

# Leveraging Community Information Exchanges for Equitable and Inclusive Data: **CIE Community Profiles**

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The information generated through this activity has informed RWJF's public health data infrastructure portfolio.

# Introduction

*“A Community Information Exchange (CIE) is a community-led ecosystem comprised of **multidisciplinary network partners** using a **shared language**, a **resource database**, and **integrated technology platforms** to deliver enhanced **community care planning**. A CIE enables communities to have **multi-level impacts** by shifting away from a reactive approach towards **proactive, holistic, person-centered care**. At its core, CIE centers the community to **support anti-racism and health equity**.”*

Since publishing the [Community Information Exchange \(CIE\) Toolkit](#) in 2018, 211/CIE San Diego has been fortunate to provide national thought leadership and mentoring to our CIE Ambassadors, communities across the country that are planning or in the early stages of implementing a CIE. Over the years, we have seen these communities grow and offer innovative approaches to all of the strategies we presented in the toolkit. One of the most rewarding benefits of our growing national membership network is to learn and share the experiences and approaches applied by these communities, particularly around engaging Community Voice.

As featured in our recent publications, [A Vision for the Future](#) and the [CIE Data Equity Framework](#), it is critical for institutions to work from a place of anti-racism, shifting the focus from solely considering what technology works best to who benefits from the system and who needs a seat at the table to reimagine our systems of care. In this brief, we highlight 211/CIE San Diego, along with six other communities working to build better systems of care that truly benefit the people they serve. We are honored to have this opportunity to share approaches, experiences, challenges, and recommendations to engaging Community Voice to improve population health and advance health equity.

Engaging community members who are most impacted by services is one of the most critical elements to the successful design and implementation of a CIE. As such, these Community Profiles were developed to explore strategies and provide examples of how community members can be involved in the development and maintenance of community data systems, like CIEs. The Community Profiles detail current and planned work for engaging community members including novel approaches, challenges, and lessons learned:

- Approaches to community member engagement (e.g. contribution of lived experience, leadership, input and decision-making);
- Challenges and opportunities to encourage more community members and CBO participation; and
- Resources and policy that could support continued growth in this area.

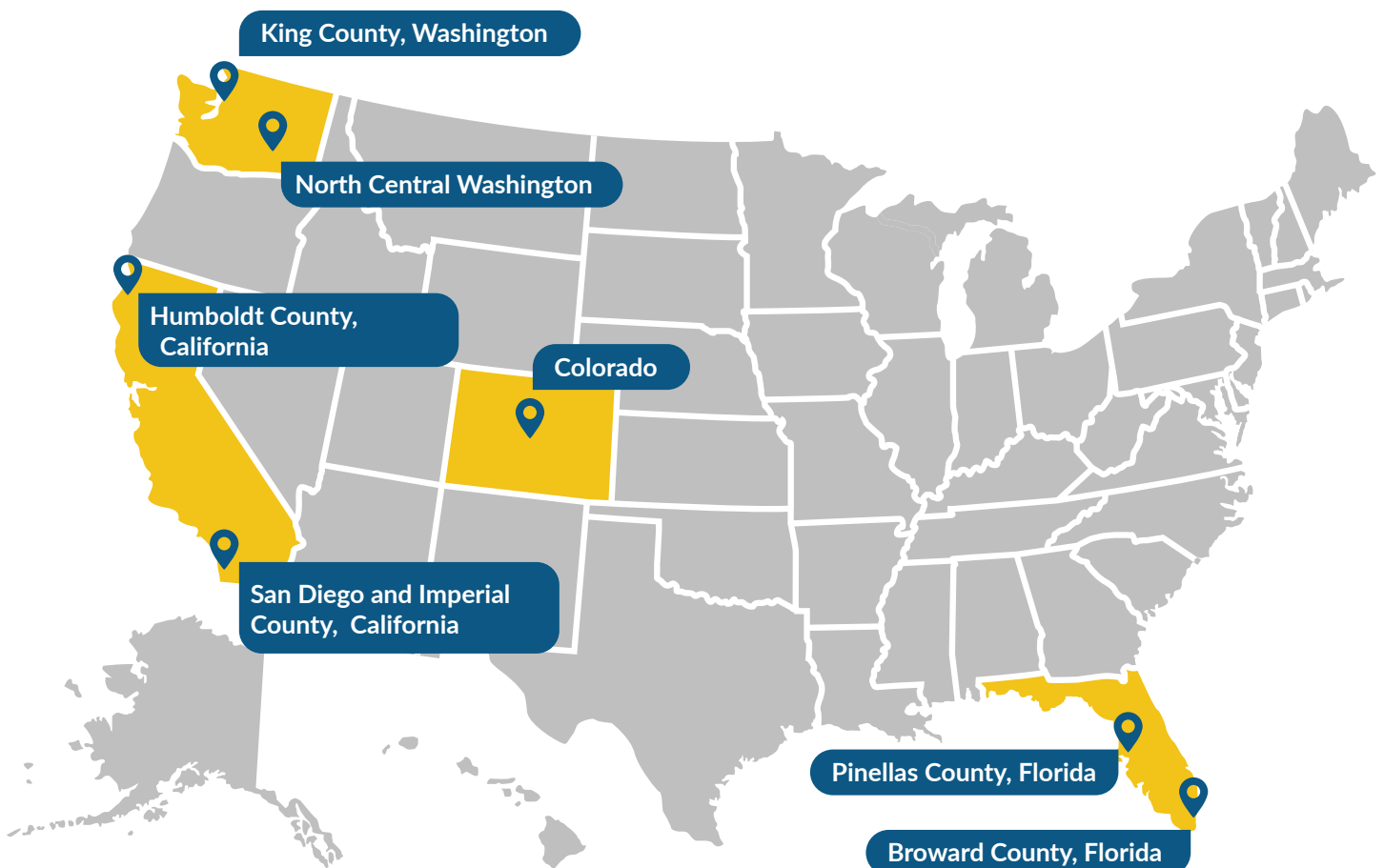
# Project Approach

The project team conducted stakeholder interviews with seven (7) communities that are currently in planning and early implementation stages for their CIEs.

Topics explored included:

- **Strategies** for and examples of meaningful engagement of community members in the development and maintenance of community data systems;
- **Approaches** to community engagement;
- **Challenges and opportunities** for community member engagement;
- **Compensation**;
- **Tools and resources** to cultivate relationships with community members; and
- **Policy and resources** that could support continued growth in this area.

## CIE Communities



# Community Profiles: Characteristics



## King County, Washington

*Geography:* Mixture of urban and rural communities  
*Stage:* Planning and early implementation



## North Central Washington

*Geography:* Rural  
*Stage:* Advanced planning



## San Diego and Imperial County, California

*Geography:* Mixture of urban and rural communities  
*Stage:* Scaling and sustainability



## Humboldt County, California

*Geography:* Rural community  
*Stage:* Early implementation



## Colorado

*Geography:* Scope of CIE initiative is statewide, encompassing urban and rural communities  
*Stage:* Early implementation



## Broward County, Florida

*Geography:* CIE initiative spans eleven counties in southern Florida. Mixture of urban and rural communities.  
*Stage:* Advanced Planning and technology selection



## Pinellas County, Florida

*Geography:* Urban  
*Stage:* Planning

<sup>1</sup>Community Profiles detail stages of planning and implementation from January-April 2020, at the time of this study.

## HealthierHere King County, Washington

[healthierhere.org](https://healthierhere.org)



"From the beginning, our partners have guided what the Connect2 Community Network looks like based on their expertise serving the community. We're excited that in 2021 we were also able to hear directly from community members about what is important to them. We need this community voice to shape a network that benefits the community and brings value to their lives."

### *Community Overview*

HealthierHere, a non-profit organization based in Seattle, is working with local partners to eliminate health inequities and establish an integrated system of whole-person care in King County, Washington. Together with their cross-sector network partners, they have collaborated over the past three years to develop a shared vision and plan for the development and implementation of a local CIE in Seattle/King County.

The COVID-19 pandemic underscored their community's need to implement a CIE. The network spent 2020 planning the CIE vision and designing a governance structure, as well as an approach for technology architecture. Connect2 Community Network, their unified CIE, has been collaboratively developed by health, social service, and American Indian / Alaska Native serving organizations in King County, WA. Community-owned and governed by a multi-sector Advisory Group, it is dedicated to reducing health disparities and improving outcomes. To enable In this early implementation phase, they have partnered with Unite Us to pilot with early adopters in their network.

The network is building relationships and co-designing tools and policies to enable health, behavioral health, tribal, community and social service organizations to responsibly share information and coordinate services – so that no matter what door someone enters, they will receive the whole-person care and support they need to be healthy and thrive.

### *Community Engagement Approach*

- Leveraging existing equity and engagement efforts, for example, by developing deep relationships with community partners, they have been able to inform Connect2 Community Network outreach, planning, and implementation.
- Devoting time (throughout the year) to their visioning and planning process. This has included collaboratively developing a workplan with partners. Through this process, the themes of consumer engagement, consent, and privacy were highlighted. In response to its values of equity and inclusion, the network took a comprehensive approach to embedding community voice in CIE

planning, design, and stewardship. Key questions that were asked during the planning process included:

- What do consumers need in order to feel comfortable having their data stored?
- How can we make sure consumers maintain control of their data?
- How would consumers want to be able to access the data they want to store in the CIE?
- What kind of process, policies, and protocols should be in place around making requests for consumer data?
- How would consumers benefit from CIE?
- How would partners and community members want to continue being involved in CIE long-term planning and implementation?

The team has taken several approaches to ensure their community engagement process is comprehensive and inclusive:

- King County is home to 5 Tribal Nations and urban Native Americans from all over the country. All HealthierHere team members participated in Tribal Sovereignty training.<sup>1</sup> The team collaborates with HealthierHere's Tribal Engagement Manager and seeks the input of HealthierHere's Indigenous Nations Committee.
- Worked on building governance process to ensure Indigenous data sovereignty is embedded in CIE planning.
- Involving Indigenous Nations Committee in review of legal documentation and contracting.
- Developed Advisory Group seats explicitly for Tribal representatives.
- Reached out to partners who have more community-facing roles to help with their efforts.
- Embedding practices into Network Partner Workgroup spaces that help foster a sense of belonging for participants with different identities, backgrounds, and lived experiences. For example, embracing and respecting multiple ways of communicating and of knowing.
- The project team adopted the protocols and policies established by HealthierHere's Equity & Engagement team, related to gathering community voice and doing participatory data analysis and feedback loops with data related to consumer feedback and input on their experiences with healthcare.
- Worked with community partners to conduct interviews and focus groups with community members, deriving insights to better understand what functionality and privacy measures community members prioritized.
- Followed community partners' lead on how to appropriately compensate community members for participating in interviews and focus groups.

## PROJECT SNAPSHOT



## Population and Geography

**Geography Type:** Metropolitan

**Population:** Over 2.2 million, including 5 Native American tribes

**Size:** 2,307 square miles

<sup>1</sup>Tribal sovereignty refers to the right of American Indians and Alaska Natives to govern themselves. The U.S. Constitution recognizes Indian tribes as distinct governments and they have, with a few exceptions, the same powers as federal and state governments to regulate their internal affairs. Source: <https://www.ncsl.org/legislators-staff/legislators/quad-caucus/an-issue-of-sovereignty.aspx>.

## Action Health Partners and North Central ACH North Central Washington

[ncach.org](http://ncach.org)  
[communitychoice.us](http://communitychoice.us)



Photo courtesy of Humble Honey Photography

### *Community Overview*

Action Health Partners (AHP) and North Central Accountable Community of Health (NCACH) have been partnering for the past five years on a variety of efforts to advance whole person health and health equity. AHP is a community-based, non-profit supporting residents in eleven counties across North Central and Eastern WA. AHP provides services via three service networks – care coordination, health benefits, and health education – that embody AHP’s mission to educate, support, and empower individuals to improve quality of life and well-being. As one of nine Accountable Communities of Health in Washington State, NCACH is in a unique position to unify stakeholders, support collaboration, and drive systemic change, with particular attention to the social determinants of health.

Since coordinating care across sectors is critical for people with complex health and social needs, efforts of on-the-ground partners have underscored the need to develop and fund strategies to build capacity for sharing data, resources, and referrals. In 2020, AHP and NCACH participated in the DASH mentor program and collaborated to explore the application of a CIE model with 30 community partners. Since then, NCACH funded AHP to pilot a local and bilingual Community Resource Specialist position (in partnership with Greater Columbia 211) to improve knowledge of and usability of the WA211 resource database. AHP is participating in another DASH mentor program to further explore CIE elements, and NCACH continues to convene regional partners to explore and co-design opportunities for integrating siloed care coordination elements (including resource directories and closed-loop referrals efforts) into a more cohesive cross-sector system.



## Community Engagement Approach

- Utilizing health ambassadors through clients that Action Health Partners has been serving for the last eight years to identify ways in which we can best empower individuals who have been impacted by the system.
- Providing information in a way that allows community members to go from disenfranchised to empowered.
- Exploring ways to secure community representation in leadership (such as a Community Advisory Board) and designating people to go into the community and participate in already established groups and coalitions.
- Engaging community partners to build trust, shared purpose, and join established efforts.
- Structuring participatory meetings that ensure community partners can identify what they are excited about, their concerns, and the most important components to our community.
- Being intentional about the language we use when describing a “CIE” and what it could do for the community to build shared understanding.

Significant barriers that have affected community engagement efforts include:

- Reconciling developments at the state and regional levels, and, in turn, conveying the modified scope and timelines to community members and partners.
- Knowing when and how to strategically engage community members.
- Breaking down the complexity of “CIE” and figuring out where to begin, especially given our multi-county region.
- Securing the type of funding necessary to support a rigorous community engagement approach.

### PROJECT SNAPSHOT



### Population and Geography

**Geography Type:** Rural (Chelan, Douglas, Grant and Okanogan Counties and beyond)

**Population:** 260,000+

**Size:** 12,684 square miles

## 211/CIE San Diego San Diego and Imperial Counties, California

211SanDiego.org  
CIESanDiego.org



“It is easier to think about the future state than the now and how we get there. When we think about community voice and the impact on populations, we are really looking to see what is going to be of value for them. When we start thinking through that lens, we can start implementing a model that is more representative of impacted people. We absolutely strive in today’s world to have outcomes that speak to equity and betterment of daily living and situations, but without community voice at the table, how do [we] know we are measuring the things that really matter? From where we sit, we are trying to have a better understanding of what models really resonate with the people we are aiming to serve.”

### *Community Overview*

211 San Diego is an informational hub that connects more than 500,000 community residents, families and individuals to more than 1,500 organizations providing valuable navigation support to community, health and human, and disaster services. Clients call in search of food assistance, health insurance coverage, financial assistance, food and shelter, mental health services, and other services that will address their immediate needs.

In 2017, 211 San Diego officially launched our region's first Community Information Exchange (CIE®), an integrated technology platform that streamlines care coordination across health, human services, and social services sectors. 211, strengthened by CIE network and partnerships, plays a vital role in helping those in need navigate complicated systems – making access to critical services and resources seamless and efficient. Built upon the Social Determinants of Health, the Community Information Exchange (CIE®) is an ecosystem that uses the collective impact model, a shared language and an integrated technology platform to deliver enhanced community care planning for residents. The CIE is a movement toward systems change. The CIE has shifted San Diego’s paradigm of care to one that enables partners to integrate data from multiple sources and make bi-directional referrals to create longitudinal client records that promote a proactive, holistic, person-centered system of care. The CIE shares data across multiple systems to better understand people within their environment, more effectively coordinate care, and expand local knowledge of how systems can influence key social determinants of health—health care, education, economic stability, housing and neighborhood environment, and social and community context.

## Community Engagement Approach

The value of community voice is that it creates an opportunity to identify what is working, common interests, and solutions that benefit all. The CIE team has been taking a comprehensive approach to engaging community in ongoing CIE planning and design of new system features intended to enhance the delivery of care to underserved populations. 211/CIE San Diego has taken the following approaches to ensuring community engagement and inclusive representation in CIE planning and implementation:

- Used human-centered design approaches to better approach care coordination redesign for integrated/collaborative care
- Conducted exercises to highlight community experiences, for example, having clients draw their experiences navigating through current social and health service systems
- Hold regular partner network meetings with an ongoing discussion of the current composition of the network and what perspectives are missing that need to be engaged
- Understand what community advocacy work CBOs in the network are doing to better inform CIE's outreach efforts
- Holding community voice conversations with representatives from underserved populations, including immigrants, to understand current needs and transcribe experiences in a way that holding community voice conversations with representatives from underserved populations, including immigrants, to understand current needs and transcribe experiences in a way that can shift how network partners design service delivery resonates with network partners
- Through our conversations with the most impacted communities, we have been able to understand that often the fractures in social service delivery systems leave people feeling disregarded and at fault for needing help "All my life I have worked hard to take care of my family and it takes a lot for me to call and ask for help, and when I do the questions that are asked are not relevant to what I am trying to get help for, why do you need to ask intrusive questions?"
- Offering all stakeholders, including clients, to sign up for the CIE newsletter so they know about current and upcoming developments with respect to the partner network and data sharing
- Created opportunities for community members in CIE governance, including participation in CIE Advisory Board and CIE Community Voice working group
- Conducted focus groups to present ideas, collect feedback, and ascertain whether this is the right approach to get community involvement and work towards shared empowerment.

### PROJECT SNAPSHOT



### Population and Geography

**Geography Type:** Urban and Rural

**Scope:** San Diego and Imperial

**Size:** 4,526 square miles

**Population:** 3.3 million

## North Coast Information and Innovation Network Humboldt County, California

[nchiin.org](http://nchiin.org)



“Communicating the complexity [of the system] and managing timelines are two of the most notable challenges to developing a CIE, and those issues can cause more hurdles to building trust and engaging community members in the planning process. We have found it useful to communicate the ACH’s vision to bring services to the community.”

### *Community Overview*

The North Coast Health Improvement and Information Network (NCHIIN) was chartered by the Humboldt Independent Practice Association, a large physician organization providing HMO and ACO delegated, risk, products in Humboldt County. NCHIIN was formed in 2010 to provide a health information exchange in Humboldt County as a way of improving medical care, connecting to almost all of the county medical organizations. NCHIIN later added community health improvement as the second organizational goal with the recognition that community care (broadly) was necessary to improve the health and lives of county residents.

With support from the California Accountable Community for Health Initiative (CACHI), NCHIIN began work to form an Accountable Community for Health (ACH) in 2017 focusing on substance use disorder (SUD). That work included establishing ACH Governance and partner workgroups composed of cross-sector community leaders including residents with lived experience, community systems mapping to capture existing SUD and Behavioral Health resources, analysis to identify gaps and redundancies, developing and reviewing community data and collectively identifying indicators to track progress on the ACH efforts. The initiative also developed an ACH wellness fund.

ACH partners include most of the larger organization in Humboldt working in this and allied areas including government, justice, education, community and medical organizations and the ACH has developed a portfolio of interventions in different stages from prevention and resiliency, to justice and treatment. Several of the interventions focus on cross sector data exchange as a way of addressing Humboldt's SUD problem.

A priority strategy for the ACH has been to develop a community information exchange (CIE), branded locally as "North Coast Care Connect." NCHIN is the backbone organization for North Coast Care Connect, and the organization recently partnered with QS Systems to serve as the technology vendor for the CIE. They are currently in the early stages of CIE implementation.

## Community Engagement Approach

- Community members are part of the ACH Governance Committee, which has authority over ACH projects.
- Humboldt County residents have contributed to the CIE planning and design process. In particular, residents have been asked to provide significant input on issues around data ownership and consent.
- Having a clear intention to heavily involve individuals with lived experience and those who have an equity mindset.
- The partners involved in the North Coast Care Connect co-design process developed an equity value statement for the CIE.

### PROJECT SNAPSHOT



## Population and Geography

**Geography Type:** Rural

**Population:** 135,000, including 11 recognized Native American tribes and 7 incorporated cities

**Size:** 3,568 square miles

## Colorado Health Institute State of Colorado

[coloradohealthinstitute.org](http://coloradohealthinstitute.org)



“It’s not our job to decide what is most impactful to the community. We want this work to be impactful and feasible, but it is CHI’s job to listen, understand, and figure out what is feasible and realistic. The point is to make a positive impact in people’s lives.”

### Community Overview

Colorado Health Institute (CHI) has been providing research, insight, and expertise to inform policy, promote cross-sector collaboration, and advance health for all Coloradans since 2002. CHI is a nonprofit, nonpartisan organization whose stakeholders include state and local agencies, health care organizations, community partners, philanthropic organizations, and Colorado legislators. Recognizing the systems that support people's overall health – including medical, social, and economic well-being – are usually disconnected, CHI and local partners identified an opportunity in a social health information exchange (S-HIE) ecosystem. A S-HIE ecosystem is an effort to build a community care around individuals and families. A S-HIE ecosystem creates connections and strengthens coordination among health, human, and community-based service providers to offer more holistic, customized care for people in need. S-HIE is built upon cross-sector partnerships and harnesses interoperable technology to connect disparate systems, such as health information exchanges (HIEs) and resource and referral platforms (e.g., Find Help, Unite Us).

The Metro Denver Partnership for Health, a local, cross-sector collaborative, identified S-HIE as a local priority, and CHI now serves as a trusted convener for the effort, offering strategic planning, facilitation, and evaluation support. Activities include:

- Convening the MDPH S-HIE partners for cross-sector coordination and collaboration.
- Designing and implementing ongoing collaboration infrastructure and integrative governance structure. This includes identifying lead and supporting partners, creating a decision-making framework, and securing Memoranda of Understanding or other agreements as needed.
- Developing and implementing a S-HIE Interoperability Plan to coordinate technical interoperability activities, including ensuring alignment with the state Office of eHealth Innovation to ensure scalability.
- Determining the financial vision, structure and strategic priorities for S-HIE implementation and sustainability.
- Developing and implementing plans for a Community Board to ensure authentic and sustainable engagement activities and community-driven priority setting.

## Community Engagement Approach

- CHI and MDPH partners generated mutual understanding and established common language among partners, including health care, public health, human service, and community-based organizations.
- CHI conducted focus groups and key informant conversations with community-based organizations (CBOs) on the frontlines of coordinating services and community members with lived experience navigating currently siloed systems. Input from these focus groups and conversations informed the development of the S-HIE Value Proposition.
- CHI and MDPH partners identified community engagement best practices and spoke with national experts on health equity and community engagement work. These practices and conversations led to the vision for a Community Board within the overall S-HIE integrative governance structure, to ensure community leadership in the development of S-HIE.
- The Community Board will be facilitated by CHI, supported and seated by local health alliances, CBOs, and community members from diverse backgrounds. The Board will contribute to decision-making and community engagement strategy to ensure the MDPH S-HIE initiative continues to address community-identified priorities.
- Because community partnership is essential to developing and advancing S-HIE, the Community Board will be resourced with onboarding, facilitation, and financial support so that CBO's and community members are properly compensated for the value and expertise they bring to the table.
- CHI is actively pursuing funding, to implement the S-HIE integrative governance structure, including the Community Board, in 2022.

### PROJECT SNAPSHOT



### Population and Geography

**Geography Type:** State (mix of rural and urban), with the Metro Denver Partnership for Health focused on the metro Denver region.

**Population:** Over 5.7 million, including 49 Native American tribes

**Size:** 104,094 square miles

## 211 Broward Broward County, Florida

[211-broward.org](http://211-broward.org)



“Community member participation deepens and informs research and humanizes benefits of the CIE. It also uncovers biases. We recognize that trust building is essential and it is not a process that stops. The value and impact of engaging community members is in doing so we have recognized that ensuring sustained engagement means generating space for meaningful, ongoing conversation.”

### *Community Overview*

Serving the entire population of their region, 211 Broward connects people with community, health and disaster services through a free, 24/7 phone service and searchable online database. Using the power of technology and innovation, they connect people to the help they need.

At 211 Broward, addressing the Social Determinants of Health and identifying a technology solution to streamline coordinated care delivery have been top priorities. With the understanding that effectively reducing health disparities improves population health outcomes, achieving racial health equity is stated in their goals and visioning. This has translated to more dedicated time for staff training and reserving time and space to talk about racial health disparities and related issues. The COVID-19 pandemic helped to further demonstrate the value of having a CIE in the region.

211 Broward’s reach recently extended to eight additional nearby counties. This change has significantly affected their CIE planning and implementation progress, and has generated more funding and support for their efforts.



## Community Engagement Approach

- 211 Broward conducted rigorous outreach to 116 community-based organizations in their region. They organized focus groups with representation from veterans, older adults, and child caregivers, among others. Although the pandemic prevented them from meeting in-person, they were still able to gather feedback and data that will inform their CIE planning and implementation.
- Every aspect of their planning has a racial equity lens attached to it. They have also been able to secure significant investment for social service providers to participate in the CIE and have been generating trust among partners. They are approaching the system build with the mindset that clients who share their data in the CIE must have access to that data.
- 211 Broward also created a CIE Steering Committee with seats reserved for community member representatives. Moving forward, no less than 20% of Steering Committee seats will be held by community members.

### PROJECT SNAPSHOT



### Population and Geography

**Geography Type:** Urban and Rural

**Scope:** Broward County and 8 other surrounding counties (Alachua, Bradford, Dixie, Gilchrist, Levy, Union, Lafayette, and Marion)

**Population:** Approx. 3 million total

# COMMUNITY SPOTLIGHT



## 211 Tampa Bay Cares Pinellas County, Florida

211tampabay.org



### *Community Overview*

211 Tampa Bay Cares has been providing information, referral, and crisis intervention services in Pinellas County since 1971. Over the past 15 years, they have participated in several data-sharing collaboratives. First, from 2003 - 2016, they were the homeless management information system (HMIS) lead for Pinellas County Homeless Continuum of Care until our Board of Directors no longer felt it was mission-centric. In October 2016, the project was transitioned to the Homeless Leadership Alliance (HLA) of Pinellas County. Second, 211 Tampa Bay Cares have been actively sharing a one-way data exchange from 211 to all Pinellas County Mental Health providers starting in 2013. Third, as the largest financial assistance provider, they work with Pinellas social service partners by providing them access to the 211 database to submit financial assistance requests on behalf of their clients. This provides homeless shelters, domestic violence shelters, homeless diversion programs, and families with minor children a direct path to move to the next step in their self-sufficiency journey.

211 Tampa Bay Cares provides training to partners on the use of the technology and the process for submitting cases throughout the year. Lastly, in 2019 the Foundation for a Healthy St. Petersburg funded 211 Tampa Bay Cares to develop a next-generation 211 data and technology plan that includes incorporates a multi-sector collaboration approach to outcomes.

211 Tampa Bay Cares have been actively working towards CIE planning, but though the COVID-19 pandemic presented many challenges and hurdles.

## Community Engagement Approach

211 Tampa Bay Cares intent is to plan with community voice in mind and included in all aspects of CIE planning and implementation. We define “community voice” as the inclusive representation of community perspectives that will guide our CIE design and promote and work towards equity.

- Aligning provider needs and resident needs with respect to CIE planning and timeline to be challenging.
- Developing a survey tool to elicit feedback from residents that will guide future planning efforts.
- Resources that would help to jumpstart our efforts include:
  - Clear CIE value-case that can be shared with funders, partners, and community members.
  - Funding support to seed planning and implementation efforts that includes support for a neutral convener or consultant to connect with community members and elicit feedback.
  - Integrating community voice requirements in a CIE accreditation process to guide communities in early planning.

### PROJECT SNAPSHOT



### Population and Geography

**Geography Type:** Metropolitan area located in Pinellas County, Florida

**Size:** 273.80 square miles

**Population:** 974,996 residents

# Summary of Key Themes

## Perceived Value and Impact of Engaging Community Members

Communities stated that actively planning for community member engagement added the following benefits to the overall process of developing a CIE:

- Ensures that we are working towards designing a culturally competent system that is in tune with needs of the community and has processes in place, based on human experience
- Deepens and informs research and humanizes benefits of a CIE
- Uncovers biases
- Helps to emphasize that building trust is essential and an ongoing process
- Elicits different and the most important perspectives that are vital to the success of the CIE
- Clarifies role with a CIE is to listen, understand, and figure out what is feasible and realistic

## Vision and Planning for Community Voice

Community Voice is the inclusive representation of community perspectives that guide a CIE design to promote and work toward equity. The communities we interviewed planned or are planning to embed Community Voice in the following ways:

### Design and Infrastructure

- Developing an organizational chart that includes at least one dedicated staff member to support planning an implementation approach to Community Voice.
- Designing CIE and access to data around insights from community members.
- Co-creating a CIE governance structure with community members in an effort to share power.
- Community members draw their experience accessing services to help shape and redesign human-centered services.

### Implementation and Practice

- Developing an equity value statement for CIE.
- Creating a Community Advisory Board.
- Participating in tribal sovereignty training and applying Indigenous data sovereignty principles to all aspects of planning and implementation.
- Leveraging CBOs that represent marginalized communities or community health workers.
- Designating people with lived experience and a connection to the community to serve in leadership positions.

# Establishing Trust

The following approaches have been employed by communities seeking to build trust and among community members:

- Compensate community members for their participation
- Clearly communicate the purpose of and vision for a CIE and how the community will benefit; Provide the information community members need to go from disenfranchised to empowered.
- Be transparent about the process, timeline, and progress. CIE is about systems change, so be honest about when plans change or when input may not lead to action.
- Create a phased infrastructure for active participation by community members in a CIE by involving them in discussions, offering training, and finally employing them in the system
- Contract with community-facing CBOs to create focus groups to collect feedback and input from community members on CIE planning and visioning

# Compensating Community Members for Their Participation

The communities we interviewed worked collaboratively with community members to determine what types of compensation may be offered in exchange for their participation and input. Examples of compensation offered by communities included:

- Monetary stipend to cover pre-determined time commitment and contributions
- Gift cards for gas or food
- Monetary support for time (e.g. hourly fee)
- Travel reimbursement
- Free meeting space and related materials
- Loan of resources to foster participation (e.g. iPad with web-enabled meeting application installed)



# Barriers to Community Member Engagement

While all the communities we interviewed shared novel approaches to community engagement, there were also common challenges and barriers to engaging community members. The challenges listed below range from ensuring participation to navigating political, geographic, and infrastructural complexities. These challenges are amplified for rural communities, as well as efforts that care for a smaller population relative to the size of the state.

## *Creating Meaningful Community Member Participation*

- Identifying champions in the community that can agree to the time commitment for CIE planning discussions
- Identifying times to hold CIE meetings that will not compete with community member work obligations
- Structuring CIE meetings in a way that is informative for community members and that clearly communicates the strategic vision, purpose and next steps so all attendees understand progress of CIE planning efforts, and short-term and long-term goals
- Creating a safe space that encourages community members to contribute and share their lived experiences
- Clearly and effectively communicating CIE purpose, vision, and goals in a way that is accessible to all partners
- Managing community member input and complex project timelines. You can only work as quickly as you are able to establish trust and develop a strong connection with community members.
- Explaining why sharing data can help community members now and in the future, as well as assuring community information and privacy will be safeguarded

## *Navigating Oppressive Systems and White Institutional Culture*

- Making the case for more inclusive representation to current leadership that does not grasp the benefit of bringing diverse perspectives and lived experience to the table
- Working against the notion put forth by others in leadership that the person who is the “professional” is closest to the solution instead of the person with lived experience
- Confusing a sense of urgency from stakeholders to implement a system, with intentionality to build a system that addresses community member needs and is designed to benefit the most impact populations
- Addressing stakeholders’ lack of understanding that “traditional” practices are not always culturally relevant and explaining the relevance of and need for an integration of non-traditional practices
- Creating opportunities for different types of meetings that will encourage honest and vulnerable input from community members and partners

## *Political and Geographic Complexities*

- Integrating timelines and project developments at state and local levels risks delaying progress and thus eroding trust with community members
- Reconciling funding timelines with desired planning and implementation dates agreed upon by partners and stakeholders
- Circumnavigating competing efforts in the same state or region complicates overall progress
- At least two communities did not have a method of communication or neutral body to connect their efforts even though they exist in the same state.
- Planning and implementation in an urban versus rural setting
- Large funders, health systems, and other influential stakeholders in this space do not always plan with smaller communities in mind, affecting their ability to efficiently plan, launch, and sustain efforts.

## *Infrastructure Challenges*

- Limited ability to measure and understand the true nature of population needs and root causes of population health issues
- Demonstrating proof of concept and return on investment to secure seed funding for the CIE
- Securing a separate pot of funds and resources for community engagement work

# Recommendations for Changes, Policy, and Resources

The following policy and resource recommendations were identified to benefit community member engagement efforts:

- Develop a CIE accreditation process that includes requirements for integrating Community Voice and that has a primary component of building a true CIE
- Identify policy advocates to highlight the benefits of including community-based organizations to inform community solutions
- Dedicate public and private grant funding to elevate Community Voice as a way to drive solutions versus focusing solely on technology-based solutions
- Existing and future grant mechanisms should include dedicated funding for CIE infrastructure that would facilitate easier community member engagement. Elements could include:
  - Requirements for including Community Voice and lived experience in a project work plan.
  - Dedicated funding for a community engagement manager, director, or consultant as a part of the project staffing plan.
  - Funding for CIE planning and implementation that includes realistic timelines to account for cultivating relationships and collecting community member input to inform CIE design. Along these lines, funders should consider collecting input from communities on how best to scope future funding opportunities that are realistic and more responsive to community needs.
  - Requirements for a human-centered design component in project narratives.
- Build incentives in policy or funding for community member engagement. Often, CBOs have existing relationships with community members that would like to participate in CIE planning, but funding may restrict stipends and payment for time.

