

CIE Perspectives

# CENTERING COMMUNITY VOICE

Community Engagement Toolkit



A group of field experts from diverse communities across 5 States discuss proven and innovative strategies to authentically engage communities; to address equity, through shared power and centering the voices of those who use systems of care. Community Voice in CIE governance relies upon trust and those with years of earned experience, will share best practices, to move beyond one-time focus groups, one-way surveys and other elementary engagements, to offer tangible resources and proven outcomes highlighting how trusted governance of data sharing effectively shapes health and social systems.



- Individual collaborator credits are available in each region represented -  
Toolkit designed by: Angelica Esparza Bañuelos

# KEY OBJECTIVES

Recognize the importance of centering communities throughout the development, building, and maintenance of a CIE.

Compare and contrast approaches to center communities in the work of CIE based on the local context and lived experience of residents.

Describe how to identify, manage, and eliminate power differentials between multiple actors in the CIE ecosystem, such as residents, community leaders and systems leaders.

Participants will be able to identify current community engagement practices on the spectrum from predatory to liberatory, and what if any movement they hope to make along the spectrum.





## COMMUNITY SNAPSHOT

Region represented: Chicago and Cook County, IL

System: [Chicago Regionwide CIE](#)

CIE Maturity Level: Early  
Implementation/Launch Phase: Piloting CIE with a small set of partners.

### CIE by the Numbers:

- ~12 partner organizations
- Integration with HMIS covering 100+ homeless service providers

### Key Community Characteristics:

- Urban, anchored in City of Chicago, extending to suburban Cook County
- Chicago metro area of ~ 9.5 million people
- High number of vulnerable, overburdened communities

## COMMUNITY ENGAGEMENT APPROACH/DESIGN

- 1 Collaborative governance model that places community engagement at the center
- 2 Integrating Lived Experience from Inception to Implementation
  - Actively engage people with lived experience since the project's inception
  - Establish lived experience workgroups that can help identify the initial use cases during the design phase
  - Create a foundational place for lived experience voices throughout all aspects of the project (especially data sharing and privacy)

## ENGAGEMENT PRACTICES THAT WORK

- Being flexible and planning around participant needs.
- Communicating in clear, simple language.
- Listening and responding.
- Showing how people's input is being operationalized.

## COMMUNITY ENGAGEMENT RESOURCES & OUTCOMES

Commitment to share any collateral, work products, research and findings.

### People want:

- Engagement on "their terms"
- To be treated with dignity and respect
- To be heard
- Their input to make a difference
- To see their suggestions acted on

### How do you know it's working?

- Positive feedback from lived experience workgroup members and community partners
- Original lived experience group members continue to be involved

*Rashidat Balogun MPH, Managing Director, Community Information Exchange, Illinois Public Health Institute, Illinois*



## COMMUNITY SNAPSHOT

**Region represented:** Southeastern Michigan (e.g., Macomb, Oakland, Wayne, Washtenaw counties)

**System:** [United Way for Southeastern Michigan](#)

**CIE Maturity Level:** Scale Phase, Growing CIE network and infrastructure

**CIE by the Numbers:**

- 40+ integrated/referral health and human services partners
- 35+ collaborative governance partners
- Vendor agnostic & committed to interoperability
- 7 years in operation

### Key Community Characteristics:

- 4,292,079 people: 62% White, 23% Black or African American, 6% Asian, 5% Hispanic or Latino, 4% Multiracial
- 39% are between ages of 25-54
- 28.5% live below 200% of the poverty level
- Life expectancy ranges from 73 to 80 and infant mortality rate ranges from 3.1 to 8.9 per 1,000 live births

## COMMUNITY ENGAGEMENT APPROACH/DESIGN

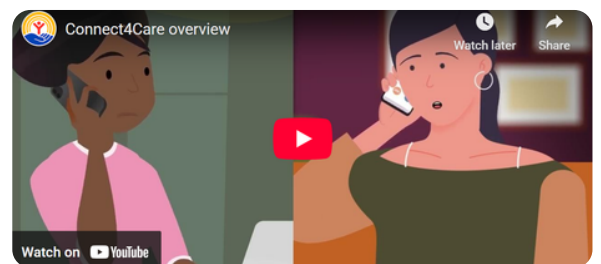
Transitioning from project-based partner engagement to collaborative governance focused on planning, standards, assurance, and stewardship

- 1 Reciprocity as a core value where feedback loops are an ongoing mechanism
- 2 Collaboration, co-design, and distributed leadership are key across integration projects and collaborative governance

## COMMUNITY ENGAGEMENT RESOURCES & OUTCOMES

“The Connect4Care™ network is made up of health and social services organizations in Southeastern Michigan. They provide services such as food, health care, child care, employment, transportation and housing assistance. Participating organizations share information about their services to connect clients and partners in the network.

Connect4Care™ depends on input from community members and collaborators. Input found in committees, feedback, and surveys are used to create standard practices and policies. There is no Community Information Exchange without community.” - *United Way for Southeastern Michigan Website*



- [Hope Starts Here Imperative 5 Recommendations: Integrated Data Systems](#)
- [Environmental Scan](#)
- [Resident/Client Interviews](#)
- [MDHHS SDOH Strategy, Michigan's Roadmap to Healthy Communities](#)
- [CIE Task Force Reports](#)

**Esperanza Cantú, MPH, Senior Director, CIE & Integration Services, United Way for Southeastern Michigan**



## COMMUNITY SNAPSHOT

Region represented: Muskegon, Michigan

System: [Access Health](#)

CIE Maturity Level: Early Implementation Launch Phase. Piloted/deployed CIE with a small set of partners

CIE by the Numbers:

- 2 clinical partners
- 2 payor partners
- 3 workforce partners
- 1 reimbursement pilot
- 7 CBO partners
- 10+ years of codesign

### Key Community Characteristics:

- 176K residents; 44% rural
- 43% of residents have HS diploma or less
- 75% White; 13% Black; 6% Hispanic; 4% 2+ races
- 45% of Black households and 19% of White households earn below \$29,900

## COMMUNITY ENGAGEMENT APPROACH/DESIGN

- 1 Co-design approach to platform development with community organizations and social navigators, community members, clinical, payor, and vendor partners
- 2 Community priorities identified through annual [Livability Lab](#) process, our version of a 100-day challenge accelerating data-driven, community-led change.
- 3 Alignment with existing collaboratives.
- 4 Clear, defined steps to maintain engagement

## COMMUNITY ENGAGEMENT RESOURCES & OUTCOMES

### Activities:

- 1 Leverage community collaboratives and roundtable spaces to gather community perspectives that break down core community findings and emerging priorities.
- 2 Consider journey mapping with community members. The prioritization of user perspective can be crucial for various phases of development but particularly for designing self-service pathways.

### How do you know it's working?

- Sustained engagement at all levels
- Word of mouth community linkages



*Samantha Cornell, JD, Chief Operating Officer, Access Health, Michigan*



## COMMUNITY SNAPSHOT

Region represented: Columbus & Franklin County, Ohio

System: [Smart Columbus](#) (a non-profit civic innovation lab)

CIE Maturity Level: System Build Phase

CIE by the Numbers:

- 38 Care Coordination Council Members
- \$16 million in funding from city and county
- 26 submissions for technology platform RFP
- 13 residents + 13 caseworkers on the Experience Council

### Key Community Characteristics:

- Urban, state capital with 1.32 million residents
- 200,000 people live in poverty
- 9% without health insurance
- Ranked 3rd nationally for economic development and 1507th (out of 3210) for life expectancy

## COMMUNITY ENGAGEMENT APPROACH/DESIGN

**Approach:** → Human Centered Design and Cross-Sector Stakeholder Engagement

**Successes:** → Experience Council and their involvement in the RFP process  
→ Consent and Data Sharing Workgroup  
→ Data Leaders Group  
→ Care Coordination Council  
→ Annual Care Coordination Summit

**What is working:**

**What is not working:**

Keeping pace with the community's needs. As more often than not, capacity is a determining factor & can present challenges in keeping up the pace with rising community needs.

## COMMUNITY ENGAGEMENT RESOURCES & OUTCOMES

"Co-design is a collaborative design approach that emphasizes shared decision making, prioritizing relationships, using participatory methods, valuing diverse perspectives, and centering lived experience. This co-design framing combines equity, human-centered design, and community collaboration methodologies." ([CIE Initiative Plan, Pg. 33 - Centering Lived Experiences](#))

### How do you know it's working?

→ Documented acknowledgement for use of consent materials, which were developed with direct community input

→ Prototype commitments from 4 network partners in multiple sectors involving 23 CBO partners



Ayaz Hyder, PhD Data and Integrations Lead, Smart Columbus, Ohio



# MISSOURI

## COMMUNITY SNAPSHOT

Region represented: Greater St. Louis

System: [Greater St. Louis CIE](#)

- Led by [United Way 211](#)
- [Integrated Health Network](#), University of MO - St. Louis

CIE Maturity Level: Scale Phase, Growing CIE network and infrastructure

CIE by the Numbers:

- All major local health systems, 150+ CBOs, 13,750 referrals in 2024 alone, over 14,300 unique people served since 2020

Key Community Characteristics:

- 16 county St. Louis region, largely urban, bi-state, aging/decreasing population, significant health and racial disparities

## COMMUNITY ENGAGEMENT APPROACH/DESIGN

- 1 Some early engagement with people seeking services as part of CIE development
- 2 Rapid implementation of software during early pandemic for widely used rental assistance that shortened governance buildout
- 3 Exploration of how the CIE can work with existing governing bodies to avoid overburden— but never followed through
- 4 Challenge of infrastructure (not always direct client/patient interaction) + old school partners
- 5 Classic example of “for, not with”

## COMMUNITY ENGAGEMENT RESOURCES & OUTCOMES

What are the consequences?

- Decreased engagement over time
- Disconnect from the “why” of the work —and the “how” of person-centered design
- Stuck in institutional silos and pressures

Some hope?

- Major statewide and local investments in connecting health and social services
- Prioritizing how community voice is centered in infrastructure redesign and governance



*Paul Sorenson, MSW, Co-Director, University Missouri St. Louis Community Innovation & Action Center, Missouri*



# CALIFORNIA

## COMMUNITY SNAPSHOT

Region represented: San Diego County

System: [CIE San Diego](#)

CIE Maturity Level: Scale Phase, Growing CIE network and infrastructure

CIE by the Numbers:

- CIE SD launched in 2014
- 142 Organizational Partners
- 369,000+ Individuals consented into CIE
- 400,000 Program Enrollments
- 302,000 Records w/ Shared Client Data
- 200,000+ Direct Referrals w/50 partners accepting Direct Referrals

### Key Community Characteristics:

- Over 3.3 million residents
- Over 34% of residents are Hispanic/Latinx with growing populations of immigrant & refugee residents
- Approx. 1.2 million receive public assistance
- Border & Military Town

San Diego County-Demographic & Regional Data source, [San Diego County Website](#)

## COMMUNITY ENGAGEMENT APPROACH/DESIGN

Engage community members with lived experience and grassroots organizations, to advance equity and inclusion, across the CIE Network infrastructure including: its governance structure, ongoing development and future expansion.

- Prioritizing and elevating community voice, grassroots & culturally diverse organizations
- Leveraging community connections to enhance service delivery (in progress)
- Hosting cross-sector collaborative opportunities & connection building
- Learning & adopting best engagement practices rooted in equity & intersectionality

*"Funding or no funding, I'm down to do the work!"*  
Community Voice Advisory Board Member

## COMMUNITY ENGAGEMENT RESOURCES & OUTCOMES

[Community Voice Website](#) is now live and hosts materials such as Collective Community Care Plans.



These plans are intended to inform providers and agency sectors, who uplift and support coordinated care efforts, in San Diego County. The recommendations proposed will help utilize: lessons learned, insight into journey of providing/receiving care & services (both provider & client perspective) and innovatively rethinking the way coordination could be maximized cross-regions.



**Client Choice**



**Justice Impacted**



**Food Access**



**Youth & Children**

**Zenia Torres, Director of Partner Engagement, 211 San Diego/Community Information Exchange, California**

# RECOMMENDED ACTIVITIES

## DISCUSSION TOPICS

To be used during break out sessions:

- Compensation considerations for Lived Experience Experts
- Engagement Practices: Predatory to Liberating
- Building a culture of data sharing through engaged communities
- What happens when a CIE doesn't effectively center community voice
- Community co-design process
- Interplay of local & state

## REPORT OUT

Each table can select someone to report out and share “aha” moments and/or connections made from your break-out discussions. These could include:

- Overall learnings
- Practical applications that will be useful in your project design or approach
- Connection building or cross-collaborative opportunities

