Leveraging Community Information Exchanges (CIEs) for Equitable and Inclusive Data: A Vision for the Future

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Introduction

211/CIE San Diego, along with our partners, is pleased to contribute the enclosed work to inform future strategy for public health data system infrastructure. The key concepts, framework, and vision presented here define the Community Information Exchange (CIE®) model as a community-driven solution that thrives under a clear and ongoing commitment to health equity and antiracism. Inherent in the CIE model is the principle of and pledge to an entire ecosystem that is community-owned and community-led.

Health Equity[1]: According to the **Robert Wood Johnson Foundation (RWJF),** health equity is achieved when everyone has a fair and just opportunity to be as healthy as possible. This requires removing obstacles to health such as poverty, discrimination, and their consequences, including powerlessness and lack of access to good jobs with fair pay, quality education and housing, safe environments, and health care.

Anti-racism[2]: Anti-racism is a set of actions that respond to the systemic racism, or racism that is engrained in the policies, laws, and regulations of an institution or system. Anti-racism refers to the process which includes both unlearning and learning, abolition, and building, divesting, and reinvesting necessary to create systems – in this project, CIE systems specifically – that advance racial justice.

As a supplement to the **CIE Toolkit**, this resource introduces a framing for the ideal state a CIE seeks to achieve. While the CIE Toolkit aims to provide the "how" for developing a CIE, this document intends to provide the "why." As such, this work is meant to enhance the understanding of the vision, value, and potential impact of a CIE, so that communities can articulate the unique attributes and principles of a community-led model. Throughout this document, our goal is to highlight the importance of genuine community ownership to existing systems of care. Organizations, communities, and institutions are encouraged to use this resource to help initiate and inform conversations around social and health issues with an equity and anti-racism lens.

This resource is intended for communities looking to build or enhance their existing social and health care coordination efforts through the vision of a CIE. CIE is an ecosystem, which needs to be supported and addressed across sectors and throughout the entire system of care, including healthcare, government, social services, education, public health, for-profits and other institutions. Our hope is that audiences across sectors can use this resource to clarify find value and understanding in their role within a CIE.

[1] https://www.rwjf.org/en/library/research/2017/05/what-is-health-equity-.html
[2] https://stanford.app.box.com/s/5lwrmad6ww2k7mkh8d7r5i3215on10p0

Current State

Interest and Investment in Social Determinants of Health

Institutions across the nation – including health care, education, businesses, and others – are recognizing the necessity to address the social determinants of health (SDOH)[3] that impact the wellbeing of their patients, students, employees, and clients. For example, U.S. health systems have been among the first institutions to invest, investing at least $2.5 billion in programs around SDoH from 2017 to 2019.[4]

Yet, to address these social needs, some institutions have focused their investment on third-party technology solutions that enhance better information and referral capabilities rather than in community infrastructure and social services programs supporting the services capacity. Investment in a community-led infrastructure is essential to address inequities to prioritize the needs and expertise of those bearing the most health burdens. Investments that are not led or driven by the community, are often not adopted, accepted, nor sustained. To avoid this lost opportunity, the interest and investment in SDOH should center on the principle that funders, investors, and institutional stakeholders trust that communities, particularly the most impacted community members, must be part of the solution to the overarching problem.

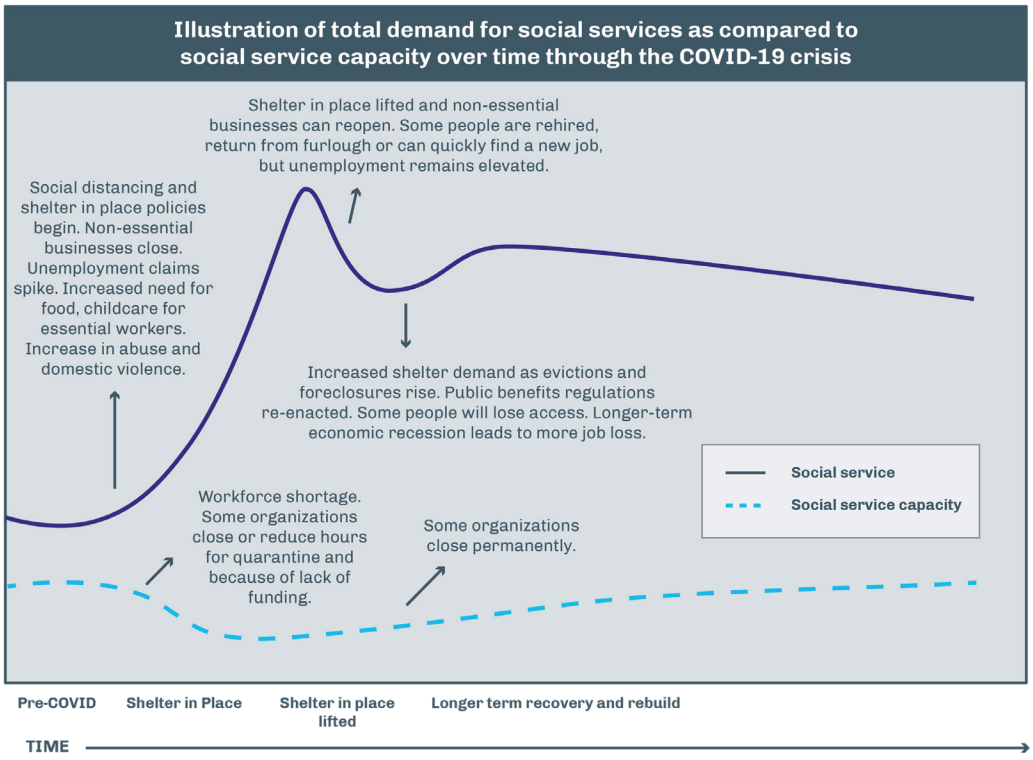
Social determinants of health (SDoH) will be referenced throughout this document, but a movement towards understanding these environments often have root causes in racism due to racism within our core elements of society. These can impact the determination of health and social situation of many, specifically people of color.

[3] Social determinants of health (SDOH) are the conditions in the environments where people are born, live, learn, work, play, worship, and age that affect a wide range of health, functioning, and quality-of-life outcomes and risks.
Social Determinants of Health - Healthy People 2030 | health.gov

[4] Horwitz L.I., Chang C., Arcilla H.N., & Knickman J.R.. Quantifying Health Systems' Investment In Social Determinants Of Health, By Sector, 2017–19. Health Affairs. 39, No. 2 (2020): 192–198. https://doi.org/10.1377/hlthaff.2019.01246

COVID-19 Disparities and Inequities

The COVID-19 pandemic exposed extreme variations in impact across populations,[5] specifically affecting marginalized[6] communities the most due to lack of resources. Across the country, we have observed disproportionate differences in health outcomes among those who contracted COVID-19 according to race, socioeconomic status, age, and gender. Further, in the context of an already strained social safety net, the total demand for social services has far exceeded the social service capacity over time through the COVID-19 crisis.[7]



As referenced in the illustration,[8] even prior to COVID-19, the U.S. presents large racial disparities across health outcomes, food insecurity, income, access to adequate housing and education. Those inequities were further perpetuated as connecting to resources became more difficult due to the changing landscape and shelter-in-place orders caused by the pandemic.

[5] Centers for Disease Control and Prevention. COVID-19 Racial and Ethnic Health Disparities. (2020) https://www.cdc.gov/coronavirus/2019-ncov/community/health-equity/racial-ethnic-disparities/index.html

[6] Marginalized populations are groups and communities that experience discrimination and exclusion (social, political and economic) because of unequal power relationships across economic, political, social and cultural dimensions. Marginalized populations | National Collaborating Centre for Determinants of Health (nccdh.ca)

[7] Health Leads. Flattening the Next COVID-19 Curve – Our Essential Resources. (2020) https://healthleadsusa.org/communications-center/blog/flattening-the-next-covid-19-curve/

[8] Source: https://healthleadsusa.org/communications-center/blog/flattening-the-next-covid-19-curve/

In an April 2020 survey, Pew Research Center showed that 61% of Latinx households and 44% of Black households experienced job or wage loss because of the COVID-19 pandemic compared to 38% of White households. In the same survey, Black (48%) and Latinx adults (44%) were more likely than White adults (26%) to say they could not pay or could only partially cover their monthly bills. In turn, as institutions seek to invest in addressing SDoH, it is even more imperative for investments to focus on rebuilding and reimagining the social service infrastructure with a racial equity lens, otherwise underserved populations will continue to disproportionately suffer in the aftermath of COVID-19. A health equity-oriented solution is needed to meet the needs and ensure the health of impacted populations.

Historical Impact

The challenge of advancing a more community-driven, person-centered approach is compounded by the state of **systemic racism**, impacting the way our systems and data are collected, analyzed, and applied. Historically, the method in which data has been gathered and interpreted by public health systems has created harms that are disproportionately borne by communities of color.[9] This has contributed to a service delivery infrastructure that reinforces systemic racism, exacerbating local resource inequity, and distorting the perceptions of populations who rely on public services. Absent the awareness and acknowledgment of systemic racism, as well as a real commitment to combating it, a systemic solution remains elusive.

Systemic Racism: The historical and contemporary policies, practices, and norms that create and maintain white supremacy.

[9] Williams, B., Brooks, C., & Shmargad, Y. (2018). How Algorithms Discriminate Based on Data They Lack: Challenges, Solutions, and Policy Implications. Journal of Information Policy, 8, 78-115. https://doi.org/10.5325/jinfopoli.8.2018.0078

What is a Community Information Exchange?

A CIE is a community-led ecosystem comprised of multidisciplinary network partners who use a shared language, resource database, and integrated technology platforms to deliver enhanced community care planning. A CIE enables communities to shift from a reactive approach to addressing social needs, to an approach that is more proactive, holistic and person-centered. At the very core of a CIE is the community it serves, and with the community as its compass, a CIE seeks to support antiracism and health equity.

Defining a CIE

A CIE...	**...cultivates trust and capacity within the community.** Coordination and collaboration among community members and the sectors that serve them (healthcare, social services, government, for-profit, etc.) is key to ensuring more equitable access, often facilitated through technology.
A CIE Is Not...	**...a specific technology or platform, nor is it dependent solely on technology to connect individuals to services and resources.**

Technology is a key component of the CIE, but it is not the primary solution to health and social issues. In a successful CIE, technology must adapt to and grow with local community needs in order to adequately improve the needs of the community. Though an electronic referral can be an effective tool for community providers to address individuals' articulated needs, it is not designed to analyze and address the root causes of the problems that drive the needs and disparities within those communities. An effective CIE has a shared governance infrastructure with a learning network that has the ability to track history of services over time and supports true care coordination that supports the evolving needs of the community.

A CIE...	**...enables individual agency and understands root causes of resource gaps.** • A CIE aims to incorporate an individual's or family's wants, priorities, culture, and capacity into care planning while also being sensitive to the trauma and systemic oppression impacted community members endure. • The CIE seeks to empower community members at every interaction, ranging from care coordination to data usage, to address root cause issues while aiming to reduce potential harm and exploitation. • A CIE is interoperable and can de-silo existing data and technology systems while maintaining the diversity of sectors.
A CIE Is Not...	**...a generic one-size fits all solution that does not address existing local community capacity, readiness or infrastructure.**

Diagnosing resource gaps and associated needs in the community without addressing root causes of the resource gaps at a systemic level is not sufficient. Furthermore, input from and collaboration with all sectors, is critical to understand underlying problems and potential solutions.

A CIE...	**...drives systems change.** • A CIE focuses on the individual/family, institutions, and the community at large. • Its role in the community is to support the local infrastructure, create sharing and coordination across sectors, and share data to inform policy change that benefits the community and facilitates investment back into the community. • A CIE is accountable to the community.
A CIE Is Not...	**...intended to solve one issue. The goal should not be on solving for one organization or sector, but for the entire system of care.**

A focus on individual care planning with the goal of connecting individuals to services is a great starting point, but limiting that focus to the individual level will not improve the overall well-being of the community. However, this starting point can help orient institutions toward problems in need of systemic solutions, and identify additional partners and sectors with whom to explore these solutions.

A CIE...	**...is a community-led collaborative.** • A CIE engages cross-sector partners, including community voice, to develop a vision and strategic agenda. • The work is inherently collaborative, inclusive, and intentionally and equally distributes power across all sectors and the impacted community. • Core values assign control to community members and the system is designed to value the best interests of community members.
A CIE Is Not...	**...led by one organization, nor is the strategic direction dictated by the desired outcomes of one sector.**

No one institution or sector can be the sole driver for change. The effort must be collaborative with other sectors, inclusive of community members, and aimed at addressing root causes through advocacy.

A CIE...	**...is designed to uplift and assist in providing agency to those communities who experience disparities and inequities.** • Equity is a core tenet. • A CIE supports data for public good or utility which would equally distribute power to all sectors and to the impacted community. • Outcomes and impact are defined by the community. • Core values assign control to community members and the system is designed to value the best interests of community members. • Aggregated and disaggregated data is shared back to community organizations and members for interpretation and use for advocacy.
A CIE Is Not...	**...centered around institutional goals or interests.**

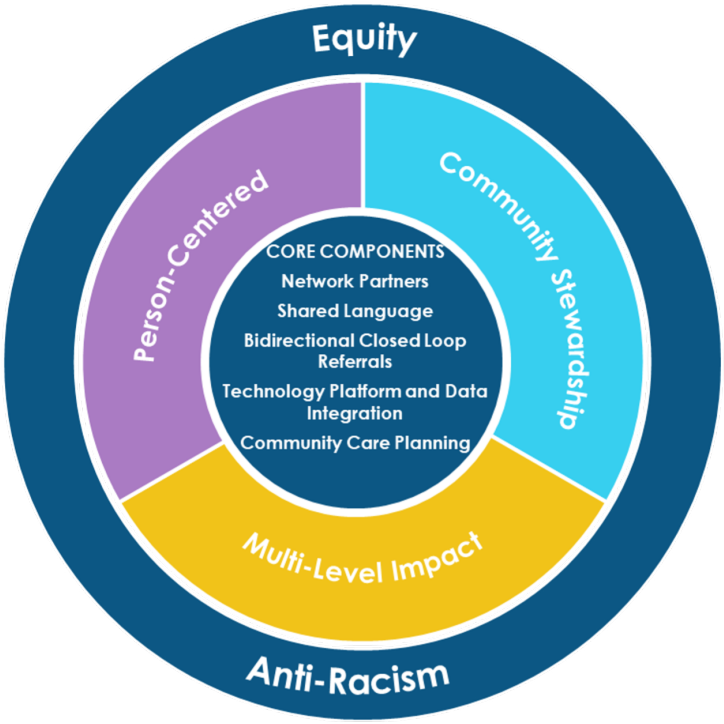
Social needs cannot adequately be addressed in the same way as health or other needs are addressed. As such, institutions or backbone organizations (e.g., government, academia, healthcare, etc.) alone, should not determine the mode, investment, and needs to inspire SDoH strategies. Rather, community perspectives should inform the direction of a CIE. Social needs cannot adequately be supported without community engagement or an explicit focus on equity. Goals and interests should stem from the community, not prioritize institutional goals.

CIE: Tenets, Fundamental Approaches, Core Components

This section will dive into the core principles, structural elements and fundamentals that comprise an effective CIE.

Tenets

Core to a CIE are the overarching tenets or beliefs that drive the intention of the model. Absent explicit commitment to these tenets, there is risk of developing a system that puts the needs of institutions before the community members it serves, and exploits historically neglected and underserved populations.



Equity. Equity exists when all people have the opportunity to thrive and no one is limited in achieving comprehensive health and wellness because of their social position or any other social factors/determinant of health (i.e. income, education, race/ethnicity, sexual identity, disability).[10] The CIE ensures accessibility to all community members regardless of demographic or geography. It is rooted in equity-centered community design, which acknowledges and utilizes the role of people, systems and power when developing solutions to ensure a positive impact on the community.[11]

Anti-Racism. Anti-racism refers to the process required to achieve a liberating system of care. This process includes both the unlearning and learning, abolition and building, divesting and reinvesting necessary to create systems that advance racial justice. Anti-racism is a set of actions, not a set of values. The benefit of practicing anti-racism is that it offers opportunities to reimagine ways of understanding and addressing human needs without re-entrenching a hierarchy of needs in society. It also offers opportunities for intersectional solidarity between individuals facing other systems of oppression and individuals, systems, and communities.

[10] https://astho.org/Programs/Health-Equity/Affiliate-Health-Equity-Position-Statement/#:~:text=Health%20equity%3A%20Health%20equity%20exists,%2C%20sexual%20identity%2C%20disability)

[11] Creative Reaction Lab. Equity-Centered Community Design Field Guide. https://www.creativereactionlab.com/store/p/field-guide-equity-centered-community-design

Fundamental Approaches

The following fundamental approaches drive all aspects of CIE visioning, planning, design, and implementation.

Community Stewardship

A CIE must be led by the community through a neutral convener, backbone organization or leadership structure that ensures engagement of community voice, considers the human perspective in all aspects of system design, and promotes shared power and partnership within the network. This governance infrastructure ensures data stewardship, collection and use that meets ethical standards and shares value with community members who institutions have traditionally benefited from.

Multi-Level Impact

The role of a CIE is to support the needs of the individual/family (micro), across organizations and institutions (mezzo) and the larger community (macro). A CIE is responsible for sharing and using data to highlight inequities as well as understand improvement in needs met. CIE data should be used to design community-level interventions as well as inform community-level investment and policy. Locally, a CIE inspires movement with the goal of systems change, rather than solely addressing needs of individual organizations.

Person-Centered to Community Autonomy

Centering individual and family goals, motivations and urgencies is core to a CIE. This person-centered focus prioritizes meeting the needs of the individual and family, rather than the institutions or organizations that serve them. A CIE reimagines the way care is provided and supported through a comprehensive, informed, culturally competent approach that creates space for agency and advocacy. The CIE leverages human-centered design practices and embraces learning and iteration to ensure systems are adaptable to ever evolving community needs, thus supporting community autonomy.

Core Components

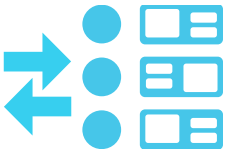
The following core components are the sociological, operational, and technological constructs that are critical to a CIE's infrastructure.

Network Partners

As a community-led initiative, a CIE is stewarded by multi-sector community-based organizations including healthcare, government, for-profit, and other entities who are involved in prioritizing community member's needs and allocation of resources. Partner engagement is guided by a standard Participation Agreement, a Business Associate Agreement, and individual consent. This engagement includes shared partner governance, ongoing engagement, and support.

Aligned Language

A CIE sets a framework of shared measures and outcomes through 14 SDoH using constructs from the Comprehensive Social Continuum Assessment, an embedded tool used to determine immediacy of needs, barriers to services, available supports, and the individual's knowledge and ability to utilize resources.



Bidirectional Information Sharing

A shared and continuously updated resource database of community, health, and social service providers is embedded in a CIE. Bi-directional information sharing enables partner organizations to streamline the delivery of person-centered care, monitor individuals' progress, and capture outcomes in real-time.

Technology Platform and Data Integration

A CIE is technology agnostic, leveraging an interoperable, customizable platform to facilitate data sharing between other platforms or portals accessible to partners and individual CIE community members. The technological infrastructure allows for proactive alerts and insights to help make information actionable.

Community Care Planning

A CIE creates access to a longitudinal record with a unified community care plan that promotes cross-sector collaboration and a holistic, trauma-informed and equitable access to care, inclusive of family needs and strengths.

What Does it Mean to Prioritize Health Equity?

In light of the COVID-19 pandemic and increased awareness and action around persistent racial and social injustices, the interest to align systems to share data and coordinate care has vastly increased. Although various approaches are being adopted as promising practices, prioritizing health equity is often not rooted within the design of those approaches. The following section details two theoretical examples that present different approaches to a care coordination model and the impact on community well-being.

Community A: Community-Centered Model

Community A has designed a cross-sector care coordination model that has been implemented to address community-identified needs. Its person-centered model is realized through a care coordination system that is led by a wide range of community stakeholders across health, human and social service sectors. Many of the stakeholders represent the most impacted populations.

The governance structure includes healthcare, social services, government, non-profits, as well as community members with lived experience who are poised to review data, practices, and policies at every level of decision-making. Consumers own their data at every step of their care navigation process, including consent-in requirements and the ability to refuse consent at any time. Coordination of care improves services day-to-day on the individual and family level of impact as well as creates avenues to design, interpret, and narrate data at the population level. Through the shared community-centered model infrastructure, stakeholders are able to identify systems-level solutions that address barriers and root causes of health inequity through ongoing community resident input and community-based organization feedback. The model continues to adapt to what the community wants to see in this solution, defines it as a high priority, and is relevant to new scenarios as they arise.

When an unexpected pandemic occurs, network partners are able to communicate emerging community needs quickly through the model's inclusive governance structure and learning network, with the means to observe changing needs in real-time.[12] Communities – including residents, community-based organizations and other stakeholders - know what is happening with their data,[13] and direct how to adapt solutions to address issues as they surface. Due to the direct collaboration and coordination with the community, the model contributes to and supports a responsive and informed system of care. The system houses a shared client record, allowing providers who are practicing strengths-based care management to better address individual and family needs.[14]

Community B: System-Centered Model

Community B has a similar group of convened stakeholders who desire to work across sectors to improve provision of coordinated, person-centered care. Solutions are largely designed by a major institution that is funding the technology for the collaboration. The institution and technology vendor desire to improve community member health outcomes and improve experiences for users and organizations. Success is also determined by the cost savings for the paying institution and the solution is largely contingent on the adoption of technology and measures related to utilization of the singular, predetermined technology platform. Based on the funding institution's experience and their own sector's measures, they have defined clear and narrowly scoped pathways to support community member participation in this solution. They will monitor engagement and success using these defined measures and outcomes.

Community-based organizations and community members are engaged initially, but engagement fades with time. As the focus is on technology adoption, community input consists of occasional customer satisfaction surveys. To make operational processes efficient and to encourage timely network onboarding, the system is designed to assume that all system users consent to data sharing and sharing of other organizational information. Those who have reason to hesitate sharing their data based on past breaches in trust, may get excluded from opportunities for funding and collaboration within the community.

When an unexpected pandemic occurs, sectors respond to their own needs, but many are still overburdened, and the data sharing platform and its features are minimally utilized, if at all. As a result, the opportunity for valuable data generated by the care coordination technology is lost, and so is the opportunity for the systems supporting the community to use that data and respond to rapidly changing community needs.

[12] http://ciesandiego.org/wp-content/uploads/2020/11/Leveraging-CIE-Infrastructure-to-Manage-Community-Needs-and-Response-During-the-COVID-19-Pandemic-1.pdf

[13] https://211sandiego.org/wp-content/uploads/2021/03/Evolution-of-Client-Needs-through-February-2021.pdf

[14] Brun C, Rapp RC. Strengths-based case management: individuals' perspectives on strengths and the case manager relationship. Soc Work. 2001 Jul;46(3):278-88. doi: 10.1093/sw/46.3.278. PMID: 11495372.

	Community A Snapshot	Community B Snapshot
Value Proposition	Person-centered care	Institutional interest to address SDoH and potential impact of cost-savings within the system of care.
Impact	Shared governance by community members and key stakeholders from non-profit, government, education, social services, healthcare and for-profit sectors	Supports individual population social needs but limits collective ability to support and save money for multiple institutions and sectors
Design	Led by the community via human-centered design.	Led by the institution who is funding the care coordination technology.
Governance	Shared governance by community members and key stakeholders from non-profit, government, education, social services, healthcare and for-profit sectors.	Primarily led by the institution who is funding the care coordination technology, with limited CBO engagement.
What are you solving for?	Health equity, shifting the current model of care to a comprehensive and upstream approach.	Closed loop referrals to address institution- identified needs, often not based on needs identified by individuals/ community members themselves.
Peak	Pandemic hits, model facilitates responsive, effective community support and coordination with social services, and has a lasting impact on Community A.	Pandemic hits, model yields a limited response with low community support, and results in multiple overburdened community sectors, and a short-term, limited impact on Community B.

Considerations

Both Community A and Community B are striving to help and support the needs of their community, yet the approaches are designed differently and highlight distinct challenges. Community A requires much more time to build trust and gain buy-in across sectors, as well as either a shift in or creation of leadership and resources. Community B's impact is limited and may not be effective in truly meeting the needs of the community. This tool is meant to provide a framework for the ideal, future state of a Community Information Exchange®, accounting for the many components of this work and considering the various opportunities and challenges. We recommend you use this in conjunction with the CIE Toolkit to help design a CIE-like model that strives towards an equitable and inclusive model of care.

Call to Action

Communities who are in the visioning or early planning stages of building a CIE should consider using the *CIE Framework* as a tool to align partner expectations and root the engagement and inclusion of community members who can have a real influence on the impact of the system on the people and populations it is intended to serve. We invite all communities to join our CIE National Member network so that, together, we can continue to explore the most impactful ways to help underserved populations and build care systems that work to dismantle and rise above historically oppressive systems and infrastructure that continue to cause much of the inequities we see today. We call on our fellow communities to:

- Set aside time to reflect and truly understand the broad and deep impact of systemic racism on the ability to provide quality care to all populations.
- Read and complete the institutional and individual reflection exercises provided as a part of the *CIE Data Equity Framework*[15] to reflect on your institution's history and current processes that could be perpetuating oppressive behavior to populations that are in dire need of care and support.
- Meaningfully engage and collaborate with community members to plan for and design a system that supports individuals and families in the places which they live, work, breathe, learn, and play.
- Make a public commitment to uphold the CIE tenets of equity and antiracism, and only engage network partners that are able to make the same commitment.
- Hold accountable vendors, institutions and other key stakeholders in the tenants that ensure true community governance and leadership.
- Promote goals and objectives that are in the best interest of the community.
- Regularly engage with the CIE National Member network to learn about innovative approaches to this work and share experiences that will help other communities learn and grow.

[15] CITE DATA EQUITY FRAMEWORK