services. Another SOC effort has been strategic use of grant funds to support school- and community-based clinical services. Project directors for the SOC do the hiring in order to place providers where they are needed and ensure training for them is available. A focus group participant described activities undertaken over the last two years from the perspective of school partners:

> *Since the System of Care Grant kicked off, we have 11 school buildings in the District, so the system-wide mental health screener was our first step and that was trying to get a mental health screener to every single family…We started with two schools our first year in which we provided the mental health screener using the pediatric symptom checklist…We would have loved to implement it to all 11 buildings.*

The project director as well as some focus group participants also mentioned screening efforts for youth who are in juvenile detention. Training and professional development to support children's mental health services and to provide follow-up services as a result of screenings has also been an important part of SOC implementation to date. According to one project director:

> *We have trained a lot of staff in district 118. I would say probably around 300 or so over the past three years in youth mental health first aid. Of course, they're ever changing staff, so we need to keep training, keep training… We've probably trained 20 people total in the juvenile justice system…And we also purchased a curriculum for the detention center specifically, to talk about trauma and the amount of trauma that the kids experience.*

## 5.4 Organizational Structures and Processes

Participants were asked questions in focus groups and interviews about the structures and processes of SOC implementation. They talked about formal agreements, teams and committees, leadership, communication, decision-making, and use of data to inform implementation.

**Structures.** A community partner described the structure of the SOC with Chestnut as the lead agency:

> *Everything's kind of spearheaded through* [project director] *and the Chestnut system, getting everyone together and pushing the hiring of the individuals to make those connections and getting everybody together to discuss kind of not only the implementation but what the finished product looks like and – and where we can identify those gaps. But it's definitely run through the Chestnut side who kind of organizes everything.*

Within that structure with Chestnut at the center, individuals noted that there are formalized agreements in place with partners. Among those partner agencies are youth clinical and residential services (including some faith-based), child welfare, substance use treatment providers, juvenile justice staff and administrators, representatives from the local mental health board and school districts, and child abuse advocacy organizations.

The SOC is perceived to have broad participation among organizations in the community, according to one parent:

> *I think it's great that everybody that works in the mental health or refers family to the system, they're all together in the same room now, and I think they just have to work on now how do they officially work so that the community is involved too and recognize that there's some people missing from this space.*

Beyond the implementation activities of the project directors, the St. Clair SOC structure also has a core leadership team. One project director described its participants; in generalized terms they include the project directors from the lead agency, directors of community agencies, the president of the mental health board, school district administrators, and individual from the state court who "also doubles as a parent," and the COFI parents who are now part of the team. A project director indicated that leadership team meetings initially were held monthly but more recently had moved to occur every other month instead, noting issues of scheduling and workload for many partners. The Leadership Team meets to identify needs in the service system (e.g., a mental health screener in the juvenile detention setting), to problem-solve challenges, and to share resources and updates. One project director talked about SOC structure, noting two additional committees that are more task-focused compared with the general leadership team:

> *There are three committees…one of them is the parent piece. Because everybody struggles with that. Keeping parents involved, getting parents to serve on like higher level committees at places like the detention or places like Chestnut or school districts, so that they can inform the…And there's one…we get together and we staff cases that are difficult for one agency to handle. So, I want to say that's it's just called the work group. The youth work group. And we usually, we meet once a month unless we need an as-needed meeting. But typically, at least two agencies bring a client that they're struggling with, that we're working and doing this, but we're missing X, Y and Z. And then the other one is the leadership table, that I am normally involved in.*

**Leadership.** Site visit participants were asked to describe the leadership for the SOC implementation. Several comments highlight perceptions of leadership provided by the grantee agency as well as the project directors. The following are one person's thoughts:

*She's a great leader. She has that style that it's motivating but laid back at the same time. She doesn't belittle anybody or make anybody feel – it's all about teamwork and building people up. Her position is like, how can I help or what can we do?*

Her words highlight leadership qualities connected to relationship-building, a critical piece of SOC implementation. Another individual also thought of the grantee agency as demonstrating effective leadership for the implementation process:

[Project director] *is very supportive as far as if our staff are having issues or if I'm having issues and we can talk it out together and she promotes, the same with me and my staff, promotes an atmosphere where it's, "Well, what do you think is best and why? Let's talk about it."*

**Communication.** Participants discussed communication processes within the SOC. They highlighted use of email communication, SOC leadership team and committee meetings, and the benefits of virtual conferencing. One professional described:

*I think the monthly meetings are key. If not, even more so there are e-mails that go out that say if anyone is able to, we can talk about this at this time. You can jump on a Zoom. We have had in-person meetings just to – it's different when you're in person and virtual. So, we've done both. I think it seems like to me the communication has always been very open. People just throw things out via e-mail or if we talk about something that needs to happen at a meeting there's always follow-up with what we talked about. Here's what we wanna do. This is when we're gonna start it, that sort of thing.*

A project director discussed continuing efforts to expand access to information for SOC partners and their use of different communication platforms:

*I think in person meetings are wonderful when we can do that. If not, Zoom. Teams meetings. A lot of lot of e-mails. We just really implemented Teams here at Chestnut. And so, I'm creating a system of care chats. And I think that'll be easiest, like a text message modality where everybody can always hop in and hey, I got this. Or hey, I want to talk about this. Or we need to hear about this. Just so that everybody has that open line of communication.*

The following words from a community partner highlights the importance of common goals and expectations to the implementation of a new system. It also reflects a point in time in which formal implementation leadership team meetings had been inconsistent and project directors were working on getting back to a regular schedule:

*We need to all be on the same page…because I don't know that everybody's operating the same. So, it was like, okay, we're all eating lunch. We're all sitting down. We're talking through this. And so, we made another plan to do that again in February, so that we continue, and then again, in May, to talk about services over the course of the*

*summer. So I think we put a plan in place going forward, I think up until then, we were maybe grasping a little bit, and it was more texts, or calls, or e-mails, like, hey, you know, is there anybody for [school]?...but it wasn't anything systematic…I think it could be done more frequently.*

**Decision-making.** Participants were asked to describe decision-making processes that occur as part of the SOC implementation process. One project director talked about seeking an egalitarian approach that involves exploring possibilities and finding a solution that works for everyone:

*I would say its typically consensus. So, we all throw out ideas, and then we, let's try this. And it's sort of trial and error. If this doesn't work, then let's revert to plan B, C, whatever we need to do.*

One professional partner also described her perception of a shared decision-making processes:

*Even when* [project director] *has an idea or has not just an idea, but it's, "okay. Here's what we need to do," she's still very much, "What do you think about that? Does that sound okay? Is that something you think sounds right?" So, it's never just, "Here's what you're gonna do or here's what I think needs to happen. Now you go do it." It's very much a collaboration between myself and the staff who are on the implementation team.*

Somewhat in contrast with the intent of the project directors, community partners were sometimes uncertain about decision-making so far or their role in that process. As evidenced in this focus group comment related to the SOC providing clinical professionals where needed in partner schools:

*We certainly aren't necessarily involved with any type of staffing, or where that where the allocations may go whether you know, we're not really involved with that part of it. It's more if there are particular curriculum needs or, you know, if there are anything that our therapist, or our social workers, or anybody has identified, any of them have identified needs for our kids. That tends to be more where we're involved with it.*

This quote highlights both the responsiveness of Chestnut as the lead agency to the needs of providers and youth in school settings as well as a perceived disconnect related to hiring of those clinicians.

A COFI parent reflected on the question of involvement in decision-making since they have been partnering with the SOC:

*Yeah, because there's not a real way for – like they don't ask me to weigh in on anything. They do ask me to do outreach for their events, but I feel like that's not my job. I don't do outreach. [Laughs] I don't pass out flyers. But still, I feel like there's a better use of my*

*knowledge of the community and who's in the community, but I think it does lack the effort to really integrate families into their decision-making in their system. There's things that are happening, and I think they think it's in the best interest of families, but it's not transparent I don't think, so that's not the way it should happen, in my opinion.*

**Data collection and use.** One question asked of participants related to use of data for SOC implementation. Participants talked about data collection, managing data, and translating data for decision-making. A project director talked about internal data collected to measure the efficacy of mental health training being offered to service providers:

*…they take a survey at the end, just like how do you feel that was? What did you learn? That kind of course evaluation. But then when you put the Youth Mental Health First Aider into the youth mental health first aid system, then every 60 days they get a survey monkey [that asks] whatever you learn in youth mental health first aid, have you used it in the last 60 days? Are you always thinking about referring a kid when you notice signs and symptoms?*

Such evaluation immediately following and again after the participant has had time to utilize new knowledge in the field provide information about the efficacy of the training for increased access to mental health services.

**Other supports.** A few other supportive factors were mentioned that participant felt have facilitated implementation so far. Institutional supports provided by the umbrella lead agency were highlighted:

*Our IT department is great. Our data team. We always say, "I'm not a data person." I'm like, "Uh-oh, me neither." But we have had – our data team is great. They put together – we can e-mail them and say, "This is what we need. Help us figure this out."… Same with our finance team and figuring out budget type stuff and where we're all that. We have people who can help us with that and keep us organized…our administrators. It seems like we have a lot of people who help us with the components when we need help.*

## 5.5 Parent and Youth Involvement and Leadership

One important aim of the site visit study is to gain descriptive data about implementation from as many perspectives as possible. Critical to that aim and to the spirit of systems of care are the contributions of parents and youth. Site visit participants were asked about how parents were involved in the SOC implementation. Their responses indicated that parents primarily provide input on their personal experiences with help-seeking and systems, and that input can inform decision-making for this SOC. COFI parents go through their own processes of capacity-building and the engagement of COFI with St. Clair is at the beginning of that purposeful process. As discussed above, parents who are part of COFI will be working with the leadership team to provide their perspectives on mental health needs, services, and systems. The COFI training process for parents unfolds over time and builds from the establishment of personal and family

goals to engagement in community and sometimes policy goals for the benefit of family wellbeing. That process helps equip participating parents with the knowledge, skills, and confidence that will support their own journey. The new partnership between the St. Clair SOC and COFI has been established to enhance parent participation in decision-making and implementation. Similar to other sites, without a structured organization like COFI to facilitate meaningful parent involvement, this has been an intractable challenge.

A project director talked about her perspective on the process of parent involvement so far:

> *In our planning phase, I would say that we had more parental involvement and youth involvement than we do now…I think that the idea of what we wanted to happen, and how we were going to roll it out, was good. And we had pretty much involvement until it actually started, you know? We started with maybe eight or so parents, and that it really went, there was a time where it fizzled to nothing. No parents were showing up to meetings. I know that it's right when COVID started, so maybe they were struggling to figure out life and what was going on.*

She also talked about specific strategies employed toward facilitating parent engagement in service planning. The following quote highlights efforts to integrate parent feedback on choice of screening tools to be used in the school setting:

> *So, what we wanted them to do at the beginning was figure out what behavioral health screening tool we wanted for the school. And so that took about three or four meetings. And then they chose one, which was the pediatric symptom checklist. The school was like, wonderful, you know. Thank you for your input. It was, you know, the school and parents all working together. And so, once that was done…until we have something else to work on, actionable, we're just kind of fizzled out. So that's what happened.*

The above statement indicates successful work with parents on a specific task, however, when that task was complete, the involvement was not maintained. The same project director went on to talk about the process of reviving of parent involvement via the COFI partnership:

> *Now in the past six weeks or so, we have enlisted the help of COFI. And so COFI is doing their parent training with about 13 parents. And they've been pretty consistent over the past six weeks…I think she said they've averaged about 13 per meeting…then I think from that…they chose a parent leader and then they choose how they want to go forward in leading the group…it was a really good group, they were very open and honest about issues in your community. And then the third week was about now how do we go about changing what's going on with these issues…and I felt like they had a great dialogue about what the issues were. They were mostly about school or juvenile justice, which is exactly where we're trying to impact…they just didn't even know of many resources that are available to them. So, I think working together was already like oh my gosh, this is wonderful.*

Participants who are service providers as well as parents talked about this expansion to a substantive COFI partnership:

> *COFI already has an established parent network…COFI is very involved in the East St. Louis, Cahokia, like some parts of St. Clair County. I don't know that our families are very involved with the COFI network…I think the hope was that COFI could take that parent ball and run with it…I don't think it's been as successful as they had hoped in getting the parent involvement.*

The above quote provides more context for the local COFI region and what sounds like a continuing gap between their work and families impacted by the SOC. A COFI parent also talked about the process of partnering with the St. Clair Youth SOC and how they can contribute to implementation:

> *I think COFI is what brings the families to – COFI supports in bringing the families to this work because what I know from having conversations with the Chestnut staff is that they were having a hard time engaging families for advisory council on their own….we trained 17 bilingual families in our first part of our training. Our training is three parts…It's like teambuilding, but they're learning to work together, build their relationships with each other to complete a team goal around mental health.*

The family advisory council discussed by parent participants was in its beginning stages at the point of data collection, but was described as a formalized group consisting of trained COFI members who would meet with the leadership team and provide the parent perspective related to mental health service needs. Another parent described more of what has been accomplished so far in terms of providing feedback to mental health professionals:

> *What I know is that at the end of the training that I'll facilitate with the parents is that they will hopefully agree to be a part of it and then they'll work to create some norms and guidelines on how they'll operate within the system of care. They may serve as advisory to the – I don't know what it's called – formal committee of this systems of care for St. Clair County, and they'll do their own activities. They might do some forums on mental health for other families. It's just all up to them and how they want to operate as a council.*

Based on this quote, the COFI family advisory committee would function as a separate group from the SOC leadership committee, communicating with them about implementation activities but also functioning in their own right, with their own goals and processes. Another parent talked in more detail about her perspective on the purpose of the SOC and the role of COFI parents in implementation:

> *The goals for that is forming – is for our counties, our families to form a family advisory council… where us families can partner, can form some form for relationships with the system of care people. The purpose of the family advisory council is exactly what it says,*

*us families providing advice or recommendations, but we see it as families or communities being a part of the work instead of the work being a part of us…often at times, people with higher power or authority base decisions off of us families. We offer input or the say so or the recommendations that we as parents have or feel that meet our families' expectations.*

A critical element of the above quote is the recognition of the power differential that exists between clients and professionals in mental health settings, both in terms of services received as well as the decision-making behind those services. The expressed visions of the family advisory council are grounded in the desire to equalize that power and to truly engage parents as partners. The same parent provided some additional perspective about what meaningful parent involvement would look like in practice:

*I think there would be a space or time in the agenda to really talk to parents…hopefully it's not tokenizing them. Then some intentional recruitment on their behalf to bring in the families they work with. That would also support building the capacity of families in that group, in the system, and then asking parents first...and then developing a number or a program or a resource and then go on back and asking...and then believing me…It's like you can say it and people will be like, okay, I hear you…but it's really like a savior syndrome to me. It's like, we have to save these Black people. They can't save themselves.*

This parent's honest reflection about the impact of race for the power differential that already exists between mental health providers and clients is important. She continued to talk about what families value in terms of forging partnerships with organizations and systems:

*I think it doesn't always have to be about giving out a resource and that the meeting can just be about building those relationships so that we can have something that's sustainable and the parents will want to remain there. I think that's the difference in my work and what other community organizations do, is that I'm not handing out anything but dignity and respect and a relationship. You can have a relationship with me and I want to tell you all the good things that I see in you and how you can use that to build power in your community and make change.*

Many parent comments indicated that they perceive mental health and social service providers to be well-intentioned but perhaps missing the mark with parents in terms of what is motivating and valued. The above illustrates the idea relationship-building and human connection may be more valuable currency for some than material incentives. At the same time, project directors described efforts to provide compensation to support parent involvement:

*We ask them what they wanted or what they would choose…I don't want to dictate what somebody wants. For the meeting so far, all they wanted is nice dinners. So, we've done that…that's part of their stipend. And then each of them are going to get a gift*

*card to Aldi. They thought that could be helpful for Thanksgiving. I think we're going to do $100 for parents.*

A project director also discussed efforts to make meetings more accessible to parents in hopes of enhancing attendance:

*We do have two families that are from, [town]. But they're largely Spanish speaking. So, they attend and bring their own interpreter…then also to those parent meetings, they can bring their children. We have a person who's there that can help watch them. I mean, they're still in the same room with the parent.*

**Youth involvement and leadership**. Youth involvement in implementation has been difficult to initiate and sustain. Site visit participants acknowledged that this is an area that they need to develop better strategies. One project director stated:

*I think if we're able to build groups and find people who are advocating for whatever is going on within their group, I'm hopeful that we can get those youth to be leaders for us. So, nothing really yet, but I think there's – we've been talking about that and trying to figure out how to do that.*

Another participant talked about youth engagement in the initial SOC planning process:

*I would just say it was more at the beginning, when we had a family engagement specialist. They have, we did have one youth who helped participate in that original, like let's figure out what screening tool to use. And he was wonderful and gave great feedback. He went to college, so I think we're just looking for COFI to help us with that also…*

One avenue for the future might be working through COFI to generate youth engagement as evidenced by this exchange:

*Interviewer: Does COFI ever sort of branch out to working with youth in addition to parents?*

*Parent: Yeah, it did. I've done it before maybe a few years ago with a group of high school students. I trained them in our model and now they – sometimes I'll see then work with [a community-based] organization. They hired a youth support person to continue the work with them.*

## 5.6 Barriers to Implementation

**Workforce shortages.** Across the state and nation, there is a shortage of mental health providers. This challenge was entrenched even before the COVID pandemic exacerbated it to crisis levels. This was acknowledged by SOC partners and they discussed the impact for workload and the capacity of agencies and professionals. Put simply by one participant, *"So staff turnover is just a huge barrier. It definitely makes it hard to implement all the things you talk about implementing when there's no one there to do it."* One service provider talked about workforce-related challenges:

> *It seems much more difficult to find people, even at the current time…we're kind of seeing it across the board where we used to have 30 or 40 applicants, now I may have four or five so – and – and we're currently about five officers short at detention and that's, you know, a staff of 20 – 20 officers and really hurts us.*

Managing the demands of turnover and shortage has had an impact on the project director's time and overall ability to engage with partners and build relationships and collaboration. She stated, "our staff turnover has been a huge barrier…just the amount of time that I have had to also put towards training new people…". The shortage of providers has been a barrier to the ability of the SOC to hire mental health providers to fill school-based positions. According to one provider:

> *We're still waiting for our counselor from [lead agency] to come. We did have one last year for a short amount of time. It was extremely helpful while she was here. But now that there is problems with getting people. We haven't had anyone in the facility.*

The SOC has engaged a number of strategies aimed at mitigating the impact of the workforce shortage including incentives, bonuses and competitive pay aimed at hiring and retention. Support in the form of competitive compensation was also noted:

> *Chestnut, not too long ago, bumped up all of the pay for almost all employees. I think we had a lot of people who have told us since then, "I wouldn't have stayed long if it wasn't for that." They're grateful for that now. We have hiring bonuses now and referral bonuses and things like that. So, I do think that helps.*

**Lack of buy-in from partner agencies.** Another barrier to SOC implementation identified during the site visit was that fact that not all community agencies that serve children and families are aligned the aims of the SOC. Operating from a trauma-informed perspective was one example of a paradigm that has not been adopted widely in juvenile justice in the area, one of the two populations of focus. This has resulted in a process of demonstrating the value of the SOC to potential partners:

> *I'll say like the detention center we really struggle with. Obviously, I want to train everybody. And I don't know that they don't see the benefit. I mean, they haven't done it*

*yet…for instance if I'm not feeling like the process is moving forward or implementation is moving forward, then I will say several times, like hey, let's get this schedule. Let's get this handled…I don't know if it's disagreement or just like, we don't really know what the benefit might be so we're not really inclined to schedule this. So, I think just we're just being patient and hopeful that at some point, they'll see the benefit.*

A lack of buy-in and resistance to implementation activities like mental health screening on the part of a partner like the detention center is clearly a substantive barrier to achieving SOC aims.

**COVID pandemic.** The COVID pandemic coincided with SOC implementation and has of course had impacts on the process. At the same time, participants talked about how they withstood the challenges:

*Yeah, I think obviously COVID. But we've pretty quickly you know, could move to telehealth and still provide services. Again, like with our meetings and kind of leadership, we moved to virtual as well. I don't think that, I mean, COVID's just a barrier in general. But I don't think it was too terrible for implementation. I do think when kids weren't in school, obviously we weren't getting clients referred to us, so I think service provision was a little bit less.*

Pandemic restrictions also created delays in the ability to engage SOC implementation activities like training:

*You know, so we are waiting to train that still. We did have a date, and then…the detention center was on lockdown because somebody had COVID. And then it was like, okay, let's reschedule. And then we never have. So, we are still hopeful to train that.*

# 6. Results – Youth Empowerment Services (YES) System of Care for Youth and Families

Youth Empowerment Services (YES) – System of Care for Youth and Families services Knox, Warren, and Henderson Counties in Northwest Central Illinois. According to the 2020 U.S. Census, Knox County has a population of 49,967. The largest city in the county is Galesburg. In 2021, the median household income in Knox County was $45,994. 16.2% of people the county live below the poverty level, which is higher than the state average of 12.1%. Additionally, 18.2% of children (18 years and below) in the county live in poverty.[21] In terms of race and ethnicity in the county, 82.4% of the population are White (non-Hispanic), 8.73% are Black or African American (non-Hispanic), 3.9% identify as multiracial (non-Hispanic), 3.33% are White (Hispanic), 1.15% are Other (Hispanic), 1.47% identify as multiracial (non-Hispanic), 1.08% are Asian (non-Hispanic), 0.791% are multiracial (Hispanic), 0.344% are Black or African American (Hispanic), 0.266% are American Indian or Alaska Native (non-Hispanic), and 0.114% are Other (non-Hispanic).[22]

Warren County has a population of 16,835. The largest city in the county is Monmouth. In 2021, the median household income in Warren County was $59,673. 12.2% of people the county live below the poverty level, which is slightly higher than the state average of 12.1%. Additionally, 17.8% of children (18 years and below) in the county live in poverty.[23] In terms of race and ethnicity in the county, 83% of the population are White (non-Hispanic), 4.81% are White (Hispanic), 4% are Black or African American (non-Hispanic), 3.78% are Other (Hispanic), 1.5% are Asian (non-Hispanic), 1.2% identify as multiracial (non-Hispanic), 0.648% are American Indian and Alaska Native (Hispanic), 0.453% are multiracial (Hispanic), 0.377% are Other (non-Hispanic), 0.0353% are Asian (Hispanic), and 0.0294% are Black or African American (Hispanic).[24]

Henderson County has a population of 6,387. The largest village in the county is Oquawka. In 2021, the median household income in Henderson County was $62,202. 8.4% of people the county live below the poverty level, which is lower than the state average of 12.1%. Additionally, 14.2% of children (18 years and below) in the county live in poverty.[25] In terms of race and ethnicity in the county, 95.5% of the population are White (non-Hispanic), 1.84% identify as multiracial (non-Hispanic), 1.66% are White (Hispanic), 0.668% are Asian (non-Hispanic), 0.163% are Black or African American (non-Hispanic), and 0.163% are multiracial (Hispanic).[26]

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[21] Census profile for Knox County, IL: https://data.census.gov/profile/Knox_County,_Illinois?g=050XX00US17095
[22] Knox County DataUSA: https://datausa.io/profile/geo/knox-county-il
[23] Census profile for Warren County, IL: https://data.census.gov/profile/Warren_County,_Illinois?g=050XX00US17187
[24] Warren County DataUSA: https://datausa.io/profile/geo/warren-county-il
[25] Census profile for Henderson County, IL: https://data.census.gov/profile/Henderson_County,_Illinois?g=050XX00US17071
[26] Henderson County DataUSA: https://datausa.io/profile/geo/henderson-county-il

According to the grant application submitted by the lead agency, Bridgeway (https://www.bway.org/), it is a community-based nonprofit organization serving rural areas across 20 Illinois counties. The agency endeavors to provide services that are individualized to each person or family and that highlight strengths and empowerment. Bridgeway provides a broad service array for adults, children and families that include behavioral health care, supportive community housing, and rehabilitation related to mental health, developmental or intellectual disabilities, and substance use. Behavioral health services include outpatient therapy, case management, mobile crisis response and school-based supports.

The grant application stated that the SOC would focus on children (0 to 21) and families, regardless of need or diagnosis. There would be a focus on target populations including children and youth with or at-risk of serious mental or emotional disorders who are involved with at least one of five major child-serving agencies and who demonstrate impaired functioning in at least two areas of daily living. Additionally, the proposal indicated that the SOC would also focus on children and youth who are currently or are at risk of out-of-home placements and who receive services from multiple partner agencies. A final goal was services to transitional-aged youth (16 to 21 years) who need additional or more intensive supports. Strategies for meetings these aims at the time of the application included the provision of education and prevention for all ages, early intervention, and intensive interventions and supports. The grant proposal also notes a number of specific goals, including increasing the types and number of services provided in the community; reducing symptoms, stressors, and unmet mental health needs; enhancing use of evidence-based interventions; decreasing school-related concerns; increasing placement stability; increasing parent and community involvement; and decreasing juvenile justice referrals and psychiatric hospitalizations for youth.

One full-time project director is employed by lead agency, Bridgeway. This individual has been in that position for most of the life of the grant and is supported by her agency-based supervisor. No additional staff to be funded by the grant were noted in the proposal. The YES 3.0 application included a stated requirement that the Community Planning Team include partners from education, primary care, mental health, and be inclusive of at least 25% self-identified consumer parents/caregiver/youth. At the time of the site visit each of these categories was represented in implementation efforts except caregivers and youth.

A total of eight individuals participated in the site visit, including both project directors, and six community-based professionals. No parents or youth participated. The community partners represented an agency that provides for families' basic needs, administrators from the school district, and behavioral health and early childhood service providers.

## 6.1 Pre-grant Activities

Along with the other 3.0 grantees, YES applied for the CMHI 2.0 funding from the Illinois Children's Health Foundation. Following that unsuccessful application, they were provided feedback and reapplied. We asked participants about the activities undertaken during that year, to understand how the site used feedback from the first proposal and planned for the

development of the SOC during the interim year. This exchange between two providers from SOC partner agencies describes activities and attitudes of partners during the interim year:

> *Person 1: I feel like we just continued our work. I don't feel like anything stalled or halted…when that grant was not received the first time. I feel like we continued to push forward and work together with all the agencies at the table to try to figure out what we could continue to do and create opportunities.*
>
> *Person 2: Yeah, that was a timeframe where we were refining our referral process and what that looks like. We just – like she said, we continued the work…The grant was offering money, but we were all still at the table from the beginning as well and it didn't interfere with what we were doing. Everyone was still coming to meetings, and I do remember that we were refining the consent form. So yeah, the work just continued on.*

Other participants echoed the perception that people continued to push their work forward between funding cycles:

> *I don't feel like we lost a lot of buy-in from what I remember. I mean, we continued to come to the table and just talk about ways that we could structure an organized effort…we continued to move forward regardless of that first time not getting the funding.*
>
> *When we initially applied and didn't get the grant the first time, we knew then that we were going to move forward with the system of care that we wanted to build, that we thought was important in our community...We knew there needed to be a centralized kind of hub or location for people in our communities to be able to go to so that there was no-wrong-door approach. People were just beating themselves up going to so many different references, referrals, resources, and having to start over, so we really started developing our system.*

This second quote highlights the idea that this community was united in understanding their needs and their commitment to act to meet those needs via whatever pathways they could forge, regardless of any specific funding stream. In this rural area, providers commonly cross paths in their work and have shared challenges regarding mental health services in the community. One project director talked about her involvement with the overall effort that is funded by, but also transcends, the ILCHF grant:

> *I have been with Bridgeway in the position of system of care coordinator for our program called YES. That stands for Youth Empowerment Services. But I have actually been working within the system of care since 2018, after this project didn't get funded the first time around, and I was actually working for another organization, and I was what was considered a case manager with a case that was referred into the system. So, I've been able to see the system work both in the trenches and as well as in the director role of the grant.*

The following quote from a project director offers more insight into the feedback that was received and what it meant for moving forward:

> *[*The first grant *application] was spearheaded by the Regional Office of Education, Bridgeway, OSF Health Care and a couple others...When it was sent out and denied, the reasons were in relation to the people. They liked the project, but they weren't going to reach as many people as the other projects that were funded. But in 2018, January of 2018, they were already ready to start serving kids and to start to work the system.*

This quote reflects consistent efforts toward finding the right formula of funding, community engagement, timing, and commitment from professional partners to move the vision of a system of care forward. Site visit data all pointed to the fact that regardless of funding status, their efforts to better coordinate services and utilize shared staffing of cases were happening by early 2018. Ensuring broad participation in the community was an aim that the proposal writers focused on for the 3.0 application, which included the goal of including self-identified caregivers as at least 25% of the implementation team.

## 6.2 System of Care Goals

Site visit participants were asked to describe their perceptions of formal goals of the YES SOC. Participant perceptions of YES' goals appear consistent, with the primary goal of the project to serve families with multiple needs through system-level service coordination:

> *Really, the primary goal for us is that no-wrong-door approach. If somebody is referred and they have five different needs, those five people are sitting at the table and they're doing the reaching out instead of families trying to track things down…instead of having people running around trying to get all their needs met. Smaller things, like bringing on more providers or bringing on more partners, staying up to date, making sure that we're communicating with each other, we've recently started the IRIS system, which I think is going to be great… But I feel like it's that one overarching goal in how we can be that no-wrong-door approach for the people who need it.*

One of the project directors also described the overall aim of ensuring there are services in place to meet whatever needs families are experiencing through system-level coordination and collaboration:

> *I think the main goal now is to create a system of care for families. So, it's bringing a family and their needs to the table and then each organization reaching with the piece that they can provide or the place that they can support that family. We're doing some of the communication to where families aren't having to go from door to door, to agency to agency, and we're able to communicate with each other...*

This quote highlights the SOC focus on family-centered service design and provision, networking and close professional collaboration, and developing and expanding resources and

partnerships to continue to address unmet need. Part of YES' aim of coordinated service provision is the use of supportive models like streamlined referral, wraparound, and elimination of redundant services:

> *I think one of the things is we have several agencies doing great work in our community, and then each one of the agencies, including ourselves, had different ways that families would be referred. We've been working hard to create ways that we don't overlap or duplicate services and that we work to wrap around families, I think. So, it was just as conversation of leaders from all the agencies that support families and the best way to work together to do the best work we could for individual families and children.*

Part of that collaboration is service coordination and finding strategies for more seamless referral, response, and follow-up. YES has begun the process of adopting the Integrated Referral and Intake System (IRIS)[27] developed by the University of Kansas. IRIS is a collaboration tool that helps communities and systems provide and manage service referrals for families, collect and make use of data, and connect clinicians across organizations. The program directors shared that it was the best option they found that offered referral, follow-up, coordination, data collection, and other collaborative tools that could connect individuals and agencies working within a system. Its adoption for use in the SOC was still in progress at the time of the site visit; one project director talked about the process of adding IRIS to the efforts of the SOC. Program directors discussed engaging a system of education and relationship-building with partner agencies about IRIS and its shared benefits.

> *One of the goals was to really help people to get connected to IRIS and help them understand it, give IRIS trainings, and really a thorough comfort for the agencies that are coming into it…definitely getting people comfortable with the IRIS system so that it can be effective.*

One important aim that was evident from participants' description of YES is to serve the whole person, rooted in understanding that basic needs must be met for people to be able to focus on higher level mental health intervention. Participants talked about a hierarchy of needs framework that seems to guide thinking about how to approach mental health needs as secondary to families' need for shelter, food, and safety. One person talked about how this guides the SOC:

> *These families and youth aren't going to need just behavioral health services. Sometimes they need transportation, they need food, they need case management, so that's why we reached out to people like the [agency], the food pantries in our area, any youth-serving agency, really, but anybody who also may potentially be able to serve family needs. We really kind of tried to expand it [*the SOC*].*

[27] https://connectwithiris.org/

This quote reflects the approach of expanding the lens on mental health to include working to meet the needs of the whole person and the whole family. Most site visit participants talked about the level of crisis that families in their area are experiencing and the impact for a narrow mental health focus. Another individual stated, "our project really acknowledges and understands that families can't focus on their mental health if their basic needs aren't being met."

Active collaboration is both a goal and a pathway to meeting other stated goals of the YES SOC. One project director stated:

> *I would say that obviously we've touched so much on collaboration but that really is one of the biggest goals of YES. And really, because without the community partners, YES wouldn't be what it is.*

## 6.3 Activities and Progress Toward Goals

A project director reflected on moving from aspiration to implementation of the YES SOC, noting the importance of that initial vision and purpose. The director also noted what is working so far in terms of direct service referral and provision to families in need:

> *I just think back when we started, and I remember sitting at a table and saying my dream is that we bring a family and their issues to the table and we all talk about how to resolve those issues. We're there, we're doing the work that matters. I think the system is very strong. Every now and then I suppose we have to tweak something, but I think things are really happening, and now most of our focus is around how to serve families from our communities that need things or need the most, and I think that's kind of where we are now and the system is working very well in doing that. I just think overall this* [YES] *has been just an outstanding thing for our community.*

**Service coordination**. A core function of the YES SOC is to serve as the central organizing hub of a network of service providers to problem solve and coordinate resources on behalf of families in need. A participant described how service providers discuss family needs in the context of the services each agency provides. As stated by a program director, the community planning team *"is the system of care*" in that their time together to work on implementation is primarily used for case staffing to ensure families receive needed services and to identify gaps and redundancies.

> *Also, at the beginning of each* [staffing] *meeting, they take some time to have one organization talk about what it is they do and what their services are, because you would think that as small of an area, as rural as we are, that we know everything about everybody, and I think we like to think that we do.*

One participant described the YES Community Planning Team meetings, during which all the partners meet to discuss the families' need and put services in place:

*Well, originally, their goal was to get the system established and up and running, which they've been able to do, I think, very successfully, and they've been doing the work. I mean,* [the planning team] *meet, and they talk about the cases, and who can do what and who can help, and who is going to reach out. I mean, they're doing the system of care work. They're looking at the referrals and seeing the differences that they can make, and really reaching out and helping these people.*

Another element of service coordination is the management of referrals made for families. The project directors have spent time gathering information about software for client data management systems like IRIS (Integrated Referral and Intake System), getting feedback from partners about their needs and hopes for improving service coordination, and the experiences of other ILCHF-funded SOCs:

*We were in the infant stages of actually beginning the work of receiving referrals. So, we were working on what does that look like, how does an agency refer someone in need, and how do they know this is the right? So I remember the leads of the project had visited some other areas that had this in place and they brought back what it looks like and how it's implemented in their area and educated us at the table on what referrals look like coming in, how someone that's a referral partner knows this is the place to come and what all that entails...*

While a system like IRIS is not required for the success of an SOC, it is a tool that has been adopted by other ILCHF sites in order to enhance the practice of making relevant and effective referrals for clients following the identification of needs. It also helps systems to avoid service redundancy. This exchange between two providers in a focus group reveals more about the importance of service coordination using a system like IRIS:

*It's one door that somebody can go straight there and get 10 different agencies offering their supports. We're not filling out 10 or 15 referrals, we're not sending families to 10 or 15 different locations. There's a coordination of care. I think the communication among agencies so that we're not overlapping services but we're enhancing each other's services, I think it's created a great way for us to communicate and wrap services around our families.*

*[response:] Can I add to that? That I think for families it's the wraparound that's critical, and I think with the department, the number of partners that we have at the table, there aren't any areas that are missed. I feel like it's a pretty complete wraparound, which makes a huge difference.*

Others discussed the benefit of IRIS for one agency and for maintaining client-related communication between providers:

*That IRIS piece…I feel like its really put us a step up in our organization, like how we keep track of everything, and another level of communication with one another. I'm a visual person, so having that as a place to go to look and have something tangible, I just really think that's really upped our game, if you will, in how we are able to service everyone and do what we've been doing all this time but do it so much better.*

*One thing I kind of want to add, and it's kind of a benefit of the system that maybe we all didn't expect, and that is we all understand each other's work so much more fully, and then the benefit is that we're able to support families that don't come through the YES system and don't have those multiple of needs that would make us need to come together at the same table, but we service other families with individual needs quicker and easier.*

She further reflected on her perceptions of potentially deeper impact for families:

*I also think…so you have the services, but the families have a whole group in their corner, and they know it. That's an incredible feeling for a family that's at risk who I know from my years they often feel very marginalized, undervalued, and to have people that stand with them is almost as important as the services that we're providing for them. I think the group does an amazing job of that.*

**Professional development.** Professional development for providers within the YES SOC is also an important aim that has been supported by a number of activities to date. Specifically, the project director has been trained in Teen Mental Health First Aid, two Bridgeway clinicians have been supported in continuing education aimed at evidence-base practice, and leadership development for both project directors. A project director described her approach to developing these opportunities for staff and some examples of training topics related to both clinical practice and leadership.

*YES has also been able to send two clinicians to…EMDR training…So, we are always asking, "Is there a training that you want to take that you don't have funding for? How can we support those of you in our system as well?" We've extended that beyond just Bridgeway…*

*So thinking creatively in another way, to help combat burnout and improve retention, and also pour into some clinicians, myself and three clinicians, two substance support staff, and our community engagement specialist here at Bridgeway are all going to the Global Exchange Conference, which is the largest mental health, substance, and leadership conference in the world, and we're all going to be able to take trainings and workshops and improve those areas of our careers individually…so, our clinicians are going to get continuing education hours. Our substance support specialists and system of care coordinators are getting leadership, and they're learning new forms for treatment for the substance side of things.*

A project director talked more about professional development, citing an evidence-based program that helps students and adults become better equipped to respond to mental health concerns:

> *As we find trainings, or as there are people in the community [we] will bring that to the monthly meeting. [The other project director] was actually trained as a trainer in Teen Mental Health First Aid, and so she will assist us in going to the sophomores in local schools and training them on mental health first aid, which I think she is going to be great at. We also want her to be trained in adult and youth, too, as a trainer so that she can really bring more information to her communities, the people that she is serving, and really be that true advocate.*

As reflected above, in addition to engaging in her own professional development, the project director also works to educate and train other professionals in the community and youth in school settings.

**Community outreach and small funding projects.** Another critical set of activities for the YES SOC is their continued efforts at outreach and relationship-building, both with potential professional partners and with the community at large. One pathway for doing that has been to share resources both for their inherent benefits but also as a strategy for demonstrating the value of the SOC in the community. The project director gave an example:

> *So recently there was some money available and discussion on the best way to spend that money, so there was some outreach to the schools for that. We have a large, non-English speaking population in our communities, and so some of the money was spent on digital translators that are really appreciated by everyone who received one.*

She further described how YES has used funds to support efforts to enhance access to services that were identified as needed by community providers. For instance, she stated, "I was giving money to those individual funds saying, '*Hey, I have this money and you are in need of translation services. I just spent $9,000.00 on target translators'*…" Another example of small grants to support service provision was described by the project director:

> *We had a school reach out. They were in need of supports…So YES offered $2,000.00 to each building's school counselors…they could be used – specifically the elementary schools were encouraged to use them to be a kind of – the theme has been, "Be proactive and not reactive." So, have supports in place for students like bereavement libraries, socioemotional tools. Make sure that their spaces are welcoming and inclusive. So that was kind of how the money was intended to be spent, but it was also shared with them that they're doing the work and they are short-handed, and we want to make sure that they know that they're supported and that they can come to this group…when they have a student that's struggling, make referrals and don't do it alone, and we wanted to be a resource.*

That ability to demonstrate the benefits of the SOC through material resource sharing has been important to building relationships:

> *When we're identifying a need and we're able to actually fill that gap. People were like, "Oh, wow. There is real funding here," and now people are more interested and excited to share.*

## 6.4 Implementation Structures and Processes

Another topic discussed in site visit interviews and focus groups related to the structures and processes that support SOC implementation, including implementation teams, leadership, communication, decision-making, and collection and use of data to inform implementation.

**Organizational structure.** Participants described the types of organizations that are part of the YES SOC; disciplines and services represented included community mental health, a food bank, school district administrators, school administrators and staff, substance use treatment programs, the juvenile court, health care and others. One project director described the process of gathering participants, informed by the SOC goals:

> *We really wanted people from all areas, so we wanted to make sure that we had any behavioral health providers, any substance use providers. We knew that the schools needed to be on board…Because we are a very rural area, we really wanted to make sure that we had the local hospitals…also the local health departments. We knew that we needed to get agencies involved, like child welfare services, and so they were at the planning, but, also, we really wanted to think outside the box. These families and youth aren't going to need just behavioral health services. Sometimes they need transportation, they need food, they need case management, so that's why we reached out to people like food pantries in our area, any youth-serving agency, really, but anybody who also may potentially be able to serve family needs.*

While Bridgeway is the lead agency and grantee, participants talked about shared voice and power among partner organizations. The two Bridgeway project directors facilitate meetings, communication, day-to-day operations, relationship-building, and community outreach as part of system implementation. Based on participant responses, there are not multiple layers of leadership and implementation teams or focused committees; rather, they define the coalition of individuals who have committed to participate simply as YES. No one described additional teams or committees. One project director stated that, "*They haven't really done one-off subcommittees because they haven't needed to, but the option is always there if there is something additional that we would like to tackle that not everybody needs to be a part of*." Participants widely indicated that YES is known in the community and that there is broad participation among relevant community mental health providers, substance abuse treatment professionals, agencies that assist families with basic needs, and others that serve youth. A project director characterized different levels of commitment that professionals are able to make to participate in SOC implementation:

*I'd say we have champions and cheerleaders. We have people who really understand the work and they are really heavy in it. They show up consistently. Then we have cheerleaders, who they really believe in the project, but they don't have a lot of activity in it for one reason or another, but they really want the project to succeed. So, we have both.*

She also described how many partners are connected with YES:

*…there are 107 people listed…I would say there are around 20 of them that are without fail at every meeting, no question…Then occasionally we'll get those extra individuals that come to cheer on the project.*

A project director talked more about numbers and types of SOC participants and highlighted a growing reciprocity among community agencies:

*From 2021, when I took over, we had 60 people onboard that had signed MOUs…that were active in the project. Then in '22 when I turned it in, I have 85. So, I've grown from 60 to 85 individuals, and there are 42 agencies now involved. So, we've expanded to Big Brothers/Big Sisters, Family Planning. All of the health departments are now involved. I have school-based counselors in every district that are involved. We even go into like specific programs like WIC. I don't have any representation from DHS, but I have consistent monthly representation now from DCFS instead of sporadic…it's been a lot of networking and building.*

As implementation continues and more elements of the SOC are in place, a project director noted possible changes on the horizon. Current staffing on YES is limited: just one full-time project director dedicated to implementing the system and the part-time director in a supervisory role. However, additional staff are a possible future investment, in particular as a result of adopting the IRIS system…:

*…I can see down the line – I feel like we have a really great foundation now, but I feel like if we continue to grow, I could see where the…IRIS management could almost turn into an assistant job…managing when the referrals really start coming in by the dozens. I could see where that could potentially turn into an additional job, but right now, no. Everything is manageable.*

The YES SOC has adopted a process of formalized agreements between the grantees and active SOC team members. From the perspective of the project director, having a formal agreement like an MOU contributes to commitment and consistency among participating members:

*I think what we find is it causes people to commit a little bit stronger than if we just said, "Hey, show up once a month and we're going to do this." It kind of outlines what we want to do and what our purpose is, and I think sometimes once people put their name*

*and agency on a document, their commitment level is a little bit higher. It helps us, too, because if we have a partner who isn't really participating, we can say, "You signed the MOU and we really need you to be a part of this," so it holds a little bit more weight, I think.*

**Leadership.** Site visit participants were asked to talk about leadership in the context of YES implementation. One participant from a partner agency shared their perceptions of the leadership provided by the grantee agency:

> *So, Bridgeway provides the leadership, and it looks like a coordinated effort. The communication is fantastic. I think somebody mentioned IRIS and ensuring that all of our agencies were trained on IRIS. That couldn't have been easy, but from my perspective it was pretty smooth. I can't imagine getting all of these agencies on board to do that. I think each time we bring a family to the table we see great results. So, I think all the work that's done behind the scenes, if there's any hiccups, we really don't see them. I think it's overall fantastic leadership.*

Another individual also talked about how leadership functions in the context of YES implementation. In the below quote, the emphasis on maintaining a spirit of collaboration and equal power is evident:

> *I think that also goes back to the way the meetings are run. I think everybody is very included in the meetings, and so it's not one person saying this is what's going to happen. It's the entire group. So, I think in that regard the leadership is already shared.*

Another individual provided their perspective on balancing leadership by Bridgeway with a decentralized approach where leadership is shared:

> *I would say that [project director] provides the primary leadership for the overall system of care. Obviously, Bridgeway is the grantee, but we have worked very hard to – it's not Bridgeway's YES system of care…[she] doesn't ever want to be the one deciding factor for anything, and she really works hard to collaborate and include and get others to participate in that leadership part of it. She does not ever want to do it in a vacuum or by herself, and so she is constantly pulling those stakeholders in as a leadership group overall. There isn't a separate core leadership group, but we try to impress that all of the stakeholders or the partners are a part of that leadership of the system of care.*

A participant from a partner agency talked about her perceptions of the support that is available for the primary project director within Bridgeway. As paid staff supporting SOC implementation, project directors are engaged with one another and with community partners to provide needed support and guidance:

> *If [*the project director*] were to be absent for any reason or whatsoever, [her supervisor] would easily step in that role for her. The communication between the two*

*of them, [she and her] mentor is seamless to me on our view, on this end. If she doesn't know the answer, that is exactly what she says, is I will reach out get back to everyone, so she knows where to go to find answers.*

The focus groups consistently appraised the primary project director positively, highlighting her relationship-building skills and her professional and personal background. According to her supervisor:

*I will always sing her praises, hiring [her] was probably one of the best hires I have ever made in my entire career. She came into this position when we were really just kind of like, "Well, we really don't know, but this is our goal, this is our vision for this," and the experience that she brought with her from the school system, but also being a parent and having a great connection with schools and other parents, has been such a valuable resource to us…She has been a great resource. She loves interacting with the parents and the youth, and I think she is really that tie that binds it all together for the partners because she is so motivated and dedicated to the position that she has.*

Similarly, a community partner spoke of leadership as making human connections and being a model of commitment to the work:

*I think* [project director] *has – I think part of leadership is being able to connect really well with those around you…I think that her connection, her passion for this as well…she just really has this passion for helping kids and families, and I think that helps drive how well this has been implemented as well.*

Another professional partner discussed the importance for leadership of the primary program director's willingness to be proactive and find creative ways to ensure the work gets done:

*From an outside agency point of view, I see consistency. I see follow-through. I see someone who isn't going to ask anybody to do anything that she won't step up and do herself. The leadership by example type thing…and discover any gaps in the system, and trying to really see what she can do about it.*

**Communication.** Another question concerned communication as part of SOC implementation. Participants consistently praised the communication, as the following quotes illustrate:

*The communication is excellent. Like [others in this group] have both said, we know the agencies and the services in our communities because of this group and because of the work that we're doing together. I have followed up on families that have been referred to other agencies and the circling back that we've done, and there's some incredible things happening.*

*I also see lots of outreach. So, I know* [project director] *contacted me many times in between the meetings. I think she's a really good connector of people and really does a*

*wonderful job of – I'm going to say brainstorming, so that we're getting the best solution possible.*

Participants outlined methods of communication utilized by the project director which included Facebook posts, group e-mails, and discussions during monthly meetings. One individual described perceptions of communication from YES leadership with community partners as involving different methods of communication. They also noted considerations made around the amount of communication about the SOC:

*I think they do a really good job for as many people as there are at the table…When they're in the monthly meeting, everybody is very verbal and vocal and communicates very openly with ideas and thoughts. She's very good about also being mindful of communication overload, as well…she is very mindful of what she sends to people, how much she sends, I think they do a good job overall as a group in communicating actively and ongoing with each other.*

It also suggests that communication is somewhat one-way in terms of communication outside of the monthly meetings. The project director also spoke about her communication strategies in and between YES meetings:

*I always do a follow-up e-mail…and say, "These are the big ticket items that we're talking about." If I know that I'm in need of like a rich conversation and I want a good discussion, I will say, "I want you to come with answers to," and then put those down…*

Although most meetings are on Zoom due to the pandemic, one participant saw benefits in meeting in person:

*I would really like to kindly suggest that maybe we do a quarterly in-person networking style meeting. We had one last spring…maybe it was last fall. We were able to accomplish one and it was really well-attended. It was a great time with like 50 people…it's nice to see people outside of a computer screen, but schedules are really hard when you have that many people. To get everybody in attendance every month is really difficult. I'm just always really humbled by the amount of people who believe in the work of the project that show up every month.*

**Decision-making.** Participants were asked about decision-making in YES SOC implementation. Commonly discussed elements included processes for generating input and involvement of different stakeholders, and shared decision-making processes. Participants painted a picture of shared input among partners, facilitated by the project director. For example, one partner said the following:

*I would say that a lot of bigger decisions are consulted with our YES council, especially when it comes to needs and things like that, especially when we have talked about strategic planning in the past…I really don't see too much conflict on calls or anything*

*like that, or any disagreement about decisions…I think bigger things or "How should we use these funds; what do we think would be best?" she definitely consults the group, I would say.*

A project director talked about how her counterpart promoted group decision-making:

*Basically, if there is a decision that needs to be made,* [project director] *adding it to the agenda of a monthly meeting, or, if need be, outside of the monthly meetings, she would put it out there to everybody. But they put it on the agenda, they discuss it as a group; people are open to giving their ideas and thoughts, and then they really do come up with ideas as a group, and decisions as a group. There are times where maybe she doesn't get as much feedback as she would like…But she really tries very hard to make it a group decision. It's very rare that she and I make a decision outside of that.*

One partner gave a concrete example of this decision-making process:

*I think there's agreement. I think the group is asked. I remember the logo process, for example. Multiple logos were presented, and people talked about the pros and cons of each one and then we did some more refinement and then it was brought back to the group…you get peoples' input, you kind of go back to the drawing board and redesign and come up with a good solution that everyone agrees on…I remember the back and forth, and it was a very good process.*

From the perspective of a project director, the following offers some insight on creating shared decision-making:

*I put in [the agenda] for October's meeting, "Please come with ideas on how you would like to see funds spent." And then we would talk about those, and I would ask, "Is there anybody that would like a motion that we move forward with that?" and then we'd get a second and a vote…I will say that people are really good about sharing their concerns or what they think needs done…So, we make decisions together in that way.*

**Use of data.** Participants were asked to discuss ways that data is collected or utilized in SOC implementation. Responses focused on use of data for decision-making, data collection in process, and implementation of a referral system that will provide additional internal data. One project director talked about collecting and utilizing community needs assessment data when the SOC was first coalescing:

*When I first started, we did a community survey that went out on social media...o, we usually go off of like the people that we're serving, like when I go out to schools and I ask individually to school districts, "What are needs that you're seeing?" Then we are able to bring those to the group. Moving forward, I would like to figure out a way to send survey…to school district families, because it's easy to hear from professionals what*

*professionals think that families need, but I would really love to hear from families on what families need…*

Many participants talked about the IRIS system that is being adopted as not only a referral system for client services, but also a source of data. For instance the following discussed IRIS as another method of collecting additional needs assessment data:

*That was really the purpose of the IRIS system, the electronic system, was to help us collect data, and so we're just getting that off the ground. I mean,* [project director] *can give you data that she's kept handwritten, or we can give data that we've gotten out of Bridgeway, but this IRIS system I think is really going to be able to show us who we're really serving and what the specific needs are in our area.*

## 6.5 Parent and Youth Involvement and Leadership

Participants were united in recognizing both the importance of parent/caregiver/family engagement and the lack of substantive involvement to date and the barriers to this involvement. Participants offered their perceptions of why parent engagement is so difficult. Because YES is only seeking parent participation from those parents who are currently receiving services, the complexity and urgency of family needs were widely viewed as barriers to family engagement.

*I also think from years of experience with families, especially families that you're actively serving, when a family has a lot of needs their focus is on those needs. That's where their energy is spent, and understandably so. So, I think that ask in particular is asking them to completely – you know, this is one extra thing that you have to do.*

*They're still in that mode of, it's not just one issue. They've got a plethora of things and a generational situation to overcome. So, it could be very few and far between that we find a true success story that would be fully comfortable than coming back and being part of our group and having that viewpoint… it also takes time to work with these families. You know, the issues didn't – their current situation, most of the time, did not happen in a short time span. It happened over a number of years. So, it takes a concerted effort over time before you change that situation, and the YES system of care is still young…I think having the family involvement will become easier as we've been in existence longer.*

It is also difficult to involve families in implementation activities when there are no implementation team meetings outside of the clinical staffing meetings that occur with agency partners. Because of this, there are concerns about involving current or former YES parents (i.e., parents who have received services through the YES SOC) in the staffing meetings due to the confidential nature of the information that gets shared during these meetings. One participant recognized that, "*Sometimes, early on especially, when we're really discussing cases in our meetings...it's very private*."

A project director talked about SOC activities that may positively impact parent involvement in the future:

> *It's been really difficult for us to get families involved. I'm hopeful that with some of our expansion of mobile crisis, and having engagement specialists, that they will be able to maybe help us find some of those families who would be willing to be involved. I think that would be a great way to do that.*

A community partner also reflected on possible strategies to support increased parent engagement by using different pathways and starting with modest levels of involvement:

> *I think those are good conversations for us to have…I'm thinking maybe a better way would be a virtual meeting where a person is sitting next to me or whoever they're connected to instead of just inviting them in this room, that they're kind of next to the person that they trust and being not even on camera, but just sitting in next to someone in a virtual setting could be a step towards them being on camera and thinking about the baby steps. Really, it's asking them what would make you comfortable to come?*

## 6.6 Barriers to Implementation

**Workforce shortage and turnover.** Across the state and nation, there is a shortage of mental health providers. This challenge was entrenched even before the COVID pandemic exacerbated it to crisis levels. Because of the provider shortage, agencies often lack the capacity both to serve children who need mental health services and actively participate in a system-level team or committee. A project director highlighted these impacts:

> *Because the worst part is when somebody quits over here and then I don't have somebody showing up to my implementation…team. Then I have to get them retrained. It just is two steps forward, one step back.*

> *Right now, I would say not for the system of care in general but for our partner agencies, and especially Bridgeway, staffing is a big issue. We are struggling, and I have been in this field for many years and I have never seen it like this. I usually maybe would be down one or two therapists in a bad time…I know it's not just us, and I know it's not just Illinois, and so I would say for our partners more than anything, that's the biggest barrier.*

A community partner shared the perception that the shortage of mental health clinicians is worse than it has been in the past:

> *I've been in this business for more years than I want to admit…and I've worked a lot in administration with behavioral health programs. I have never seen the staff or the employee pool so low. I have never had difficulties in finding different behavioral health*

*staff when I needed to as it is now. The people are just not there, and I don't know why. I don't know if people are getting out of this field, or if people don't want to work in rural America. I don't know.*

Participants talked about various strategies used to moderate the impact of the mental health workforce shortage through use of grant funds. For instance, one project director discussed employee incentives aimed at increasing applicant pools and staffed positions:

*We even did retention bonuses for some of the staff, and we had people who, after they got their retention bonus, left…it's a chance you take…it used to be that people loved this work. Nobody is getting rich in behavioral health, I think we all know that, but people did it because they loved it. They did it because that was what they wanted to do, they wanted to help people, and now it's like, "I'm not going to go there because Organization B over here is going to pay me a $10,000.00 bonus or add-on or come-on fee, whatever it's called, and you won't do that, or yours is only $5,000.00." It's very frustrating.*

One strategy engaged by the primary project director is to mitigate the waitlist time created by the provider shortage by offering other resources to support children's mental health. As described by a community partner, the SOC was able to use funds to provide access to children in area schools to the Clayful app, a service that connects youth with on-demand support and coaching (https://www.clayfulhealth.com/):

*I think that [she] found some unique ways to address that though with the Clayful app in schools and just finding ways to still connect with administrators and key stakeholders. I would say workforce shortage goes along with this as well with some counseling positions needing to be filled and/or only one counselor/therapist for an ENTIRE school. Again, the app is a huge way to combat this. I think youth mental health is understood as incredibly important at this point in our community and I believe YES is a huge factor in that.*

**COVID**. Participants were asked about the impact of COVID on SOC implementation. YES began under the restrictions and stresses that have accompanied the global pandemic. As noted in a previous section, meetings that otherwise would have been in person were moved online, and family stresses were exacerbated. At the same time, the SOC either maintained or adapted processes:

*You know, COVID was hard. We made it work. For us, Bridgeway specifically, our staff went remote. They came back and have been back ever since, but we give all of our clients a choice if they want to do telehealth or in-person, and the majority of them choose in-person. Because we are a more rural area, I know that that has been hard for some of our other partners, as well.*

# 7. Results – Youth Mental Health System of Care

The Youth Mental Health System of Care (YMHSOC) serves Winnebago and Boone Counties in Northern Illinois. According to the 2020 U.S. Census, Winnebago County had a population of 285,350. The largest city in the county is Rockford. In 2021, the median household income in Winnebago County was $56,132. Fourteen percent (14.3%) of people in the county lived below the poverty level, which is higher than the state average of 12.1%. A much higher percentage of children in the county lived in poverty (25.2%).[28] In terms of race and ethnicity in Winnebago County, 68.1% of the population were White (non-Hispanic), 12.8% were Black or African American (non-Hispanic), 8.68% were White (Hispanic), 3.09% identified as Multiracial (non-Hispanic), 2.7% were Asian (non-Hispanic), 2.2% were Other (non-Hispanic), and 1.6% were Multiracial (Hispanic).[29]

Boone County had a population of 53,448. In 2021, the median household income in Boone County was $74,076. Nine percent (9.3%) of people in the county lived below the poverty level, which is lower than the state average of 12.1%. Additionally, 13.4% of children (18 years and below) in the county lived in poverty.[30] In terms of race and ethnicity in Boone County, 72.5% of the population were White (non-Hispanic), 13.0% were White (Hispanic), 6.9% were Other (Hispanic), 2.5% were Black or African American (non-Hispanic), 1.9% identified as Multiracial (Hispanic), 1.7% identified as Multiracial (non-Hispanic), and 1.0% were Asian (non-Hispanic).[31]

Rosecrance, the lead agency, has provided services in Winnebago and Boone counties for over 100 years. Currently, it provides treatment for substance use and mental health disorders to children, adults, and families. It serves approximately 45,000 individuals per year in over 60 locations in Northern and Central Illinois, Greater Chicago, Iowa, and Southern Wisconsin. Lead agency staff for YMHSOC includes a Project Director, for whom the grant pays 5% of salary, and a full-time System of Care Navigator. The grant also pays for the lead agency to subcontract with the Northern Illinois Center for Nonprofit Excellence (NICNE) to provide collaboration and capacity oversight.

The YMHSOC grant application identified several goals, strategies, and activities:

- Engage youth and parents with lived experience by forming an advisory group of parent and youth consumers and identifying ways to seek their ongoing input/feedback to inform decision-making. Ensure 25% of Planning Team consists of self-identified consumer parents/caregiver/youth.

[28] Census profile for Winnebago County, IL: https://data.census.gov/profile/Winnebago_County,_Illinois?g=050XX00US17201
[29] Winnebago County DataUSA: https://datausa.io/profile/geo/winnebago-county-il
[30] Census Profile for Boone County, IL: https://data.census.gov/profile/Boone_County,_Illinois?g=050XX00US17007
[31] Boone County DataUSA: https://datausa.io/profile/geo/boone-county-il

- Integrate systems for coordinated/integrated care management by (1) hiring a systems navigator to assist mental health service organizations and support services in building professional relationships, identify and trouble-shoot system problems, provide information on available resources and how to access them, and support organizations to assist navigating the healthcare system; (2) creating a monthly community practice for providers; and (3) providing information to the Mental Health Board.
- Build capacity of mental health service providers by providing education and training, establishing a community of practice, and identifying quarterly training topics.
- Explore virtual opportunities for community education to inform individuals of supports and services available to them.
- Develop a centralized database of services to help organizations navigate care options for their clients and more easily facilitate referrals.

During the site visit, individual interviews were conducted with the principal project staff from YMHSOC (the Project Director, System of Care Navigator, and the two contracted NICNE facilitators). We also conducted focus groups and interviews with organizational partners and parents who had been involved with the YMHSOC.

## 7.1 Pre-grant Activity

Site visit participants shared that the group that worked on the first unsuccessful grant application to ILCHF did a substantial amount of work during the year preceding their second application. This consisted of on-going planning to build a children's mental health system of care and efforts to create a local mental health board. The YMHSOC worked hard with others on championing legislative and referendum initiatives that established a local mental health board with revenue from a half cent sales tax to fund local mental health-related services and supports. Interviewees reported that the group began to meet regularly each month. It applied for and received a grant from a local foundation to continue its work and prepare for reapplication.

> *We got a local grant through a local community foundation to do a one-year planning process to better prepare us for future rounds of funding.*

> *We began meeting at the beginning of 2019. We established a project charter that had a mission, scope of work, roles and responsibilities …* [and], *levels of engagement. Who's on the core team? Who do we want to engage? What are some of the objectives?*

Participants in this regularly meeting group were solely professional stakeholders. Parents and youth were not present.

> *The group started very much as a group of elite stakeholders… It was top level decision makers for elite organizations. It was not grassroots. [*It did not have people with*] lived experience. [*There*] … was a public health administrator, an executive director of a health council.*

This group reached out to other organizations to join the effort, collected and analyzed data, met with previous CMHI grantees, defined the target population, established values, selected a conceptual framework, and established goals and a strategic plan.

> *We started to put together a list of who should be at the table, who…wasn't, ranging from probation to court services to pediatric providers…We made attempts to reach out through…personal networks to get more buy-in and…involvement from other providers.*
>
> *We did a survey [*of providers*] intended…to…identify gaps and…what services were…out there currently…We utilized the Northern Illinois University Center for Governmental Studies to help us collect that information and…used [*it*] to inform our work…We had sent [*the survey*] to probation, judges, courts, doctor services, mental health treatment providers, school counselors employed through the school district. We tried to cast a very wide net with it, and I believe we got…close to a hundred responses*.
>
> *The Erikson Institute out of Chicago shared…research on Winnebago County…with data that was…very enlightening for this system of care group, too, because it talked about the poverty areas and where there are deserts for mental health care and [*where*] transportation was lacking.*
>
> *We…set up a meeting with a couple of people from other areas that had successfully been awarded a [*CMHI*] grant and…talked through what that looked like for them.*
>
> *We had…a lot of a discussion…[*about*] what does the system encompass? What is evidence-based and data informed? Are there any existing models out there that we can draw from? We talked…[*about*] definitions of youth because there's a lot of factors at play as far as when insurance stops and when foster care youth age out of the system, so we had to set boundaries…We formed group values. We set our initial goals.*
>
> *We crafted a mission and a vision statement…We started analyzing different System of Care models…We came across one done by Dave Kunert. It was a model of how to stabilize adults with severe mental illness in a community setting. This model was developed to look at the wraparound, the whole person perspective, in terms of how to give effective care and stabilize them in the community setting. We…had [*Kunert*] talk to us and work with us…He came to some of our meetings to work with us on adapting it…to fit youth.*

One of the reasons the YMHSOC group decided to use Kunert's Community Support System theoretical framework for their work was because they believed it fit with their campaign to create and fund a mental health board that could distribute public revenue for mental health services for people of any age. Participants explained that they wanted a model, adapted for youth, that could also align with a model for adults.

> *We had some good debate…about*…[whether] *the Community Support System model … was close enough to the conceptual model of the youth system of care that we could just …adapt* [it] *rather than having two conceptual models. We…utilized the youth mental health system of care literature to inform* [this work, identifying] *what…components the Community Support System should include*…[for] *youth.* [It had been initially] *developed for adults with serious mental illness*.

One of the YMHSOC partners, who later left the YMHSOC to serve on the Mental Health Board, relayed the story of how the YMHSOC worked to establish and fund the Mental Health Board.

> *We approached…[*our state senators*]: …'Would you consider taking a look at our sales tax law in Illinois' – because it was only to be used for public safety, public facilities, and public transportation. Could we add…verbiage to allow the sales tax…to be used for mental health and substance abuse?' [*The two senators introduced a bill to make the change*.] …And by God, it passed. We had…changed the state sales tax law in Illinois. A half-cent sales tax could [*now*] be used to support [*care for*] mental health and substance abuse. Our next endeavor was to convince our local county board to allow us to have a referendum for the half-cent sales tax to support mental health and substance use services on the ballot in March…We never thought we could convince them. They went along with it. [*In our*] system of care committee…we decided…we needed to have a clinical model in which we could all agree. [*After research and discussion*] we decided as a group [*to use*] the Community Support System framework, which [*puts*] the client, the child living in the community, in the middle and all the services needed to sustain [*the child in the community*] wrapped around… housing, dental, transportation, medical, mental health, substance abuse, education….[*We examined*] each one of those pie pieces* [elements*] to figure out what was lacking ….*

> *We used our YMHSOC…gap analysis data and the Community Support System model to really…push [*the Mental Health Board referendum*] at a community level. We started attending presentations, speeches, community networking events to…talk about how this referendum could add services…based on our data…Our data and our work [*were*]… instrumental in getting that referendum passed.*

## 7.2 System of Care Goals

We asked site visit participants to identify shared goals for the YMHSOC. The variety of the goal statements suggest there is not yet a firm sense of shared goals. Several interviewees referred us to written mission, vision, values, and principles statements, and to a strategic plan consisting of five goals: data collection, community engagement, system design, community of practice, marketing/roll out, and evaluation. These goals however, seem more to designate areas of strategic activity.

Many individuals expressed that the shared goal was equitable access to high quality services for all children in need.

*One of the things that has been…emphasized is that it's equitable for all that are in our counties, so that everyone has access to the same high-quality services.*

*Our shared goals revolve around…increasing access to care in an equitable way to anybody who needs it...Within that we've had action items pertaining to...finding trainings to boost the competency of staff, combating stigma, finding and implementing a system for ease of referrals and ease of access for clients so people could easily search for providers in the area and easily make referrals for their clients, with their clients.*

Another added that creating a consumer-led system is a goal.

*I think another goal that's been emphasized…would just be to make sure that we are being led by consumer needs…so that we are sure not to just…do things that we as the providers feel are in the best interest of the consumer, but for that to be really driven by consumers and those families in the community.*

Several participants identified implementation of the Integrated Referral and Intake System (IRIS) as a goal.

*The main, big goal right now that everyone is kind of focused on is getting IRIS implemented and rolled out.*

Another identified building a comprehensive array of services as an important goal.

*It should be comprehensive…multiple different areas that would be supported and youths that needed support for ADHD, autism, anxiety, PTSD, reactive attachment disorder.*

Two staff members explained that informing the mental health board of areas in which funding is needed is also an important goal of YMHSOC.

*One of the other goals we have is to inform the Mental Health Board as to what type of programming the community is wanting and what type of programming will fit…what type of gaps or what type of obstacles or solutions that either providers…or the community is telling us exist, so that when they get…requests for funding and program proposals they can hopefully find ones that best fit the needs of the community.*

## 7.3 Activities and Progress Toward Goals

Participants informed us of the following activities since receiving their grant: engaging and re-engaging organizational partners; administering surveys; deciding to implement and implementing IRIS; piloting Practice Wise; creating a resource directory; constructing a website; creating a community of practice and administering training to professionals; facilitating

conversations on elements of the Community Support System framework; and holding monthly meetings with the Mental Health Board.

**Engaging and re-engaging partners.** Interviewees shared that since being awarded their grant they have invested time in re-engaging and engaging new partners.

> *I've been trying to reengage old partners…[*who*] fell off because we…lost…momentum when [*the System of Care Navigator*] position was vacant. And then also bring[*ing*] new partners to the table…so we can continue to grow…Re-engaging partners has been a huge part of the last ten months.*

> *We have three hospital systems in our community that we've been working at establishing connections with…The area hospital networks are a huge player in the system of care, but we have not been successful at engaging them.*

**Administering surveys.** Interviewees shared that they administered a survey to people with lived experience to identify strengths and weaknesses of the children's mental health system in their area. They also shared that staff and members of the Community of Practice Committee administered a survey to area mental health clinicians to identify their desires for training.

**Implementing IRIS.** YMHSOC participants reported that after considering several referral software packages, they decided to pursue community-wide implementation of IRIS and purchased it. IRIS is a web-based referral system. Participants described that coming to a decision about purchasing and implementing IRIS required a great deal of work. This work was described as including research on alternative referral software packages; internal discussion with organization decision makers; collaboration with the Mental Health Board, which agreed to incentivize participation in IRIS and manage its data; outreach to service providers; piloting; and tailoring the software to the community's needs.

> *It was a lot of work…picking IRIS…We looked at several systems…We had three software companies come and do presentations to the committee.*

> *[*We are*] introducing [*IRIS*] to all of the key players in the community…having big meetings…to introduce…IRIS…to all the different stakeholder and decision-makers.*

> *We're at the stage where we're identifying…community champions because the implementation stage…needs people to…pioneer…the data piece. We've…put together a list of pilot agencies...We're going to…test software…to…figure out what would best su*it [our] *needs in terms of customizability and search options.*

**Piloting PracticeWise.** Interviewees shared that they piloted PracticeWise with approximately 20 mental health clinicians working with YMHSOC organizations, including the Rockford Public School district.

**Creating a YMHSOC website and an online resource directory.** The System of Care Navigator created a website for the YMHSOC and compiled an online resource directory for the two-county area that is housed on the website.

**Providing trainings and creating a community of practice for clinicians.** Interviewees report that the YMHSOC virtually administered several trainings for mental health clinicians. When the trainings they offered drew many participants from outside of their community, they revised their strategy to strengthen the quality of mental health services and tried instead to build a "community of practice" for local clinicians.

> *In the last two years we had a lot of trainings for mental health providers and organizations...Because it was free online programming – we saw it draw from all over the place. So, we've revamped our approach…and are focusing more on…deep, local engagement with mental health providers to build the capacity in our community… professionalize the work and help them build a network so we don't see…high turnover and we see consistency across treatment approaches in the community.*

> *[Our] Community of Practice Committee, which is made up…of five or six members of the larger professional committee is focused on developing and creating a community of practice for mental health clinicians and doing a deep dive into certain topic, so that we can specialize in those areas…We're doing a deep dive into attachment. We found a psychiatrist that…has expertise in that area and is going to be doing some local training … for…12 months so that at the end of that period we have professionals…[*who*] are certified in attachment and can then teach others in our community.*

**Facilitating discussions.** Interviewees shared that they have and will continue to administer discussions for providers, parents, and youth groups on each element of the Community Support System Framework. They report using those discussion groups to recruit more YMHSOC participants and sharing the content of these discussions with the full YMHSOC.

> *We are at the point now where we're digging into the pieces of our model. We just had this month our first conversation with mental health providers and some parents – there were three parents…or family members that signed up. And we had…at least a couple of hours discussion about treatment services in our community…what works well, what wasn't working well, and…what an ideal system looks like. We had about…35…in the room…and* [there were] *quite a few people that were interested in joining the planning group or engaging with the planning work in a different way…We have our second discussion on…crisis services…on February 22nd. As we…contact…folks in the community, we'll continue to inform them of the work that's being done, the purpose of the work, what's next, and offer them ways to get engaged. We did ask them to connect us to families and youth if they had those connections.*

**Meetings with Mental Health Board.** Interviewees shared that the YMHSOC meets monthly or bimonthly with the Mental Health Board. They explained that they have presented their survey results to the Board, have kept the Board informed of their activity and progress, and have been collaborating with the Board to implement IRIS.

## 7.4 Organizational Structures and Processes

**Organizational structure.** The lead agency, Rosecrance, employs the Project Director and a full-time System of Care Navigator. It also contracts with NICNE for facilitation and internal communication. The Project Director is also the Vice President for Child and Adolescent Services for Rosecrance, Inc. His VP responsibility includes developing a comprehensive system of care for youth served in Illinois. The grant from ILCHF pays 5% of his salary. The System of Care Navigator is the only paid staff who is 100% dedicated to the work of the YMHSOC. The position is supervised by the Project Director. Interviewees described three aspects of this role: implementing decisions of the full group of partners, coordinating workgroups, and outreach/relationship building.

> *"[*The System of Care Navigator is responsible for*] implementation…We had a lot of providers at the table, a lot of well intentions, but a lot of people who didn't…have time to…move the needle forward…Taking action steps would usually be mostly on the [*System of Care Navigator*]...With everybody in a staffing shortage it's…hard to get people to dedicate time outside of their job. A lot of…follow up…[*and*] closing the loop comes down to this individual because everybody else…has a lot of other things that they're doing for their job.*
>
> *Her role…[*is also*] to sit in all of the subcommittee groups…to make sure they… [*are*] running. To…be the lead in them to get the conversation going to…[*move*] projects* [forward*]. I think that position is especially important for…building out community relationships…and relationships with professionals…She worked…hard at engaging [*healthcare*] professionals…building that network, establishing communication channels…drawing people into the work, letting them know what was going on…*
>
> *And then her job …[*is*] to…network with other agency providers who …[*are not*] at the table, or maybe they had somebody at the table but due to…turnover…needed to…pass it on to somebody else in that same agency. A lot of what she …[*has been*] doing …[*is*] meeting with people…trying to rebuild our committee, as well as…trying…to get…people with lived experience engaged.*

Rosecrance subcontracts with NICNE, an institute at Northern Illinois University, to provide facilitation and internal communication services to the YMHSOC. These services are provided by NICNE's CEO and Assistant Director. The Project Director describes that 30 to 35% of ILCHF funds are used to compensate NICNE for these purposes. The Project Director shared that there is a strategic reason for subcontracting with NICNE to facilitate the meetings:

> *The reason we did that is because in this community, unfortunately, Rosecrance…the primary recipient of the grant, isn't looked at favorably because of [its] size. The worry was that…other agencies [*would be reluctant] to join [the YMHSOC]. *We wanted to filter it through NICNE…to make it clear…this is not a Rosecrance project. This is a community project. [*Rosecrance is*]…the fiscal agent for it…This is not…Rosecrance's attempt to suck in…referrals.*

There is a full group of partners that meets monthly that was called by different names, including "project management team," "steering committee," "main steering group," "planning group," "system of care committee," and "professional task force." This full YMHSOC group was characterized by the Project Director as combining the 'leadership' and 'community implementation' teams of the ILCHF model. Interviewees shared that the group consists of 10-12 professionals, a mix of direct service providers, middle managers, and executives of area organizations, who work for organizations such as the local chapter of the National Alliance for Mental Illness (NAMI), the federally qualified health center, a nonprofit child welfare agency, mental health treatment providers, the regional health council, the regional Office of Education, the Rockford Public Schools, county health departments, and the United Way.

Interviewees shared that this group meets monthly, and they identified this group as the decision-making body of the YMHSOC. Its members volunteer to participate on workgroups and they present any updates on their workgroup activities at the monthly meetings. No youth or parents (who are not also professionals) had participated in this group at the time of data collection.

> *[*There are*] around 10 to 12 [*people in the System of Care committee*] right now. [*They are all providers*] unfortunately. It's a mix [*of professional levels*]. Initially, pre-grant, it was all executive level. You have…executive level…supervisor level and…direct care.*

A recently updated YMHSOC document that interviewees asked us to review, *Governance and Workgroup Structure,* calls this group the "professional task force" and describes its future membership and responsibilities.

> *Made up of mental health professionals, wrap-around support providers, and* [Youth Engagement Steering] *(YES) Team representative(s). Responsibilities include collecting needed data, analyzing data, sharing data with YES Team, developing the Community of Practice with professional development, distribution of surveys within organizations and networks, shared data tool decision, evaluating SOC components and effectiveness working with University of Illinois, and developing a manual for the funder (Children's Healthcare Foundation) documenting the process for the system design.*

Interviewees describe that the full group reflects on progress at its monthly meetings and continually updates the strategic plan.

*The whole planning group has been working on the strategic plan…for such a long time. ...They made different iterations of the plan and vision, mission, so it's been something that they're constantly working on and editing, trying to be in tune…[*with*] what the region's needs are.*

Staff shared that there is also a regularly occurring check-in meeting that take place among the Project Director, the System of Care Navigator, and the NICNE CEO.

*The three of us would discuss…deliverables…projects…strategies for creating the agenda for the meetings and stuff of that nature. But…when it came to problem solving or finding solutions to moving the needle forward, we would always have that discussion openly* [in the meeting of the full group*]. The three of us wouldn't make a decision behind closed doors and then just tell everybody what's happening. We would discuss, 'these are some of the things we're seeing. This is some of the things we're falling short on…per those six-month updates [*we*] have to provide as part of the grant…These are some of the things that we're not progressing on. Why don't we bring that up in the next meeting and…see what peoples' thoughts are?'...We try to do things collaboratively…Those [are] 20…[to] 30-minute meetings.*

The strategic plan identifies seven workgroups, and two "system design" groups. Workgroups have included Data Collection, Survey Analysis, Community Engagement, Front Door, Community of Practice, Marketing, and Evaluation. The system design groups include a Professionals Task Force and a Youth Engagement Steering (YES) team. The Governance and Workgroup Structure document, that updates the strategic plan, omits the Front Door workgroup, collapses the two Data Collection and Survey Analysis groups into one Data Collection and Analysis Workgroup, identifies the Professionals Task Force and the YES Team as two components of the governance structure, and provides information on the YES team that is not included in the earlier strategic plan.

Both the strategic plan and the Governance and Workgroup Structure document describe the responsibilities of the workgroups that continue to meet.

- The Data Collection and Analysis workgroup designs and administers surveys to providers and consumers to inform SOC design and development, ensures data is available in multiple languages used in the community, and reports findings to the YES Team and Task Force. It also determines other data to be collected.
- The Community Engagement Workgroup advocated for the Winnebago County Mental Health Tax, investigated and chose referral system software, is recruiting IRIS participants, identifies key service providers and referral points, develops a plan to engage them in the System of Care, and develops an on-boarding process.
- The Marketing Workgroup develops "mechanisms for regular communication and … promotion of system of care progress and roll-out."

- The Evaluation Workgroup meets monthly with the CFRC evaluation team, encourages local providers to participate in the evaluation, and shares information on local data collection and system design with CFRC.

As of the time of the interviews, workgroups had contained only staff and professionals that also sit in the full professional group that meets monthly.

> *The subcommittees are comprised of volunteers from the [*System of Care*] committee. So it's different agency providers...We've had trouble with community member engagement, so it's been primarily providers, unfortunately.*

The Governance and Workgroup Structure document aspirationally includes the following description of the YES Team as a governance group. We understood from staff that the YES team at the time of the interviews had consisted of two professional members of the large group and did not yet include any parents or youth with lived experience as team members.

> *The YES Team (Youth Engagement Steering Team) is a group of people with lived experience with youth with mental health support needs. This includes families, caregivers, or young adults. [It] identif[ies] issues, opportunities, and barriers from the consumer perspective to enhance the design of the system of care and ensure "nothing about us without us." [*The*] YES Team is made up of consumers ONLY, and its purpose is to engage in planning the System of Care in coordination with the Professionals Task Force. The YES Team should inform the work of the Professionals Task Force, make sense of survey data, and co-create the System of Care plan and model. All components of the system of care must be vetted by the YES Team prior to being incorporated into the system design for implementation. Representatives of the YES Team will participate on the Professionals Task Force to tie recommendations to implementation* (pg. 1).[32]

Interviewees appeared to have a variety of understandings about who is on the YES Team. Some interviewees understood the YES Team to consist of individuals with lived experience, and others described it as consisting of only two professionals belonging to the full group who worked with youth and parents. Some interviewees said these professionals worked with youth only.

> *The YES committee…is a group of individuals with lived experiences.*

> *There's the YES group…They are working on identifying groups of youth…that are already in existence*.

[32] Youth Mental Health System of Care. (2022). *Youth mental health system of care governance and workgroup structure.* Rockford, IL.

*There's this youth engagement group…a couple of individuals who have…taken that on …to try…to engage these individuals, to facilitate meetings and then compile that feedback data and bring it to the group to…inform what we're doing.*

*It was mostly just those two…[*individuals*] that ran the meetings. They kind of were the [*YES*] workgroup.*

*There's also a group that focuses on working with the lived experience individuals… called the YES group, where someone from our committee facilitates…focus groups with them to...identify what their viewpoint is on…mental health services…what's working, what's not working, that type of thing, to bring it back to the main committee and hopefully that will guide us in which way we're going.*

Several interviewees expressed that the YES team was not functioning well.

*The* [YES team] *participation has had its ebbs and flows.*

*Both…leaders of…*[the YES] *group have had…capacity issues the last two or three months and some health concerns. We're working on deciding on whether or not they need leadership support…to do the work or if they need to hand it off.*

However, one of the organizational participants, who believed the YES team consisted of youth and parents who steered the team, understood that the YES team was functioning well.

*I would say the YES group, which is the group of people with lived experience, either the parents or youth with lived experience themselves that are now older, is something that has been successful. It took a little bit to get it going, but I believe they've been meeting regularly, monthly, and each time…the group itself has come up with different topics. So, it's a…member-led group, but there are facilitators that are there to…keep notes… Because obviously the people with the lived experience are the ones that know what barriers there have been and what needs to change better than anybody else.*

**Leadership.** Interviewees had different perspectives on who their leaders are. Most interviewees identified NICNE staff as leaders of the YMHSOC. Fewer, but many, identified the Project Director as a leader. A few identified either all or specific members of the full professional group or the System of Care Navigator as leaders. Interviewees were also to describe the characteristics of the leadership they identified.

Those that identified NICNE staff as leaders said they did so because of the support NICNE staff have provided through facilitation, communication, and organization; their dedication to the YMHSOC mission; their neutrality; and their ability to help participants see things differently.

*They've really been a driver…They're very detail oriented, the driving force of overseeing everything and making sure we're on target and moving forward. Without those people*

*leading the charge, I don't think it would be successful at all. They kind of like keep it all together...They are…guiding the ship.*

*NICNE…has provided the leadership for our group, helped to give us...what we need to have in place…collect[ed]…input…to organize thoughts and meetings…I would say NICNE has been the biggest leader in it all.*

*I think* [NICNE staff are] *the two biggest leaders…they are the two…largest cheerleaders of the group...and kind of hold everyone together…If I miss a meeting…I usually get an e-mail from [*NICNE staff*] asking why I wasn't there.*

*[*NICNE staff*] are…good at asking…prodding questions, to get us to think…from a different viewpoint…a community's viewpoint. Sometimes we're all too hyper focused on our roles and what we see every day…They are…good at helping us think outside the box… view it from [a] community lens…I think that's where their leadership comes in.*

Those identifying the Project Director as a leader explained they did so because of his stature and expertise, because he administers the grant and has accountability for it, and because he has successfully championed YMHSOC objectives within Rosecrance. He is seen by some interviewees as being a champion for a system of care and an institutional entrepreneur.

A *lot of [*the Project Director's*] leadership has been as…liaison between this steering committee and…Rosecrance. [*When we*] recommend…possibilities for our community, he's … working on making sure that they…are able to support it and implement it in their own agency.*

*Rosecrance is an…entity that the other mental health organizations…defer to in [making] decisions...[*Will the Rockford Public Schools agree to participate in IRIS*?] It depends on whether Rosecrance [*does*]. These other mental health organizations aren't going to make these steps. They're…waiting to see what Rosecrance is going to do first. [The Project Director] is…leading…in that…way…NICNE has been organizing all of this and… coordinating everything, and [the Project Director] has been helping us pull through… hurdles [*at Rosecrance*].* The project director has*] been that driving force…We get discouraged when legal starts saying no, but then he's…encouraging them to push [*it*] through.*

*I think…the Project Director from Rosecrance is definitely a leader…maybe a little bit of both champion and institutional entrepreneur…big time on the institutional entrepreneur side of things…To navigate a large system like* [Rosecrance*] to take on IRIS implementation…shows…leadership on his part.*

One of the interviewees noted that there had been a loss of leaders in the YMHSOC: *Some of the early champions that created energy around it, are not…actively involved anymore.*

We also asked participants about the supports that have been available to YMHSOC leaders. The System of Care Navigator felt that training had not been available and explained that to make up for that, she had reached out to others who had been involved. Another interviewee said they believed the Sheila Pires *System of Care Primer,* intended for use as a "roadmap for those involved in building systems of care" (Pires, 2010, p. 4), was unwieldy.[33]

> Training [for the System of Care Navigator] was *nonexistent really. [*The Project Director*] gave me the System of Care Primer, that 300-page primer. But to be perfectly honest, I should have had training before…reading [*it*] because diving…into that right away, none of it made any sense…There was no formal training for me at all. [*To get support*] I met with each person individually…[*even if*] they were no longer a part of [*the*] system of care.*
>
> *Frankly speaking, the Primer is one of the most overwhelming documents I've ever seen in my life. And I don't think that anybody would ever be able to…use that as a tool for implementation because it is … insanely dense, and there are so many different tools. To me, [*it*] quickly became useless.*

**Communication.** NICNE has been contracted to convene, facilitate and document discussions among the full group of partners (not the sub-groups). Several staff described the components of the internal communication they provide.

> *NICNE sends out notices [*and*] minutes of the meetings. We have a Google Drive, where all the information is kept. So all organizations have access to any information that we have created, or utilized, or resources that we have available to us. The grant, itself, is on a Google Drive and accessible to anyone that participates. It's continuous communication. [*It is*] important…to make sure that everyone feels like they belong... They have access to all the information. They can contact each [*other*]…[*NICNE has*] on there a list of all the people and their contact information so if they need to connect with someone else in the group, [*they can*].*
>
> *NICNE…[*communicates*] with the planning group, and…a group of folks who just stay informed…like the Winnebago County Mental Health Department, for example, or the community mental health board. NICNE staff regularly communicate with folks via e-mail…sharing meeting minutes and agendas in advance. We have calendar holds. If we miss people or don't hear back on commitments, [*we*] say, "Hey, we didn't hear from you if you have something you want to add to the agenda," or, "We didn't see you at the meeting; do you have any feedback on the website before we launch it?" …It's…about relationships and consistency. That's…important. It's easy to get busy and people might think they don't have time, but if you don't do those things, you really lose people. It's critical…when people have commitments, I send out what they need, so here's your e-*

[33] Pires, Sheila. (2010). *Building systems of care: A primer.* Washington DC: National Technical Assistance Center for Children's Mental Health.

> *mail template, here's your flyer. We have it in the right format. Do we need it in a different language?…Sharing links to documents and things like that.*

NICNE has not been responsible for communications between the full group and the YES Team or with workgroups. Neither has NICNE been responsible for communication with youth and parents. Staff shared that communication with youth and parents with lived experience has been the responsibility of the YES Team or of the members of the full group whose organizations have clients with lived experience.

> [Regular communication with people with lived experience is] *through agencies and … the YES committee…We do call on the people in the group to…share [with their clients] because we don't have that regular contact [with them]. They're not going to trust [NICNE staff]. Even if [*NICNE staff*] has their e-mail address, it might hit their spam box. If they don't know [the sender], they're not necessarily going to trust that contact. So we do ask organizations…in the planning group, and on our contact list, to share…with their communities [*with whom*] they have established trust.*

The one concern that arose as interviewees spoke about internal communication had to do with communication between the YES Team and the full planning group.

> *They were meeting once a month [*and then*] stopped meeting...What's very frustrating is they didn't communicate it with us...At one of the planning group meetings, we asked, "Has the YES Team met?" And they said, "No, not this month." And that was* [how*] they left it. We assumed, 'You'll meet next month.'…It…took a couple of months for us to realize [*there were no meetings*]. And they still haven't officially told us that they're not doing it.*

**Decision-making.** Interviewees report that all decisions are made by participants who attend the large group meetings. Because there are not yet any youth or parents who attend that meeting, they are not yet a part of the group that makes decisions. Interviewees report that notice of decision-making is given, information is shared, and there is full and inclusive discussion within the group until a consensus is reached. They describe NICNE staff as facilitating their decision-making. Paid staff consistently shared it was not their role to make decisions, but to instead identify decision points and facilitate the decision-making of those who attend the large group meetings. The one exception interviewees shared was the decision of who to hire to fill the System of Care Navigator position, which has been made solely by Rosecrance.

> *The group decides*…[NICNE staff] *just facilitate that. [*NICNE staff*] make sure there's agendas and they're shared in advance…people come to the meetings. [*NICNE staff*] ask them to share input if they can't make it to the meetings; it's on them to be responsible for that. But it…just comes down to group discussions. We sit and work through the agenda and talk through all sides of the question. [*NICNE staff*]…document their decisions, and…share them out to the entire group.*

> [Decision-making] *is…informal. I know this is an assumption, but…it seems like people are…comfortable just speaking out in the group. We have some good debates. Somebody will bring an idea, and somebody will…rebut...It is very informal. There's no formal voting on anything.*
>
> *We have had a few disagreements, and what usually comes out of that is…further discussion…[*NICNE staff*] does a…good job of mediating…so that people are listening to each other as opposed to just…getting defensive…So far all…our disagreements have been resolved to where everybody is on the same page…It's nobody strong arming anybody. It's like an open conversation.*

One interviewee shared the example of how IRIS software was chosen.

> [NICNE staff] *coordinated the* [decision-making]…*Everyone was invited to…presentations of the different software companies. [*The System of Care Navigator*] set up all of that, and…[*was asked*] to talk to the other different systems of care from around the state [*about*]…what they're using and [*to*] ask…[*different*] companies to give us…a…rundown of their product and…[*answer our*] questions. All of those [*meetings*] were recorded for people that couldn't make it…[*who could*] come back with any questions…they had before…making…[*a*] final decision. There was input from the whole group.*

Interviewees shared that workgroups and the YES Team are not empowered to make final decisions and are to bring their recommendations to the full group for decision-making.

> *There are decisions that are made in the subcommittees that are then brought to the team as a whole to…approve…No action is taken until the group as a whole has a say in it.*

**Data collection and use.** The YMHSOC has collected data from several sources. It has administered surveys, used data relevant to mental health and other services from the Erikson Institute, and has collected data from a series of structured discussions NICNE and the YES Team are facilitating with service providers, youth, and parents.

Prior to receiving the grant, the YMHSOC surveyed providers to understand strengths and weaknesses of the current system. They described using that data and data from the Erikson Institute to advocate for the mental health tax and develop their grant proposal and strategic plan. Once funded, the YMHSOC surveyed parents to understand their perspective on strengths and weaknesses of the current system. They shared their findings with the local Mental Health Board. The Community of Practice workgroup also administered a survey to area clinicians to understand what training they wanted. This committee and the full planning group used this data to inform their activities with respect to offering training to mental health clinicians in their area.

In addition, NICNE and the YES team are leading a series of quarterly "discussions" with service providers, youth, and their parents on each element of the Community Support System, to "help us rebuild the system." Service providers and consumers are for the most part convened separately for these discussions. The plan has been that NICNE staff and the YES Team share the contents of each discussion with the large planning group.

> *The community discussion we just had on treatment services…all of that information was documented, and we'll go back to the [full] group at our meeting coming up in the next week and a half to talk about how we start to build out each segment of the framework. We've already built in the youth feedback. Once we build in the professional feedback, [w*e will bring it*] back to the youth* [and ask if there is something they want to add*]…We have … [*these*] meetings planned across the next year with the community and with providers to start building out each piece of the model…We'll have…quarterly reviews and an annual review…It's…an iterative process.*

In addition to these data collection efforts, the Project Director and the Evaluation Committee have urged their partner mental health service providers to, like Rosecrance, share their data on the children and youth they serve with the CFRC for its evaluation.

Finally, YMHSOC participants look forward to the data they will get from implementing IRIS. They have established a partnership with the Mental Health Board to analyze the IRIS data.

> *Once we get IRIS in, I would love to…see the flow of referrals…who was sending you referrals…which keywords are being searched the most, what type of programs are being accessed the most.*

## 7.5 Parent and Youth Involvement and Leadership

Interviewees, including four parents who had participated in YMHSOC discussions, were asked how parents and youth have been involved, what efforts were made to support their involvement, and what things facilitated and posed a barrier to their involvement. They were also asked to describe any strategies they have used to ensure that these efforts are inclusive and reflect the diversity of the community.

The YMHSOC has endeavored to solicit and consider the insights of youth and parents with lived experience but has not yet directly included them in governance or decision-making. To date, the YMHSOC has solicited parent perspective through the survey administered by the Data Collection workgroup. To increase inclusivity, this survey was translated and made available in Spanish and Arabic, in addition to English. The YMHSOC has also solicited parent and youth perspectives through discussion groups administered by the YES Team.

Our interviews revealed a stark difference in parent and YMHSOC staff perceptions of attempts of the YES Team in early 2022 to involve parents in system of care planning and implementation. While there was tremendous divergence between staff and parents regarding

what had occurred in online meetings with parents held by the YES team, there was a great deal of concurrence among the four staff and among the four parents we interviewed. (Each of the four staff was interviewed separately. We interviewed two of the parents together in a focus group and two of them separately.) The four staff we interviewed had not been present at the meetings but had a shared understanding of them. We were not able to interview the YES team members who had participated in the parent meetings. Areas of disagreement between the staff and parent perspectives included the content and quality of the meetings, the supports that had been provided to participating parents, the diversity of the parents who attended, and the desire of the parents to participate in on-going YMHSOC planning.

The YMHSOC staff we interviewed had an overall negative framing of what had occurred at the meetings. They reported that there was a mixture of providers and parents at the meetings and that the meetings devolved to angry finger-pointing between parents and providers and unrealistic demands made by parents. They understood that parents had been compensated and that attendees reflected the diversity of the community. They thought the parents had chosen to no longer be involved with the YMHSOC. This overall understanding informed a decision that staff made to not combine people with lived experience and professionals in the same meeting.

> [We brought a] *bunch of community people together to…talk about strengths and weaknesses of the system…and potential solutions. And…we asked them if you want to be continually involved…You could sit at the table with everybody else and share your opinions and you'll be heard…[*We said we were*] going to pay…30 bucks an hour to come and…voice your opinion on your experiences…We were hoping to get people who wanted to continue the discussion or continue to be involved and reimbursed…to join the actual planning and implementation…Our initial couple [*of*] groups were…representative of [*the*] community…but we got backlash from the way we approached it, and they didn't engage any more...What they expected was different…[*from*] what we could deliver…I think we were set up for failure…having the mixture we did in the initial group. We didn't want any providers in that initial group. We wanted it to be a free, safe space for the community to just vent if need be. But some providers came…because they also have children in the system…It got very competitive, unfortunately, and it was not effective.*
>
> *The mistake…they made…was that there were some people in the room that were parents, and there were some people in the room that were providers…[*It*] turned into a finger pointing activity. And it was not good…Pulling [*parents and providers*] together… was not productive…We learned our lesson.*
>
> W*e had given opportunities for them to come and share what works…what didn't work… what they needed…Consistent engagement was difficult. We…found that parents…wanted to vent…There were incentives, I believe, gift cards, offered to parents for those meetings, but engagement…dropped off.*

> W*e had two…meetings with [*parents*]…We had some providers who became really defensive at some of the things that the people with lived experience were highlighting as problems. And there was…a lack of understanding of what our vision…our goal was. …What we had was people [*telling us*] we need more residential psychiatric beds…make it happen…They were…making demands, and then [*there was*] a lot of finger pointing and defensiveness from…providers. And it wasn't the best couple of meetings…We weren't able to quickly…create psychiatric beds. And there was a lot of fall off. A lot of people disengaged from those meetings.*

However, the four parents we interviewed who participated in at least one of the discussions had a very different perspective on what had happened. They did not speak of an argument between providers and parents or even mention that there were providers at the meeting. They did remember that one of the parents shared an experience of not having been able to visit her child when her child had to be hospitalized far from home because the community did not have sufficient inpatient mental health care for children. That parent was also one of the parents we interviewed separately. The three other parents said the facilitator had shown discomfort in responding to this parent and had tried to redirect the conversation, but they themselves did not communicate any discomfort with the parent's behavior. The parents had positive memories of the meetings, did not understand why there was no follow-up with them afterwards, and wanted to be consistently involved with the YMHSOC. They each said the meetings did not reflect the diversity of the community and that they had not been offered nor received any compensation for their participation. The only support they remembered receiving was an invitation email that summarized the mission and vision of the YMHSOC. Excerpts from interviews with the four parents are included below.

> *They were asking about…our experiences, how we were served…what we liked, what we would change…I felt like it was a good discussion…To hear some of what the other parents had been through and some of the similarities…Because of the things I went through…I want to have these conversations…I think…there are other parents that deal with the same thing, and they don't know where to start…I…think about…low-income people. How do they …support their kids? That's why I take part in these conversations…I think it's important… We need to realize that…families are struggling…The more support…resources, and tools we can have, the better for our kids…I am willing to help and share my experience…*

> *We had two meetings, and then I haven't heard back…Part of me assumes that since I say things people don't want to hear, maybe I went farther than they wanted…so I wasn't invited to continue to participate…It was a Zoom meeting* [with*] about ten middle-class White women talking about mental health in our community. And I said that we needed a lot more diversity in the meeting because our community is diverse…I was saying that my eight-year-old got strapped to an ambulance and…driven during a snowstorm three hours away…to…a psych ward...I could not be with him because I am a working poor single mother…I did not have a car. And* [the facilitator*] said, "That's not really the focus of this group."…The universe [*is*] putting me in a place to do good. I would be willing to help. I have time.*

*We were able to share a lot of information…I know in the meeting [*the facilitator said a parent] *got off-topic…and* [tried to] *redirect…But it was nice to…share experiences and feel like someone was listening… I remember some saying…they wanted parent input…but then it just didn't seem to ever transpire…I don't think [*the group reflected the diversity of the community*] racially…or socioeconomically…I remember there being a common thread in the room…[about service] capacity, communication, access to the system. It…sort of bonded …us parents…We were all…sharing the struggles. Yes,* [I am interested in work with the YMHSOC]. *I didn't see any follow-up…I didn't know there* [was information*] on Google Drive.*

*I do remember that first meeting…I didn't hear anything…so I wasn't sure if I had not followed up appropriately…There was talk of [having] some sort of monthly or bimonthly … meeting, and then we didn't. You're circling back now, so I'm grateful for that. No,* [the group did not reflect the diversity of the community.*] That's actually something…we talked about at the meeting…Racially it was not reflective…I always have to be aware of time commitments, but this is a priority for me…I feel…it's something I would try to make work. Whatever I can do to try to improve access for all…our youth in the area, I want to do what I can. I don't know that I have a whole lot to offer. I don't work in the system, but I can definitely give feedback…I'm super appreciative of being asked to provide feedback.*

Interviewees shared that the YMHSOC has worked with two groups of youth with lived experience on system planning issues. These included a NAMI group and a group of teens involved in a program sponsored by a local community foundation in which youth are involved in awarding mental health grants.

In their discussion session with the NAMI group, YMHSOC staff reported that they introduced the youth to the Community Support System framework and asked them to decide which element they wanted to discuss first. The youth chose mental health treatment, discussed it, and developed a recommendation. However, YMSHOC staff reported that when their recommendation was brought back to the large group of professionals, there was discomfort and unease about how to respond to the recommendation this group of youth had made.

*We…joined up with a teen support group through NAMI, and we were meeting with them regularly…We…[*discussed the Community Support System*] framework…The youth…[*chose*] treatment as a topic, and [*we discussed*]…the values…benefits…strengths…of our current treatment system…Then we…[*asked*]…[*about*]…barriers and challenges of…[*the*] current system. [*They noted a difference in tone between mental health and other units of hospitals.*] You walk into a cancer treatment* [unit], *and it's…brightly colored, there's fresh flowers, beautiful pictures…When you walk onto an inpatient* [mental health] *floor, it's… stark white…bars over the windows…You are faced with stigma the second you walk in the door." One of their ideas was…[*to create*] a patient advisory board when designing a hospital wing…[*We*]…reassured them…we would advocate with the planning group for [*their recommendation*]. But then, I… [*reported*] back…to the planning group. [*They said*]…*

*"We don't want to offend…We…have a lot of treatment providers on the planning team…I don't know if that's going to be received well…We're trying to get them to leave the office during billable hours and come to our meeting. We can't just attack them."*

Staff explained that the youth the YMHSOC has worked with so far do not reflect the diversity of the YMHSOC target area: *They were from [*the*] Harlem School District, which is predominantly White.*

Although interviewees were unanimous in expressing their desire to include youth and parents with lived experience as leaders in planning the system of care, they often expressed ambivalence and worry about having them participate in meetings in which professionals are also present.

*We're hoping that two or three individuals from that group will trickle into the professionals' group, so we can begin to mix and have everyone at the table at the same time. But…at this point, we've consciously provided an opportunity for people to engage separate*[ly*] from the professionals' group…*[Professionals*] are meeting during the day…. As professionals, we have a whole system behind us…[*Parents and youth*] come into that group representing themselves. And it can be an extremely intimidating environment to be with professionals in that space…We don't want to provide this very uncomfortable environment where families are deferring to professionals, and not using their own voice.*

*We…went through a bunch of different ideas of how [*parent and youth participation*] should be structured…The idea was that…people with lived experience should be guiding and steering this work because they're the ones that have the information. Then [*we*] talk[ed] about how uncomfortable it could…be to be sitting on a Zoom with a bunch of executive directors of these…organizations that you are saying have failed you or your child, and how that is not a place that you would be willing to share…That's why we decided that it would make more sense to have the YES group, that is made up of the people with lived experience, and…have a couple of people from our larger group there to…bring information back [to professionals].*

Interviewees shared that they plan to increase the participation of youth and parents with lived experience in YMHSOC planning by subcontracting with local organizations that are already working with youth and parents with this experience.

*We're going to…subcontract…with some support groups that already exist to…do outreach to try to get people involved.*

W*e reached out…*[to*] a foundation that does a lot of work with youth that have been at risk and asked them if we could contract with them to be the voice of the consumer in this project, and they've agreed…They work with youth and…parents. So now we have a mechanism for an engaged audience to be begin to…provide us with some additional feedback as part of the process.*

## 7.6 Barriers to Implementation

We asked interviewees to identify the barriers they have encountered in moving the system of care forward, and we specifically asked how the COVID pandemic and workforce shortages affected their progress. In addition to the pandemic and workforce shortages, interviewees identified several barriers, including insufficient staff, inconsistent participation, loss of participants, and segregation within their community.

**COVID.** COVID pandemic safety protocols were in place when the system of care grant was awarded to the YMHSOC in December 2020. Interviewees identified several ways in which the COVID pandemic affected the progress of their work. They believed pandemic conditions slowed the hiring of the System of Care Navigator, reduced the participation of human service organizations, challenged engagement of youth and parents with lived experience, and lowered the quality of meetings.

> O*ur plan was to hire a System of Care Navigator…COVID…did impact our ability to find someone…There was a lag in hiring someone…Filling that navigator position was really difficult…Rosecrance, at that time…had 100 job openings…So filling this one position was only one of another 99…they had to fill for the organization.*
>
> *Getting leaders in the room sometimes was an issue, especially during the pandemic when there was a lot of important things going on that needed attention*.
> *COVID did not help [*our effort to engage youth and parents*]. When we were initially doing this effort, school was remote. NAMI had shut down most of their groups. All Rosecrance youth groups stopped. A lot of agencies stopped doing group work with youth.*
>
> *We kept meeting each month on Zoom. But the engagement is…just not the same as being in person with each other…People get concerned about talking over each other on Zoom…Some people don't have their face on screen, so you don't know how engaged they are.*
>
> *When we…met via Zoom, nobody was really talking. You could see people multitasking in the background.*

**Workforce shortage.** Interviewees identified that there was a shortage of children's mental health workforce that preceded and then was exacerbated by the COVID pandemic at a time in which the demand for children's mental health care was actually increasing. It was often difficult to separate out the effects of workforce shortages and COVID. Interviewees shared that this workforce shortage contributed to depressing the participation of human service organizations in the YMHSOC.

*There's a lack of mental health support in the community…[*and*] in the school system. You see people…spread thin, working overtime, [*with*] huge caseloads. [*There is*] high turnover…*[of*] case managers.*

*I have been told…[*by*] multiple people who were really engaged in the system of care work and aren't any more…their responsibilities [*for*] their job increased to a point where they can't dedicate time to this committee anymore.*

*Sometimes the engagement of folks in the system of care is impacted…like the Project Director doing clinician work and…not able to do his management level work…The demands on people are expanded because of a lack of…staff. The engagement in the system of care could have been…impacted by people needing to take on multiple roles within the*[ir*] organization because of staffing shortages.*

**Insufficient staff.** The System of Care Navigator position has been the only full-time position dedicated to the work of the YMHSOC. Several interviewees noted that one barrier to their progress was not having been able to fill this position for a full year after the grant was awarded. There were several other statements about not having the staff capacity to move forward.

*For a good part of the time when the grant was first awarded, [*Rosecrance]*…struggled to get anybody in the [*System of Care Navigator*] position…Once somebody came on board…things started moving much faster…*

*I think a big piece…is resources…staff…you can devote to engage in this group or staff … willing to be trained to learn…IRIS…There isn't a lot of bandwidth to be able to do these extra things.*

*We can afford one person. So, you have one person dedicated to implementing the stuff, and I feel…with the scope of what we are trying to achieve, we almost need a couple more…We are trying to do a very large-scale community change for pretty much every kid…It's not tailored to a specific population…We can have one navigator…but…when we move towards doing a lot more with community outreach, marketing, IRIS implementation, and working with other agencies, it would be nice to have two. One person…specializing in…community outreach, marketing, and…combating stigma. And the other one [*working with agencies on use of IRIS*].*

**Inconsistent participation.** Several interviewees noted that while there has been a core of organizations that have been consistently involved, there has also been an inconsistency of involvement that has led to some dysfunction.

*Keeping other stakeholders engaged has been a struggle the last two years.*

> *We have a core group of…12 people around the table…[*But others*] pop in and pop out. [*We try to*] make sure that…we keep folks up to speed…Everyone has access to the minutes. Everyone can read where we are and what happened at the previous meeting, but do they? Probably not.*

**Loss of participants.** Several interviewees spoke of the loss of participants. They shared that when they succeeded in creating and funding a local mental health board, some of their strongest participants left the YMHSOC for positions on the board. Because they saw the board as a potential funder of the YMHSOC, they perceived that participating in both organizations would constitute a conflict of interest.

> *A lot of the partners that were in our system of care…pushed for the…mental health board. The mental health board passed, and we lost a lot of them. They left to go be on the Mental Health Board.*

> *A lot of our senior members…people who have been executive directors, CEOs, people in the community who are providers in the system of care…became members of the Mental Health Board, thus leaving the system of care work…It was perceived that…potentially down the road the system of care may need continued funding beyond this grant that the Mental Health Board could assist with. Therefore, members of the board couldn't still be on this committee, because it would be a conflict…So right around the time [that we established the Mental Health Board], and this was right when we got our grant approved, we had a large [*attrition*] in our systems of care committee. There [*were*] only a few of us that stayed on…We…had to start…all over again with recruitment, engaging agencies, and trying to share the mission and vision.*

**Segregation within the community**. Some interviewees identified that long-standing racial, ethnic, and socioeconomic segregation has been a barrier to building a culturally competent system of care.

> *It's documented through multiple lawsuits, even in recent history, that [*Rockford is*] an incredibly racially segregated community, structurally, institutionally…There [*are*] trust issues between institutions, between groups. There are difficulties creating…governance structures that truly reflect the community because of…structural and institutional segregation.*

# 8. Cross-Site Discussion and Recommendations

As part of the implementation evaluation of the Children's Mental Health Initiative 3.0, the Children and Family Research Center conducted virtual site visits in each of the five sites at the end of their second year of implementation. The primary aim of the site visit data collection is to provide detailed descriptions of the goals, activities, structures, and processes employed in each site to implement children's mental health systems of care. The site visits also document barriers to implementation and explore the role of parents and youth in SOC implementation. For each site visit, the evaluation team reviewed the site's implementation applications and progress reports, attended implementation team meetings when possible, and conducted interviews and focus groups with individuals involved with the implementation efforts. Paid staff, community-based professional partners, and parents participated in the site visits. The information provided paints a picture of five very different communities with unique characteristics, strengths, and challenges.

Before discussing the cross-site findings and recommendations, it is important to consider the limitations of the site visit study. The data collection methods likely rendered participation inaccessible for those with limited access to the internet, primarily parents. Three of the sites had no parent participation in the site visit, and none of them had youth participation. As a result, these perspectives are underrepresented in the findings. Additionally, we attempted to obscure participant roles in SOC implementation to provide some protection for people's identities. In doing so we integrated the words of various professionals who participated without distinguishing their role.

Another limitation relates even more broadly to the methods. The value of youth and family participation and voice at every level of a system of care should by extension apply to evaluation, as well. Youth and family voice can provide insight and shifts in perspective that might otherwise go unrecognized by researchers who do not themselves possess lived experience in the area of study. For example, perspectives on what to measure may be very different between client groups and provider/professional groups.[34] The evaluation methods could have been informed by youth and caregiver input.

## 8.1 Pre-grant Activities

Site visit participants were asked to reflect on what, if any, activities occurred to build or strengthen a system of care during the year between their two grant applications. The BRIDGES SOC took feedback about lack of community involvement and went back to the drawing table with a Design Day. It was held in concert with COFI and incorporated a process of brainstorming and sharing about community needs. The event also provided a strong foundation for the parent relationships that continued to undergird the process of implementation. This led to a

[34] Friesen, B. J., Koroloff, N. M., Walker, J. S., & Briggs, H. E. (2011). Family and youth voice in systems of care. *Best Practices in Mental Health*, *7*, 1-25.

shift in how the project was framed, and the second application was done with COFI as a full grant partner. The YMHSOC group also engaged in planning and activity during the pre-grant period. They applied for and were awarded separate funding from a local foundation to continue to plan for their SOC. Though much was accomplished, no parents or youth were included in planning and preparation. Members of the SOC committee also became very active in successful work to establish and fund a local mental health board during the pre-grant year. The gains of the pre-grant year seem to have then been substantially mitigated by loss of strong leaders who participated in the SOC work in the pre-grant year. Some of this loss was reported to have been due to the resignation of some strong SOC leaders as they were hired or otherwise formally engaged by the new Mental Health Board and perceived a conflict of interest to remain active in the YMHSOC as well.

In the St. Clair County SOC, providers continued working with others in the community to build a better service network and to coordinate efforts to provide needed services. They moved forward with the broad goal of de-siloing services for families and youth. They created what they refer to as the St. Clair County Youth Coalition, and Chestnut, the lead agency for the grant, actively worked with schools toward a major service goal of embedding therapists in schools. The YES SOC widely perceived that the work of building a coordinated network of services for children and families in the area continued between grant cycles. This included continued planning and ongoing engagement between providers about families in need and how to best support them in accessing services.

The GPAYMHI SOC participants indicated that some professionals who were involved in writing the first grant continued to meet in a collaboration among three county health departments. During this interim period, they continued to see the need for an effort dedicated to children's mental health. While little activity occurred in terms of planning or community involvement, SOC advocates gained additional knowledge about what services and processes were most needed in the community.

## 8.2 System of Care Goals

Interviewees for three of the sites (BRIDGES, St. Clair County SOC, and YES) communicated a set of shared goals that were specific to their sites. Interviewees for two of the sites, GPAYMHI and YMHSOC, did not express a strong sense of shared, site-specific goals. BRIDGES interviewees expressed that their shared goal is to use an early-intervening, inter-generational, relational, trauma-informed approach to serving children 0-5 that addresses the social determinants of health and increases access to services. They also shared a goal of including parents/families in SOC leadership. St. Clair County SOC interviewees conveyed that their shared goals are to develop trauma-informed mental health screening for children and youth in the schools and juvenile justice system and build the capacity of their clinical workforce and school and juvenile justice staff to provide needed services. YES interviewees communicated a shared goal to build a strong collaboration among providers that would enable them to serve all needs of families through no-wrong-door, system-level coordination. They also expressed that implementing IRIS is a shared goal.

GPAYMHI and YMHSOC interviewees had a wider variety of goal statements, with fewer of them shared across the people we interviewed in each site. In addition, some GPAYMHI interviewees said they were unclear on the goals. YMHSOC interviewees shared a vision of equitable access to high quality services for all children and youth in need, but the goals they expressed were not shared among all participants. The shared goals that YMHSOC interviewees identified included creating a consumer-led system, implementing IRIS, building a comprehensive array of services, and informing the local Mental Health Board.

## 8.3 Implementation Structures and Processes

Studies of large-scale system change efforts tell us that the presence of certain infrastructure supports facilitate their success.[35] Primary among these supports are the presence of clear teaming structures and communication processes, collaborative decision-making and active leaders. Site visit participants were asked to describe these elements of their implementation efforts.

**SOC organizational and teaming structures.** Organizational structure varies across the sites. The BRIDGES SOC employs a full-time Project Director with others on the Leadership Team also partially funded by the grant. Parents and community partners with formal agreements receive remuneration for time spent working on implementation of the SOC as well. Teaming structures include several groups that communicate within and between themselves about needs, decisions, and planning. One is the Community Planning Team, the larger group supporting implementation that incorporates a wide range of partners. There is also a smaller Leadership Team, comprised of Rush staff and COFI staff and parents. Teams meet monthly with additional meetings. For example, members of the Leadership Team meet additionally to debrief with parent partners. The Leadership Team is more focused on big picture sustainability issues and fiscal management. Similar to other sites, they use formal agreements to cement and promote partner participation in the Community Planning Team.

GPAYMHI started with a full-time project director and full-time data manager supervised by the lead agency's Director of Outpatient Behavioral Health Services. Hiring was a challenge and required four months to reach full staffing at the beginning of the grant period. The data manager left after eleven months, and the initial project director left soon thereafter. It then took an additional six months to hire the next project director. During this period, all project groups ceased to meet. Staff was reconfigured to eliminate the full-time data manager and create two full-time community Llaison positions. The current project director is supervised by the lead agency's Manager of Outpatient Behavioral Health and Director of Outpatient Behavioral Health Services. Workgroups are reforming with the new project director in place.

[35] Permanency Innovations Initiative Training and Technical Assistance Project. (2016). *Guide to developing, implementing, and assessing an innovation.* Washington, DC: U.S. Department of Health and Human Services, Administration for Children and Families, Children's Bureau.

The project director facilitates the large implementation group that meets once per month. Members of this group must meet specified requirements related to their participation.

The St. Clair County SOC uses ILCHF funding for one full-time project director employed by the lead agency. The agency-based supervisor is also actively engaged in implementation and had previously served as project director for over a year. Funds have also been earmarked to pay for parent stipends for implementation involvement. The project director does implementation tasks of hiring for clinical positions for schools and the juvenile detention facility, leading meetings, and identifying areas of need. Formal agreements exist with community partners. A core leadership team includes paid project leaders from the lead agency, directors of community agencies, mental health board leadership, school district administrators, and parents. Meetings had been monthly, moving at the end of 2022 to bi-monthly. The leadership team also has workgroups dedicated to staffing cases and to youth and parent engagement.

YES employs one full-time project director employed by the lead agency. She has been in that position for most of the life of the grant to date and is supported by her lead agency supervisor. The project director facilitates meetings, communication, day-to-day operations, relationship-building, and community outreach as part of system implementation. A large portion of her time is spent on community engagement and building system partnerships in the context of several large rural counties. There are no subcommittees or parent or youth participants, rather the group of providers who have been working together share all elements of the process with about 25 core, consistent members. They have formal MOUs with partner organizations and confidentiality agreements with individuals who attend meetings because time is often spent staffing cases to ensure families' needs are met.

The YMHSOC has a unique structure in that only 5% of the project director's salary is funded by the ILCHF grant. Responsibility for internal communication and facilitation of meetings is contracted to a university-based institute. There is also a full-time System of Care Navigator funded by the grant, not hired until a year into funding, to assist with coordination and implementation. There has been one large governance group consisting of professionals only (i.e., no parents or youth) who also participate in workgroups formed around strategic actions (data collection and analysis; community engagement; marketing; community of practice; evaluation; engaging parents and youth).

**Leadership.** There was variation among the sites in the ways in which interviewees experienced project leadership. While BRIDGES and YES interviewees described the leadership within their SOCs as decentralized and shared, interviewees from the other three sites tended to locate their leaders within particular individuals. BRIDGES and YES interviewees described the role of the paid project director as one of supporting this decentralized, shared leadership through facilitating partnerships and relationships, sharing information, reminding, encouraging, and coordinating. In addition, BRIDGES put in place special processes and structures to create and support leadership among parent participants.

Most GPAYMHI interviewees identified their project director as their primary leader. Other GPAYMHI interviewees identified additional leaders: the central IL IRIS coordinator, because she had trained the project director on IRIS and had recruited additional participants; a participant who provided training to staff and other participants, because of her subject matter expertise and connectedness within the community; and the lead agency staff member ultimately responsible for administration of the grant because of her formal position and connections to several relevant departments within the lead agency and within the broader community. St. Clair County SOC interviewees also identified their project director as the primary leader of their implementation efforts.

Most YMHSOC interviewees identified NICNE staff, who were contracted to provide facilitation and internal communications, as their leaders. A somewhat smaller but significant number also identified the project director as a leader of their effort. Those who identified NICNE staff as leaders explained that they did so because they shaped agendas for and facilitated meetings of the full professionals' group and reliably conducted necessary internal communication within this group. They were seen as dedicated to the group's mission, neutral, and as having helped participants see points of view other than their own. Those who saw the project director as a leader explained that this was because of his professional stature, his responsibility for administering the grant, his championship of the group's vision, and his ability to advance it within the lead agency.

**Communication.** In four of the sites, project directors had primary responsibility for communications, and in the fifth site, communication was primarily managed by a contracted organization. BRIDGES has employed a variety of methods to communicate during and between meetings of various teams including e-mail, virtual meeting platforms, and social media to share information about community services. During their Community Planning Team meetings, a slideshow is presented that reviews SOC goals and process, provides information about spotlighted agencies or programs, and highlight shared values. They also do BRIDGES Bulletins and email blasts to share information or resources with partners. Leadership sends agendas to stakeholders prior to meetings. BRIDGES has also created communication strategies tailored to facilitate parent engagement and debrief parents to learn about their experiences and perspectives.

The GPAYMHI employs a project director who has primary responsibility for communication and two FTE community liaisons under her supervision who specialize in communication with partners and outreach to professionals, youth, and parents. Communication was greatly increased under the second project director, though much time was lost before this hire. A parent we interviewed who is active in the GPAYMHI raised concern about equitable and inclusive communication for parents and youth when SOC-related communication happens in professional networks outside of implementation meetings. Similarly, this concern was raised in relation to the YES SOC in which important case staffing occurs, but due to client confidentiality, there is a barrier that excludes consumers from communication among SOC members.

For the St. Clair County SOC, participants noted that monthly meetings are viewed as critical for effective communication about implementation activities. Meetings are accompanied by follow-up contact and have occurred both in-person and virtually. It was reported that some momentum was lost at the end of 2022 and that they plan to be more systematic in the future. Participants perceived that there is effective use of email to share information and facilitate participation in activities from both individuals who have been in the project director role. For some, however, there were some evident gaps in communication, for instance, in the process of hiring clinicians to fill positions in schools. A major function of the lead agency is to reduce barriers for access to mental health services for children by placing providers in schools. School-based providers perceived this as a process that occurred without communication about applicants or hires.

In terms of communication strategies, electronic communication and conferencing such as Zoom are used to some extent across all sites. The YES SOC has been able to enhance the experience of virtual meeting through use of discussions and polls, shared online documents, and social media. These elements were highlighted by participants and were widely viewed as effective in keeping SOC members connected and informed. Though people recognize the value of meeting in person and are planning to do so more in the coming year, the benefits of virtual conferencing were also discussed, especially important in the rural context.

Within the YMHSOC, contracted staff have responsibility for internal communications and have a very strong practice of engaging others. However, communications between workgroups and the full implementation team are left to workgroup members, and communications with youth and parents are left to a "Youth Engagement Steering Team." These areas of communication have been difficult. For example, the Youth Engagement Steering Team did not tell the full group they were not doing anything for months, and there were misunderstandings regarding the nature of meetings they had with parents and how the parents wished to regularly participate in SOC planning.

**Decision-making.** All of the sites have decision-making processes in which partners are informed and invited to participate in discussions leading to decisions. BRIDGES is unique among the five sites in having a Leadership Team that manages decision making processes. Its Leadership Team identifies decisions that have to be made and whose opinions should be elicited. BRIDGES interviewees explained that their decision-making processes are often lengthy because the Leadership Team endeavors to incorporate the many diverse perspectives represented among their partners. All sites have their full partners group meet to discuss and make decisions. In the case of the YMHSOC and YES, these groups do not include parents or youth. In the case of the YMHSOC, youth and parents are not yet members of the full partners group in which all decisions are made. In the case of YES, consumers are excluded from partners' meetings because they often include confidential staffing of consumers' cases. Parents who are in the new COFI group that works with St. Clair County SOC report that they have not been asked to weigh in on decisions. St. Clair County SOC interviewees also report that decisions on clinical staffing in schools that have been made by the SOC have not been shared with the full partners' group. Otherwise, project directors and facilitators across the five sites

demonstrate regular efforts to alert participants in advance of upcoming decision points, provide the information needed to make informed choices, and facilitate group discussions.

**Data collection and use.** Site visit participants were asked to describe efforts within SOC implementation related to data collection and use of data to inform decision-making. Participants talked about data collection related to community needs assessments, internal program evaluation, and team feedback mechanisms. They also discussed data collected by their own organizations as well as others in the community. BRIDGES used community needs assessment data collected by COFI to inform planning and collected program evaluation data on delivery of the Circle of Security training. The GPAYMHI has had less success with accessing data. A request went out to participating organizations to share their data for needs assessment and planning, but only one, in addition to the lead agency, did so. The St. Clair County SOC collects internal program evaluation data to gain feedback about professional development training like Youth Mental Health First Aid. Early in the process, YES was able to learn from an existing needs assessment related to mental health. The YMHSOC administered a survey to providers and a survey to consumers to identify strengths and weaknesses of the current system. Data was used from the provider survey and Erikson study to advocate for the mental health tax and board and develop their grant proposal and strategic plan. The YMHSOC apprised the local Mental Health Board of the results of the survey of consumers. The YMHSOC also collected and used survey data from clinicians to develop plans for training and professional development.

Three of the sites, GPAYMHI, YES, and YMHSOC, anticipate collecting data from IRIS. GPAYMHI interviewees expressed hope to use data from IRIS to identify gaps in services, unmet needs and highly utilized services. YES participants widely discussed looking forward to having IRIS fully operational as a primary source of client and service data going forward. They explained that data derived from IRIS can also include information related to follow-up, service redundancy, and other areas to inform future planning. The YMHSOC has secured an agreement from their Mental Health Board to analyze data from IRIS. One specific aim of the analysis is better understanding of wait times.

**Other supports.** Some site visit participants noted additional resources or supports they felt have been important to the process of SOC implementation so far. For instance, for BRIDGES, utilizing translation services during meetings for Spanish-speaking parents has been critical. Project directors mentioned the value of having the existing administrative, technology, and financial systems support from the lead agency in place so their efforts may truly focus on children's mental health services. While there are challenges inherent to one agency leading efforts that aim to be collaborative and system-focused, without these resources, several project directors reflected on how much more challenging the process would be without a lead agency and how this is an advantage of the model.

## 8.4 Parent and Youth Involvement and Leadership

BRIDGES, working with COFI, is the only 3.0 site that has come close to achieving the ILCHF goal that each site have 25% consumer (parent/caregiver/youth) representation on their community implementation team. GPAYMHI had three to four parents attending planning meetings at the time of the site visit, one of whom was also a representative of a participating organization. St. Clair County SOC had one youth and approximately eight parents involved in initial planning who are no longer involved and is now beginning to partner with COFI to build in parent participation. The YMHSOC has solicited and considered the insights of youth and parents with lived experience through administering a survey and facilitating discussion groups; however, it has not directly included youth or parents in governance or decision-making processes and decided not to mix professionals and consumers in meetings. YES has had no parent or youth involvement in SOC development and implementation.

BRIDGES interviewees report that BRIDGES has endeavored to ensure that participating parents reflect the diversity of their area by educational experience, neighborhood, language, and whether they are parent or grandparent. BRIDGES provides all written materials in Spanish and English. The YMHSOC translated their survey of persons with lived experience into Spanish and Arabic, but interviewees indicated that the groups of parents and youth they have convened for discussions have not reflected the racial and ethnic diversity of their area.

## 8.5 Barriers to Implementation

Participants were asked a series of questions about barriers that have impacted the process of SOC implementation including any impact related to COVID, the ongoing mental health provider shortage, and others they could identify. The shortage of mental health providers in Illinois existed prior to the pandemic but was greatly intensified following its onset and has continued even as the impact of COVID has decreased. The workforce crisis impacted all five of the CMHI 3.0 sites in various ways, and many of the projects lost key staff in the lead agencies or partner agencies. Turnover on implementation teams and workgroups as well as among staff paid by the SOC grant and within partner agencies slowed progress, with many positions remaining vacant for months. Many mental health agencies in the communities became short-staffed and had to reduce the number of new clients that they could serve or pause enrollment of new clients; staffing issues also impacted the ability of partner organizations to devote staff time to SOC implementation activities. Overall, workforce concerns outweighed those related to COVID and were the primary barrier identified, but there were other barriers that were more site-specific, as well.

BRIDGES interviewees noted challenges posed by staff turnover among participating organizations and long waitlists experienced by parents trying to obtain services. GPAYMHI participants talked about the workforce shortage stretching thin the existing staff, making it challenging for them to participate in SOC work. They identified that COVID had been a barrier to engaging parents and youth. They also identified barriers to implementation stemming from

the nature of their lead agency, a large health care facility with a complex bureaucratic structure that significantly delayed hiring and data sharing.

St. Clair County SOC participants stated that the mental health workforce shortage had a major impact in two ways. It limited their ability to hire school-based and detention therapeutic staff, and it limited the ability of partner agencies to fill positions to provide needed services. Given their success with providing mental health screening in schools in the fall, this limited capacity created waiting lists for services. St. Claire County SOC professionals also identified a barrier specific to integrating the juvenile justice system into their efforts to improve youth mental health. This hurdle has to do with a lack of alignment of the mental health and trauma-informed perspectives of the SOC and juvenile justice. Primarily a barrier to creating relationships and buy-in, the St. Clair County SOC project directors reported that they hope to eventually demonstrate the value of this partnership as juvenile justice sees that mental health intervention can have a meaningful impact on the youth they work with.

YES participants also recognized that the workforce shortage and high rates of turnover has had an impact on the ability of partner agencies to serve all family needs and actively engage in SOC implementation roles. Another barrier identified by YES participants related to the communities served by YES. They noted that the magnitude and complexity of family needs prevented parents and providers alike from doing more than crisis-level work.

YMHSOC interviewees believed that COVID delayed the hiring of the System of Care Navigator, reduced participation of community providers, challenged engagement of youth and parents, and lowered the quality of meetings. They recognized the workforce shortage as a contributing factor to the decrease in participation of service providers. They also cited loss of some of their strongest participants who took positions on the Mental Health Board and could not continue to participate in the YMHSOC due to conflict of interest. They identified long-standing racial and ethnic segregation in their area as an additional barrier to the progress of the YMHSOC. In addition, they cited insufficient paid staff dedicated to SOC work as a barrier to their progress.

## 8.6 Implications and Recommendations

The results of the site visit suggest three areas for further discussion and reflection. These include sites' need for an increased level of technical assistance, the impact of having to address many goals simultaneously, and the difficulty experienced by most of the sites in including consumers (youth, parents, and caregivers) in system of care planning and development.

**Increasing Technical Assistance.** The literature on systems change, generally, and in the area of children's mental health, specifically, notes the complexity of systems change and how antithetical it is to a cookie-cutter approach:

> *Different communities implement systems of care in very different ways; no two are alike…Each community must engage in its own process to plan, implement, and evaluate*

> *its system of care based upon its particular needs, goals, priorities, populations, and environment. Additionally, communities must change and adapt their systems of care based on changes in their political, administrative, fiscal, or community contexts, as well as on systematically collected data that are part of a continuous quality improvement strategy…Given the complexity of systems of care, their implementation is inherently a multifaceted, multilevel process…*[36]

Speaking of the federal Comprehensive Community Mental Health Services for Children and Their Family Program funded by the Center for Mental Health Services in 1993, Barbara Burns speaks of the significant challenges for sites that received "significant federal leadership, technical assistance, training, and other educational materials."

> *As a significant system reform effort, the Program is designed to implement the core values, principles, and continuum of services expected in state-of-the-art systems of care (SOCs). The central theme of partnership across families, service providers, governance structures, policy makers, and communities is intended to create a service system which is responsive to differing needs across stakeholder groups. The complexity of this process is greater than that which can be easily managed even by a small, cohesive group, and it is even more difficult to manage given the… multiple groups engaged in this important child and family services endeavor… Ambitious aims are facilitated to some extent by significant federal leadership, technical assistance, training, and other educational materials offered to these sites. …There is no blueprint or well-specified formula for pursuing the complex interactions necessary for system development, nor would such an approach be consistent with the flexibility necessary to respect the needs and process of individual communities.*[37]

Because SOC implementation is so complex, we recommend that ILCHF contract with an entity with appropriate expertise to work with sites through offering resources and individualized and group supports on areas such as including youth and parents in system planning; identifying critical partners; assessing needs and the public policy landscape; developing goals, strategic plans, and organizational structure and processes; leadership; communications; and continuous quality improvement. Le and colleagues (2016) suggest a systematic approach to TA to support system and services change that includes needs assessment and individualized planning, education and information-sharing, skill and capacity-building, collaboration, and focused evaluation of short- and long- term change.[38] The Technical Assistance Center on Social Emotional Intervention for Young Children, funded by the Office of Special Education Programs in the U. S. Department of Education, provides an online resource focused on the use of TA to

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[36] Stroul, B., Blau, G., Friedman, R. (n.d.) *Updating the System of Care Concept and Philosophy.* National Technical Assistance Center for Children's Mental Health, Georgetown University Center for Child and Human Development.
[37] Burns, B. (2001). Commentary on the special issue on the national evaluation of the comprehensive community mental health services for children and their families program. *Journal of Emotional and Behavioral Disorders, 9* (1), 71-77.
[38] Le, L., Anthony, B., Bronheim, S., Holland, C. & Perry, D. (2016). A technical assistance model for guiding service and systems change. *The Journal of Behavioral Health Services & Research, 43,* 380-395.

support systems change. Acknowledging that the existing knowledge base on the impact of TA on systems-level change is minimal and still developing, the author calls for more research and evaluation in this area.[39] Thus, providing and evaluating this type of technical assistance presents an opportunity to build on a scant but important literature that would help philanthropies interested in funding complex, bottom-up, multi-stakeholder systems change that involves a significant shift in practice and culture.

**Prioritizing Outcome Goals.** To varying degrees, each of the sites have struggled to implement strategies to simultaneously address all 11 of the outcome goals required by the funding agency. We suggest that sites are encouraged to first prioritize the goal of including youth and parents in system planning, a most difficult task in and of itself that requires significant resources but is key to fidelity to the SOC model. This can be done by requiring and supporting sites to include consumers in developing their grant application and in the front end of planning and implementation. Together, providers and consumers can then consider the 11 goals and three CASSP principles as elements of a vision of the ideal system they are working towards, use an empirically-based assessment of the extent to which each of these goals and principles are present in their community, and use a democratic process to develop the goals they will initially work towards in their community. These community planning teams should be supported in basing their selection of initial shared goals on a realistic assessment of the work that will be required and available resources. Additional goals can be added through this process as resources become available. Hodges et al. (2012) provides useful guidance on goals and their relationship to values, beliefs, and purposeful action in the context of complex systems change:

> *…System goals make stakeholder values and beliefs concrete and orient system activity toward purposeful actions used to create systems change…Stakeholders use goals to establish shared expectations related to system implementation. These should include: outcome goals such as the reduction of out-of-home placements; process goals such as increasing culturally competent and individualized care; and planning goals related to future action. Establishing shared expectations is intended to bring systems under the influence of a single plan grounded in SOC values and principles and can be used to set agreed-upon targets for action across system partners.*[40]

**Increasing Caregiver and Youth Engagement.** After two years of funding, only one site, BRIDGES, achieved significant consumer participation in system planning and governance. This is clearly an area in which sites need additional supports. One area worthy of reflection is whether some SOC structures and activities can have the unintentional effect of creating barriers to parent and youth participation in implementation activities including leadership and decision-making roles. For instance, in one site, SOC implementation-related meetings

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[39] Blase, K, (2009). Technical Assistance to Promote Service and System Change. *Roadmap to effective intervention practices #4.* Tampa, Florida: University of Southern Florida, Technical Assistance Center on Social Emotional Intervention for Young Children. https://files.eric.ed.gov/fulltext/ED577840.pdf.

[40] Hodges, S., Ferreira, K., Israel, N. (2012). "If we're going to change things, it has to be systemic:" Systems change in children's mental health. *American Journal of Community Psychology, 49(3-4),* 526-537.

incorporate discussion of specific cases (families in the community), which limits the opportunity for other parents to participate in implementation meetings due to confidentiality and HIPAA concerns. Though the time people can devote to attending meetings is limited, if SOC implementation is to reflect meaningful family involvement in planning and leadership, discussions of specific youth and families need to occur in separate spaces. Similarly, referral management systems like IRIS are very beneficial to the goal of increasing access to coordinated service but are only one tool for SOC implementation and are limited to the professionals who use them. The risk is building SOC structures, process, and activities around case staffing and management when the overall aims of the SOC model and the ILCHF funding are to emphasize the engagement of those who need and use services in building a better system.

It is now widely accepted that youth and their families have deep knowledge and understanding of their own experiences with the mental health service system and that involving them in implementation efforts and sharing power with them will enrich and strengthen SOC development and sustainability. Engagement is the intentional, meaningful, and sustained involvement of youth and their families in actions to create positive social change. Youth and family engagement strategies exist along a continuum that includes:

- Youth/family support – the process of equipping youth/parents with the tools to gain authority and agency;
- Youth/family input – the integration of youth/parent ideas, opinion, and feedback into planning and implementation; and
- Youth/family leadership – the structuring of initiatives so that youth/parents are leads or co-leads with equal power to professional facilitators in determining actions.[41]

Despite its importance for SOC implementation, many site visit participants acknowledged that parent and youth engagement is where they have made the least progress to date. Study participants identified logistics like meeting times and locations as well as motivational factors such as effective incentives and sustaining interest as some of the primary challenges to parent/caregiver participation. The sites' experience of such challenges and the existence of common barriers to family and youth participation are widely shared.[42] Participants serving youth discussed youth involvement as a continued goal and expressed commitment to it but were mostly uncertain about how to do it. We recommend devoting additional resources to the

[41] Shakespeare, J., O'Brien, M., & Harrison, E. (2020). *Youth Engagement in Collective Impact Initiatives: Lessons from Promise Neighborhoods.* Washington, DC: Urban Institute.

[42] Canas, E., Lachance, L., Phipps, D., & Birchwood, C. C. (2019). What makes for effective, sustainable youth engagement in knowledge mobilization? A perspective for health services. *Health Expectations*, *22*, 874-882.
Gyamfi, P., Keens-Douglas, A., & Medin, E. (2007). Youth and youth coordinators' perspectives on youth involvement in systems of care. *The Journal of Behavioral Health Services & Research*, *34*, 382-394.
Matarese, M., McGinnis, L., & Mora, M. (2005). Youth involvement in systems of care: A guide to empowerment. Technical Assistance Partnership for Child and Family Mental Health (TA Partnership). https://nwi.pdx.edu/NWI-book/Chapters/App-6e.3-Youth-Involvement-In-Systems-Of-Care.pdf.
Rudd, C., Kalra, S., Walker, J., & Hayden, J. (n.d.). How can organizations assess their readiness to co-design? Annie E. Casey Foundation. https://caseyfamilypro-wpengine.netdna-ssl.com/media/21.07-KM-LFOF-ChiByDesign.pdf.

goal of including consumers in system planning and implementation. In support of that aim, as well as the importance of using evidence-informed practices, we provide a brief review of relevant literature and resources.

**COFI.** This site visit illuminated a positive impact of partnership with an existing parent organization such as COFI on meaningful engagement of parents with SOC efforts. The mission of COFI (Community Organizing and Family Issues) is "to build the power and voice of parents, primarily mothers and grandmothers from Black and Brown communities, to shape the public decisions that affect their lives and the lives of their families." COFI provides training and family-focused organizing with the aim of transforming communities and empowering individuals. According to the website:

> *The COFI Way* emphasizes the interconnection between personal struggles and broader community issues and builds capacity for parent leaders to address these issues through collective action. Through '*The COFI Way'*, parents develop skills, confidence, and the organized power to win improvements in schools, communities, and public policies.

COFI recognizes that:

- Parents, as leaders of families, are "natural" community and policy leaders, if given the chance.
- Parents, as leaders, will prioritize an action agenda that focuses on improving the community's support of children and families and addressing racial and economic inequities that limit life opportunities for their children.
- Parents have the right and the capacity to participate in the decisions that directly affect them, including public policy decisions.

Significant barriers to parent participation exist in family service programs, school systems, government agencies, and community and advocacy organizations. COFI's innovative family focused organizing model, *The COFI Way*, provides leadership development and organizing support to overcome those barriers and assure parent participation and partnership. The positive impact for parent engagement in SOC implementation provided when COFI parents are partners in the process cannot be overstated.

**Cultivating youth engagement.** Sites can receive guidance from a robust literature on youth engagement, youth empowerment, and youth-guided services, in such areas as juvenile justice and residential treatment. A first recommendation is for systems to operationalize broad goals such as youth engagement with specific aims such as the number of youth to be involved, in what ways, over what period of time, as evidenced by what indicators. As with any goal, youth involvement in leadership and planning must be measurable, there must be buy-in from stakeholders, and some element of accountability should be built in as well. One key element of cultivating that buy-in with staff can be a process of acknowledgement of the practice of shared

power and perceived loss of control experienced by service providers.[43] What this means is that professionals working in an SOC must embrace a shift in the usual structures of power in which system, program, and implementation decisions are made for and not with or by service recipients. Meaningful and lasting shifts in power and influence are a critical prerequisite to successful incorporation of youth voice in systems of care[44] and for youth empowerment at a system level using a co-design approach.[45] For some, a true paradigm shift is required for the ability to create systems that include youth in substantive ways in leadership and decision-making.

As with other elements of building an SOC, proactive steps and ongoing commitment are necessary to ensuring this goal is achieved.[46] Staff may also need additional and ongoing training to support their ability to motivate youth and focus on their strengths and assets, to ensure basic needs are met for those youth participants, and to support them in managing this role.[47] Further, in meeting the aim of cultural and linguistic competence, professionals may also need to expand their understanding of culture beyond race and ethnicity to other areas of identify that may have importance to the youth being served (e.g., the LGBTQIA2+ community) to help ensure a welcoming and equitable experience. A similar paradigm shift must also occur among families and youth who, in a system doing business as usual, are constrained to nonexpert status reliant on others to make choices for them. This is the very definition of disempowerment and is commonly the experience of mental health consumers. The concepts of power and empowerment lie at the heart of the literature and program work in this area. The framework of Positive Youth Development (PYD) has been applied to children's mental health systems of care, youth empowerment, Youth Civic Engagement, youth-guided services, and Youth Peer Support Specialists in related areas such as child welfare and juvenile justice as well as the specific application of PYD in a system of care.[48] Additionally, sites need additional technical assistance around youth and parent engagement in SOC implementation and should seek out speakers, consultants, evidence-based models, and/or other avenues to build capacity.

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[43] Blau, G. M., Caldwell, B., Fisher, S. K., Kuppinger, A., Levison-Johnson, J., & Lieberman, R. (2010). The Building Bridges Initiative: Residential and community-based providers, families, and youth coming together to improve outcomes. *Child Welfare*, *89*, 21.
Miller, B. D., Blau, G. M., Christopher, O. T., & Jordan, P. E. (2012). Sustaining and expanding systems of care to provide mental health services for children, youth and families across America. *American Journal of Community Psychology*, *49*, 566-579.

[44] Friesen, B. J., Koroloff, N. M., Walker, J. S., & Briggs, H. E. (2011). Family and youth voice in systems of care. *Best Practices in Mental Health*, *7*, 1-25.

[45] Rudd, C., Kalra, S., Walker, J., & Hayden, J. (n.d.). How can organizations assess their readiness to co-design? Annie E. Casey Foundation. https://caseyfamilypro-wpengine.netdna-ssl.com/media/21.07-KM-LFOF-ChiByDesign.pdf.

[46] Youth.gov (n.d.). Key Principles of Positive Youth Development. https://youth.gov/youth-topics/key-principles-positive-youth-development

[47] Miller, B. D., Blau, G. M., Christopher, O. T., & Jordan, P. E. (2012). Sustaining and expanding systems of care to provide mental health services for children, youth and families across America. *American Journal of Community Psychology*, *49*, 566-579.

[48] Matarese, M., McGinnis, L., & Mora, M. (2005). Youth involvement in systems of care: A guide to empowerment. Technical Assistance Partnership for Child and Family Mental Health (TA Partnership). https://nwi.pdx.edu/NWI-book/Chapters/App-6e.3-Youth-Involvement-In-Systems-Of-Care.pdf.

Sites have provided training for professionals in such areas as evidence-based practice, wraparound services, and affirmative practice with the LGBTQIA2+ community and can utilize that commitment to learning by focusing future training on youth and parent involvement.

Friesen and colleagues identified six factors that have demonstrably contributed to an increase in youth and family involvement in systems of care. These are 1) offering some manner of incentive, 2) establishing accountability around participation of families, 3) providing clear policies and processes that support participation, 4) providing information about the value and importance of such participation, 5) sharing and cultivating knowledge and skills, and 6) building relationships.[49] These broad supportive elements have applicability for any SOC and should be localized to best function in its unique context. Sites reported activities related to many of these identified supports. We recommend that they discuss further what is already in place and consider how to integrate what needs to be added.

According to Youth Power!, a group of young people engaged with the New York System of Care, there are five key values that must inform partnering with youth: cultivating and maintaining a strength-based focus; sharing power and empowering young people; recognizing and avoiding adultism; valuing cultural and linguistic competence; and valuing youth culture.[50] Another insight from these youth is that participation in an SOC and the mental health system is developmental for each individual, that knowledge and skill for the role must be built and supported. The *Youth Power! How To's of Youth-Guided Practice* is an excellent resource for insight into the thinking of engaged youth. It also provides useful information on organizational self-assessment and concrete steps to increase youth engagement. It offers localized program examples and worksheets to help guide engagement in other SOCs.

Gyamfi and colleagues conducted focus groups with youth involved with SAMHSA-funded SOC and found that a focus on strengths, youth empowerment, and commitment to a PYD framework were essential foundations.[51] The youth respondents also stressed the importance of relationship-building, not only with adult professionals but also with one another, noting the value of the social element in sustaining youth involvement. The biggest identified barrier to youth participation was perceived lack of authentic adult buy-in and commitment.

A critical step in the cultivation of youth engagement and leadership in an SOC is the provision of training and support. Simply inviting youth to the table does not actually equip them with the knowledge, skills, and confidence necessary to make a substantive contribution in a professional setting. Proactive and sustained efforts are needed to engage and build the trust necessary for youth to raise their voices in the context of a mental health system, and to help youth express their views in ways that are productive in a professional context. Educating youth

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[49] Friesen, B. J., Koroloff, N. M., Walker, J. S., & Briggs, H. E. (2011). Family and youth voice in systems of care. *Best Practices in Mental Health*, *7*, 1-25.

[50] Valesey, B. & Orlando, S. (n.d.) The How To's of Youth Guided Practice. Youth Power! https://nyssoc.com/wp-content/uploads/2021/10/How-To-YG-Training-Guide_Final.pdf.

[51] Gyamfi, P., Keens-Douglas, A., & Medin, E. (2007). Youth and youth coordinators' perspectives on youth involvement in systems of care. *The Journal of Behavioral Health Services & Research*, *34*, 382-394.

on parliamentary process, communication, technology, program evaluation concepts, service delivery models, and policymaking not only enables meaningful participation in SOC implementation processes but also equips them with knowledge and skills that are transferable to other areas of life such as employment or higher education.

Useful examples and models for youth engagement in decision-making are available. One model is the youth leadership council or advisory board that can allow youth meaningful opportunities to engage with planning, evaluation, and governance of an SOC.[52] Another strategy for implementing youth-guided services is to involve youth in the planning and delivery of staff training. Youth voice in evaluation of the SOC has received less attention in the literature, but there are examples.[53] National resources and organizations can support local chapter of engaged youth. Youth Move National is a national organization with regional chapters in Minnesota and Wisconsin (https://youthmovenational.org/).

Finally, youth involvement at the policy advocacy level is as important as their engagement at other levels of the children's mental health system. As with other facets of youth involvement advocacy activities would require capacity-building through training and support, but with great potential rewards for meaningful youth voice in the systems that impact them. The National Consortium on Leadership and Disability for Youth, also youth-led, has created a guide to legislative advocacy for youth. Though not explicitly focused on children with mental health concerns, it offers helpful examples of concrete steps and activities to increase youth empowerment for advocacy.[54]

[52] Miller, B. D., Blau, G. M., Christopher, O. T., & Jordan, P. E. (2012). Sustaining and expanding systems of care to provide mental health services for children, youth and families across America. *American Journal of Community Psychology*, *49*, 566-579.
[53] Henderson, J. L., Hawke, L. D., & Relihan, J. (2018). Youth engagement in the YouthCan IMPACT trial. *Canadian Medical Association Journal*, *190*(Suppl), S10-S12.
[54] National Consortium on Leadership and Disability for Youth (2007). Retrieved at http://www.ncld-youth.info/Downloads/legislative_policy_guide.pdf.

# Appendix A – Program Director Interview Protocol

**Introductions:** Please begin by introducing yourself and describing your role with the SOC and how long you have been part of implementation.

The definition of system of care used by the ILCHF is: "a spectrum of effective, community-based services and supports for children and youth with or at risk for mental health or other challenges and their families, that is organized into a coordinated network, builds meaningful partnerships with families and youth, and addresses their cultural and linguistic needs, in order to help them to function better at home, in school, in the community, and throughout life." We are going to ask you a series of questions to understand how your community has worked to achieve this system of care.

1. Pre-grant activity
   Your site applied for but did not receive funding from ILCHF for the CMHI 2.0 grants. What type of continued planning efforts, if any, were put into developing the SOC in your community during the time period after you didn't get that funding and before you did receive funding for the CMHI 3.0?

2. Planning and Implementation Teams and Processes
   Tells us about the teams and processes that have been developed to support SOC implementation (such as dedicated staff, community implementation team, leadership team, other teams, work groups or subcommittees). Who participates and how? How often do they meet? What have they been working on? What have they accomplished? How have these structures changed over the timeline thus far?

3. Involving Families and Youth
   How have youth and families been involved in system planning and building? How and when were they initially engaged? How has their participation been supported (i.e., initial training, ongoing support)? What has been challenging? What has been successful? Describe any efforts to be inclusive and reflect the diversity of the community. Describe any efforts related to increase the engagement of families and youth across systems.

4. Common Agenda/Shared Goals and Values/Strategic Plan
   Is there a set of shared goals for the children's mental health system of care? Is there a strategic plan for reaching the goals? How were the shared goals and strategic plan developed, and have they changed over time? What action steps have been taken to achieve each of the goals? How is progress toward goals evaluated? (can follow up with question about use of data to evaluate progress)?

5. Leadership
   Who provides leadership for the implementation of the SOC? What does that leadership look like? What support/training is in place to support effective leadership? How are parents and youth involved in leadership of the SOC?

6. Decision-Making Processes
   Please describe decision-making processes for the SOC. Who is involved in decision-making guiding the implementation process? How are parents and youth involved? Are diverse voices included? How are data used to inform decision-making? How are disagreements or other challenges resolved?

7. Communication
   How do you communicate with participating individuals, teams, and organizations? How do teams and organizations communicate with one another?

8. Support Infrastructure
   How does the SOC ensure that there is ongoing logistical and administrative support, including facilitation, support with technology and communications, data collection and reporting? Are there unmet needs in these areas?

9. Barriers
   The CMHI projects began in January 2020, which was right before the pandemic started. Can you tell us how the pandemic has impacted the implementation of SOC in your community?

   Also, Illinois is facing one of the worst mental health workforce crises in decades. How has this impacted the SOC implementation in your community?

   Have there been other barriers that you have encountered in building the system of care? Please describe the impact for implementation.

10. Closing question
    Is there anything else you think we should know to understand your efforts, to date, to build a system of care focused on children's mental health?

## Appendix B – Community Stakeholder Focus Group Protocol

**Introductions:** Before we get started, let's go around the table/room and do some introductions. Can you tell us your name, the agency or organization you work at, and a little bit about how you have been involved in SOC planning and implementation to date?

The definition of system of care used by the ILCHF is: "a spectrum of effective, community-based services and supports for children and youth with or at risk for mental health or other challenges and their families, that is organized into a coordinated network, builds meaningful partnerships with families and youth, and addresses their cultural and linguistic needs, in order to help them to function better at home, in school, in the community, and throughout life." We are going to ask you a series of questions to understand how your community has worked to achieve this system of care.

1. Pre-grant activity
   Your site applied for but did not receive funding from ILCHF for the CMHI 2.0 grants. What type of continued planning efforts, if any, were put into developing the SOC in your community during the time period after you didn't get that funding and before you did receive funding for the CMHI 3.0?

2. Planning and Implementation Teams and Processes
   Tells us about the teams and processes that have been developed to support SOC implementation (such as dedicated staff, community implementation team, leadership team, other teams, work groups or subcommittees). Who participates and how? How often do they meet? What have they been working on? What have they accomplished? How have these structures changed over the timeline thus far?

3. Involving Families and Youth
   How have youth and family been involved in system planning and building? How and when were they initially engaged? How has the participation of youth and family been supported (e.g., initial training, ongoing support)? What has been challenging? What has been successful? Describe any efforts to be inclusive and reflect the diversity of the community. Describe any efforts to increase the engagement of families and youth across systems.

4. Common Agenda/Shared Goals/Strategic Plan
   Is there a set of shared goals for the children's mental health system of care? Is there a strategic plan for reaching the goals? How were the shared goals and strategic plan developed and have they changed over time? How is progress toward goals evaluated?

5. Leadership
   Who provides leadership for the implementation of the SOC? What does that leadership look like? What support/training is in place to support effective leadership? How are parents and youth involved in leadership of the SOC implementation?

6. Decision-Making Processes
   Please describe decision-making processes for the SOC. Who is involved in decision-making guiding the implementation process? How are parents and youth involved? Are diverse voices included? How are data used to inform decision making? How are disagreements or other challenges resolved?

7. Communication
   How do participating individuals, teams, and organizations communicate with one another across teams and between meetings? Is the information that you receive through these communications adequate in terms of frequency, timeliness, and content? In other words, does the communication allow you to participate effectively in building the SOC?

8. Barriers
   The CMHI projects began in January 2020, which was right before the pandemic started. Can you tell us how the pandemic has impacted the implementation of SOC in your community?

   Also, Illinois is facing one of the worst mental health workforce crises in decades. How has this impacted the SOC implementation in your community?

   Have there been other barriers that you have encountered in building the system of care? Please describe the impact for implementation.

9. Other
   Is there anything else you think we should know to understand your efforts, to date, to build a system of care focused on children's mental health?

## Appendix C – Parent Focus Group Protocol

**Introductions:** Before we get started, let's go around the table/room and do some introductions. Can you tell us your name, and a little bit about how you have been involved in SOC planning and implementation?

The definition of system of care used by the ILCHF is: "a spectrum of effective, community-based services and supports for children and youth with or at risk for mental health or other challenges and their families, that is organized into a coordinated network, builds meaningful partnerships with families and youth, and addresses their cultural and linguistic needs, in order to help them to function better at home, in school, in the community, and throughout life." We are going to ask you a series of questions to understand how your community has worked to achieve this kind of system of care.

1. Planning and Implementation Teams and Processes
   Please tell us about the teams and processes that are in place to implement the SOC (if needed, prompts could include asking about staff, community implementation team, leadership team, other teams, work groups or subcommittees). Who participates and how? How often do they meet? What have they been working on? What have they accomplished? How have these structures changed over the planning and implementation timeline thus far?

2. Involvement of Families and Youth
   Considering your experiences and observations as a part of the team, how have youth and parents/caregivers been involved in system planning and building? How have parents been prepared and supported to play a leadership role in implementation? What efforts have been made to be inclusive and reflect the diversity of the community? What has been challenging with getting families and youth involved? What has been successful? How can parents and youth be involved going forward?

3. Common Agenda/Shared Goals and Values/Strategic Plan
   Is there a set of shared goals for the children's mental health system of care? Is there a strategic plan for reaching the goals? How were the goals and strategic plan developed and have they changed over time? How are goals evaluated? In other words, how does SOC leadership know what progress has been made toward goals?

4. Leadership
   Who provides leadership for the implementation of the SOC? What support/training is in place to support effective leadership? How are parents and youth involves in leading the SOC implementation?

5. Decision-Making Processes
   Please describe how important decisions get made in the SOC. Who is involved in decision-making? How are parents and youth involved? How are diverse voices included in decision-making? How are disagreements or other challenges resolved?

6. Communication
   How do participating individuals, teams, and organizations communicate with one another across teams and between meetings? Is the information that you receive through these communications adequate in terms of frequency, timeliness, and content? In other words, does the communication allow you to participate effectively in building the SOC?

7. Barriers
   What barriers have you encountered in building the system of care? In your role as a parent? How have these barriers impacted implementation in general and your participation?

   How has COVID impacted your ability to participate in the SOC implementation?

8. Other
   Is there anything else you think we should know to understand your efforts, to date, to build a system of care focused on children's mental health? About involvement of parents and youth in the implementation?