Rethinking Systems Design: Moving Toward Equity

COMMUNITY INFORMATION EXCHANGE
VIRTUAL SUMMIT 2021

211 SAN DIEGO

Community Information Exchange®

Photos courtesy of CIE San Diego Partners

Speakers

ARTAIR ROGERS, MS

Director of Programs, California Health Leads

LAUREN SMITH, MD, MPH

Chief Health Equity and Strategy Officer
CDC Foundation

VIVIAN SINGLETARY, MBA, JM
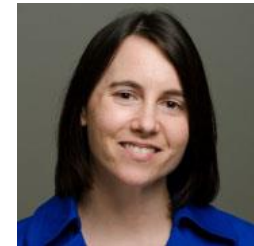
Director
Public Health Informatics Institute

KARIS GROUNDS, MPH

Vice President of Health and Community Impact
211/CIE San Diego

BETH JOHNSON, MPH

Senior Consultant, Strategic Initiatives
211/CIE San Diego

HILARY HEISHMAN, MPH

Senior Program Officer
Robert Wood Johnson Foundation
Moderator

Setting the Stage

Setting the Stage

Lisa Austin

Vice President Strategy and Client Services

Vigilant Watch Integration Inc.

Audience Polling

Whose influence is most apparent in the design of your CIE or CIE-like system? (select your top three)

Audience Polling

Within your current state, what are you grappling most right now? (select your top three)

Setting the Stage

Hilary Heishman, MPH

Senior Program Officer

Robert Wood Johnson Foundation

Transforming U.S. Public Health Data and Infrastructure to Protect Health and Achieve Health Equity

July 2021

Public Health Informatics Institute

THE TASK FORCE FOR GLOBAL HEALTH

Challenges posed by the way public health currently functions.

Persistent health inequities

Lack of interoperability

Governance, policy and regulatory constraints

Emphasis on data collection versus use

Insufficient investment in the public health workforce

PHII.org

Opportunities to transform U.S. public health data and infrastructure to protect health and achieve health equity.

COVID-19 pandemic as horrific event and enormous opportunity

Focus on equity

Need for a nationwide strategy

Importance of a common data architecture

Enhance the informatics capacity of the public health workforce

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Recommendations made to the Robert Wood Johnson Foundation (RWJF) National Commission to Transform Public Health Data Systems.

Convene a multi-disciplinary group of thought leaders from the public and private sectors to develop a vision, strategy, road map, policy framework and call-to-action

Promote efforts to make equity the cornerstone of all public health activities

Sponsor the development of a nationwide requirements project
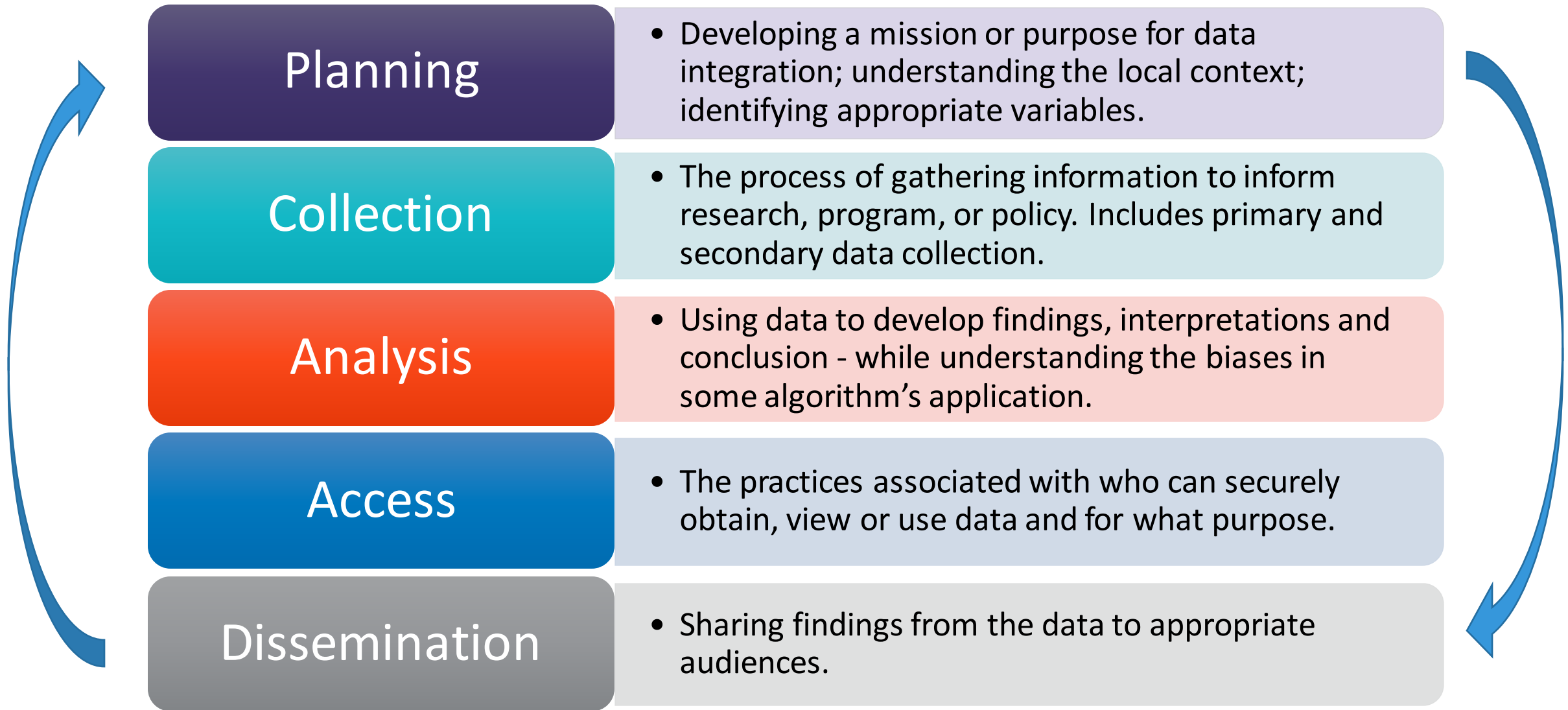
Invest in the public health workforce

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Equity Across the Data Lifecycle

CDCF Public Health Data Transformation for Equity Project

August 11, 2021

Defining the Data Lifecycle

Planning
- Developing a mission or purpose for data integration; understanding the local context; identifying appropriate variables.

Collection
- The process of gathering information to inform research, program, or policy. Includes primary and secondary data collection.

Analysis
- Using data to develop findings, interpretations and conclusion - while understanding the biases in some algorithm's application.

Access
- The practices associated with who can securely obtain, view or use data and for what purpose.

Dissemination
- Sharing findings from the data to appropriate audiences.

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Data Equity Principles

Equity principles are relevant across the data lifecycle

Recognize and Define Systemic Factors

Create Meaning Making

Planning

Use Equity Mindedness for Language & Action

Create a Shared Data Agenda

Dissemination

Collection

Provide Data Sovereignty

Allow for Cultural Modifications

Access

Analysis

DC Foundation
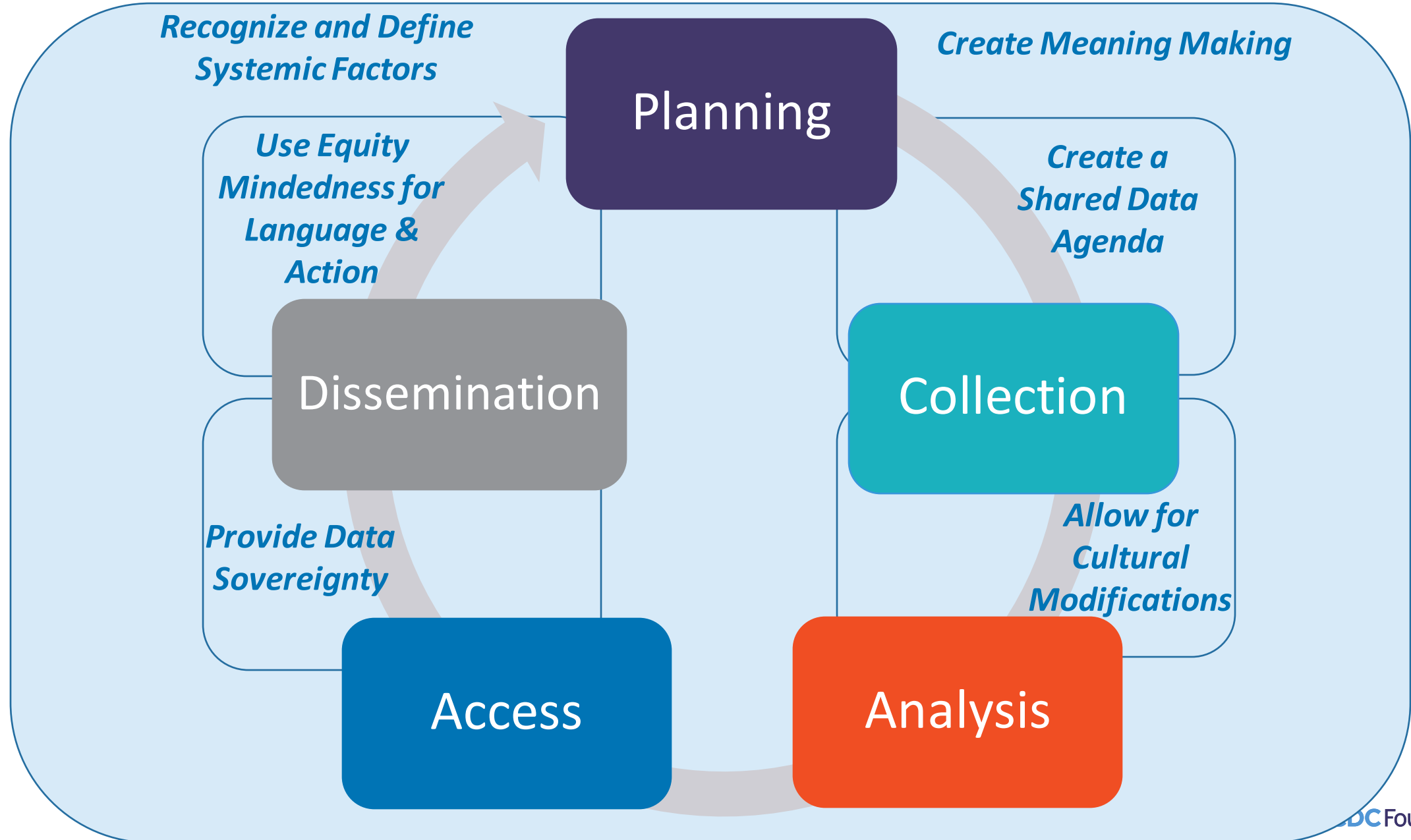
Application of Principles Across the Data Lifecycle

	Federal	State/Local	Tribal/Territory
Planning	Include health equity elements in NOFO selection criteria	Develop a research and governance plan with CBOs	Build data literacy among organizations and community members
Collection	Expand data categories beyond OMB standard	Regularly review existing data sources to determine what additional data is needed to identify inequities	Prioritize the collection of qualitative data to contextualize quantitative findings and inform how inequities manifest
Analysis	Include health equity indicators into performance monitoring systems	Use "early warning" indicators to provide meaningful services and support to populations rather than for "threat" amplification	Engage domain experts and methods experts to ensure the appropriate data model used is to examine the local context
Access	Publicize clear, accessible data release schedules and policies on CDC.gov	Clearly document of why data are unavailable such as legislation, data quality, preparation, etc	Include community stakeholders in defining which data should be reused
Dissemination	Require articles on racial health inequities to rigorously examine racism	Develop differentiated messaging for audiences that considers the appropriate level of details, jargon, format, etc	Consult with the local tribal leaders on the analysis and interpretation of the data when reporting data on or about NA/PI

CDC Foundation

Application of Data Equity Principles in the Analysis Phase

Use "early warning" indicators to provide meaningful services and support to populations rather than for "threat" amplification

- Consider any **unintended consequences** in your selection when determining the analysis plan and potential indicators use
- Consider the **human-led element** (i.e. the population should co-develop the priorities)
- Select **positively framed indicators** – with actionable resources associated with measurement – rather than leading to increased surveillance, punitive action, monitoring, etc.
  - *Example: Surge in Fentanyl related deaths in Fulton County leads to distribution of Narcan and free Narcan training events at local bars vs increased police surveillance for drug related transactions*

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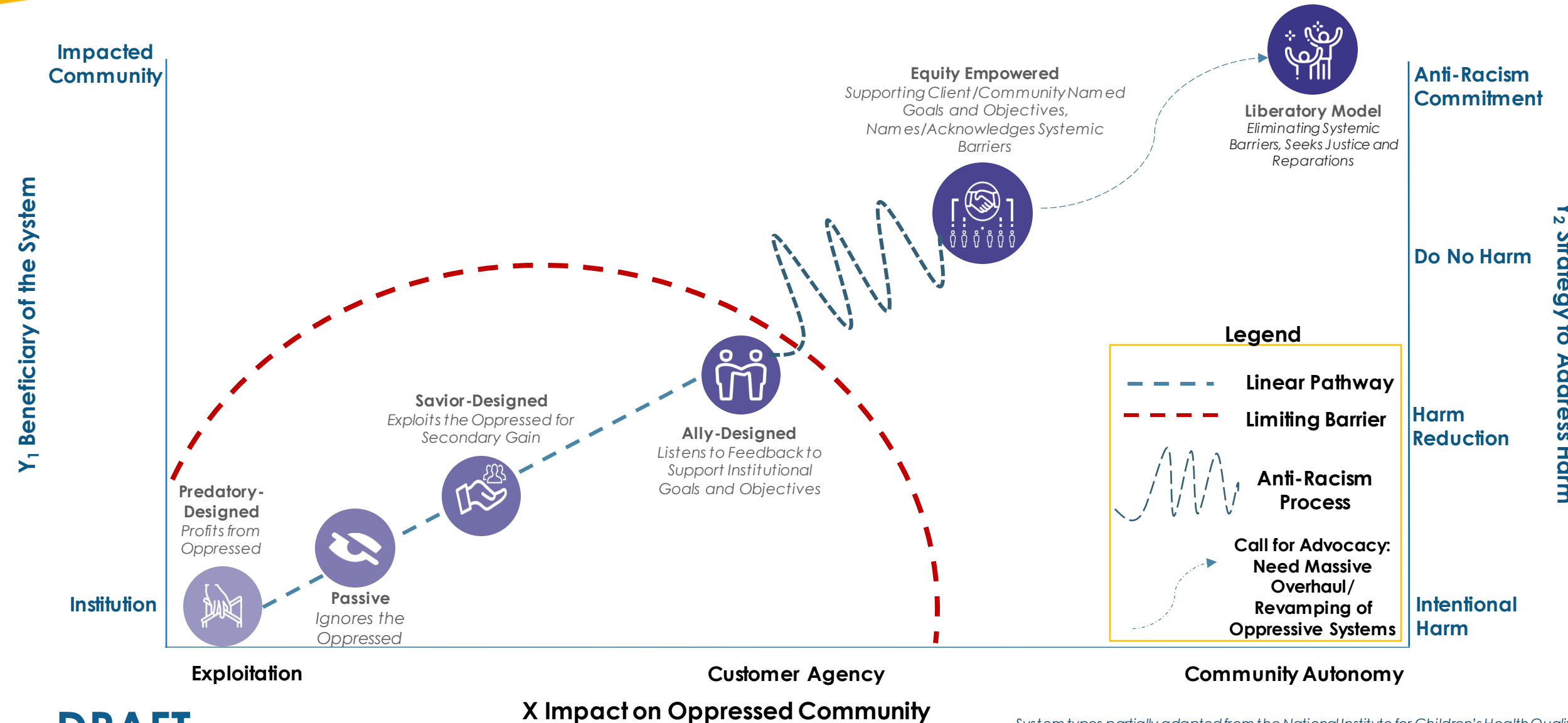
Together our impact is greater

Landscape of System Design – Institutional Reflection

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Health Leads

Y1 Beneficiary of the System

Impacted Community

Institution

Equity Empowered
Supporting Client/Community Named Goals and Objectives, Names/Acknowledges Systemic Barriers

Liberatory Model
Eliminating Systemic Barriers, Seeks Justice and Reparations

Savior-Designed
Exploits the Oppressed for Secondary Gain

Ally-Designed
Listens to Feedback to Support Institutional Goals and Objectives

Predatory-Designed
Profits from Oppressed

Passive
Ignores the Oppressed

Exploitation

Customer Agency

Community Autonomy

X Impact on Oppressed Community

Y2 Strategy to Address Harm

Anti-Racism Commitment

Do No Harm

Harm Reduction

Intentional Harm

Legend
— — — Linear Pathway
— — — Limiting Barrier
Anti-Racism Process
Call for Advocacy: Need Massive Overhaul/ Revamping of Oppressive Systems

DRAFT

System types partially adapted from the National Institute for Children's Health Quality.
https://www.nichq.org/insight/savior-designed-equity-empowered-systems

Landscape of System Design – Individual Reflection

Most Marginalized/ Community-Focused

Others-Focused

Me-Focused

Y₁ Focus of Needs, Priorities and Desires (Internally and Externally)

Equity Empowered
Supporting Client/Community Named Goals and Objectives, Names/Acknowledges Systemic Barriers

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Respecting and Honoring Most Marginalized/ Community Power

Recognition that Most Marginalized/ Community Has Power

Power Given to Others

No Power Given

Y₂ View of Power (internally and externally)

Exploitation   Discrimination   Inclusion   Equity   Liberation

DRAFT

X Impact on Oppressed Community

System types partially adapted from the National Institute for Children's Health Quality.
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Data System Drivers

These 11 key components provide detailed descriptions of existing data drivers that will help institutions and organizations understand the differences between each system design and opportunities to move towards an anti-racist model.

DRIVER	DEFINITION
INFORMED CONSENT AND REFUSAL	Process in which someone's information is shared with others, and ability/inability to stop the use or sharing of information
POWER, SYSTEM DESIGN & GOVERNANCE	Core stewardship and decision-making of a CIE, including voices that are represented and influence the system of care
DATA STEWARDSHIP/COLLECTION/USE	Who leds and stewards the collection and use of data, and role with data analysis
ACCOUNTABILITY AND TRANSPARENCY	Responsibility/Role in which information is gathered, used, and shared to make change or influence decisions for individuals, across organizations, and with the larger community.
SECURITY (ROLE-BASED PERMISSIONS AND ACCESS)	The protection and partitions in place that delineates who sees specific types of information and how information is accessed
TECHNOLOGY AND INTEROPERABILITY	The tool(s) used to share information and its ability to integrate and exchange responsibly and ethically with other technology platforms.
SUSTAINABILITY AND MONETIZATION	Process in which technology and services are financed, the initial investment, cost-savings and who is benefiting/profiting, and re-investment.
SHARED LANGUAGE	Collective definition of comprehensive health and social needs through standards and best practices across systems of care, which could include the individual/family, and infrastructure to support the communication.
OUTCOMES/IMPACT and ADVOCACY	Significance of the impact on individual/family, institutions and community and role with advocacy.
CARE COORDINATION	Infrastructure and organization of how institutions and supports participate and the care for Individual/family.
NETWORK ENGAGEMENT	Role in which participating organizations, community members, institutions are engaged on quality improvement, workflows and shared learning.

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Savior-Designed Type

CONSENT AND REFUSAL
- Data is collected with standard consent through screenings or extraction-based methods; often as a pre-requisite for services; Data is shared for a specific timeframe with ability to revoke consent, but data is always kept.

DATA STEWARDSHIP / COLLECTION / USE
- Assumes the right to use data for justified means and often used to identify or diagnose needs. Often with good intentions but can still perpetuate harm through lack of shared data ownership with impacted community members. Data is used to meet goals set by institutional power.

OUTCOMES / IMPACT and ADVOCACY
- Measures and outcomes are determined by institutional power and benefit their population, often highlighting the deficits of the community or patient population) and can be used to perpetuate or reinforce systemic racism and inequities. Data may harm most impacted population.

POWER, SYSTEM DESIGN & GOVERNANCE
- Institution driven governance model with feedback from community members or community-based organizations gathered in a trickle down community engagement manner. Design structure is based on deficit or risk and institution is "rescuing" those not in power.

ACCOUNTABILITY AND TRANSPARENCY
- Maintains only what is necessary in order to avoid legal and financial risks. Accountability structure is set by the institution solely; often puts onus on community to input data into system; community has no agency to hold institution accountable for misuse.

SECURITY (ROLE-BASED PERMISSIONS AND ACCESS)
- Access to data is partitioned based on standards of "need-to-know" access. These standards are set forth by industry or sector-based laws, policies and best practices.

TECHNOLOGY AND INTEROPERABILITY
- Maintain and apply standards set forth by industry or sector-based laws, policies and best practices. Inclusion policies are decided in the community's best interest but may lack impacted community input.

SUSTAINABILITY AND MONETIZATION
- Data is often used as cost-saving mechanism, no payment structure for CBOs or only through a medicalized care or administrative burden. Well-intentioned philanthropic or institutional investment that is dictated by priorities and the timeline of institutional power; investment discontinues if institutional goals are not met: no or limited community reinvestment; community does not participate in how reinvestment occurs.

SHARED LANGUAGE
- Medicalization of Data (Screening and binary) With an aim to assist others, communication infrastructure, including language used, developed by and reinforced by institutions. Language makes assumptions about communities, often is not culturally relevant or appropriate, and paternalistic. Establishment of best practices set and verified by institutional power without community input.

CARE COORDINATION & AGENCY
- Assumption that referrals result in care coordination. Does not push or influence to shift status quo care coordination.

NETWORK ENGAGEMENT
- Institution determined engagement and focused on adoption of technology solution vs. community needs. Includes shifts in workflows to accept referrals.

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Liberating Model Type

CONSENT AND REFUSAL
- Community-defined consent process. Consent not required to access services. Community members control who can/cannot access their information

DATA STEWARDSHIP /COLLECTION / USE
- Reciprocity use and outcomes. Community Data Trusts and data sovereignty, ensuring data acquisition is bi-directional. Community owns data narrative and being used to address community-identified problems while promoting agency and community autonomy. Data seeks to provide healing, restore dignity, and liberate the oppressed (i.e., reparations). Community benefits most from data collection and usage.

OUTCOMES/ IMPACT and ADVOCACY
- Outcome/Impact measures defined by the community with ability to advocate and influences political, government and non & for-profits. Data is used for advocacy and provides agency for the most marginalized. Data seeks to provide healing, restore dignity, and liberate the oppressed (i.e., reparations). Community owns data narrative and is used to create and increase agency for the most marginalized.

POWER, SYSTEM DESIGN & GOVERNANCE
- Community has the power and has a governance structure that ensures voices from traditionally oppressed communities. Designed to protect and support community members and institutions and systems us this to inform operations and investment.

ACCOUNTABILITY AND TRANSPARENCY
- Community ownership, controls data and community determination on outcomes, risks, and determination of how-to best address funding that reflects community priorities. Community Data Trust model: Data gives clients power to hold systems responsible for outcomes.

SECURITY (ROLE-BASED PERMISSIONS AND ACCESS)
- Individuals have access to their own data with the choice on who accesses info, including family members. Community members elect what organized body or infrastructure will administer access to data and define the circumstances in which access is allowed.

TECHNOLOGY AND INTEROPERABILITY
- Interoperability standards center community needs and community access over industry or sector-based standards.

SUSTAINABILITY AND MONETIZATION
- Braided funding model that aims to dismantle power constructs and center the voices of the community. Reinvestment model prioritizes those who are experiencing the starkest disparities: "those that are losing the most get the most." Reinvestment and data focus on creating and furthering agency for the most marginalized (i.e., reparations).

SHARED LANGUAGE
- Language for community members. With an aim to facilitate and provide agency for the most marginalized, communication infrastructure, including language used, is developed by and reinforced by community. Language is culturally relevant and appropriate and highlights resiliency, empowerment, and assets in the community. Establishment of best practices set and verified by community, particularly those most impacted.

CARE COORDINATION & AGENCY
- Care team and equal power is defined by individual and family including a multi-generational understanding and perspective into care.

NETWORK ENGAGEMENT
- Infrastructure allows for predictive modeling from community identified variables (quantitative or qualitative), predictive modeling is analyzed to ensure that results are not discriminatory; using the Network to support prevention; responsive; continual process and quality improvement; providing community member voice in all aspects of feedback and insights.
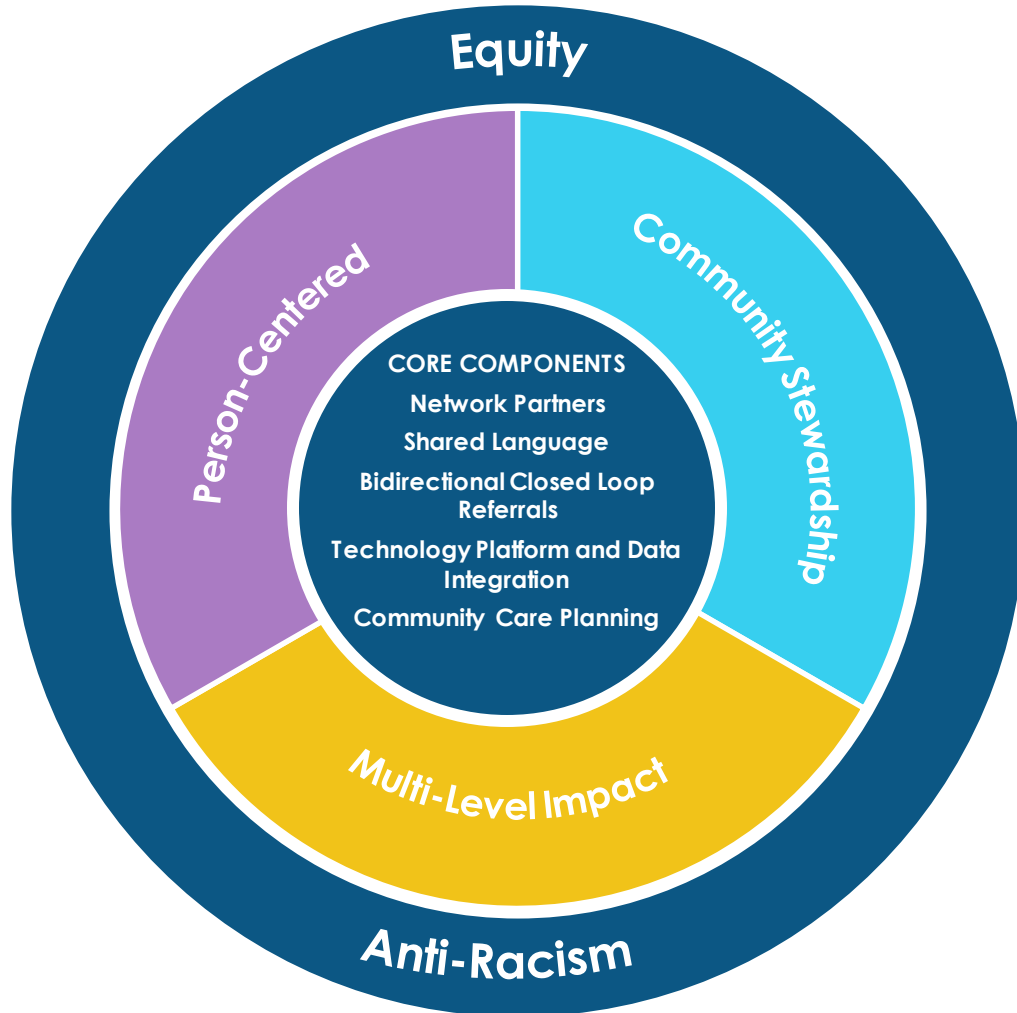
What is a Community Information Exchange?

"*A 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 equity**.*"

CIE Tenets
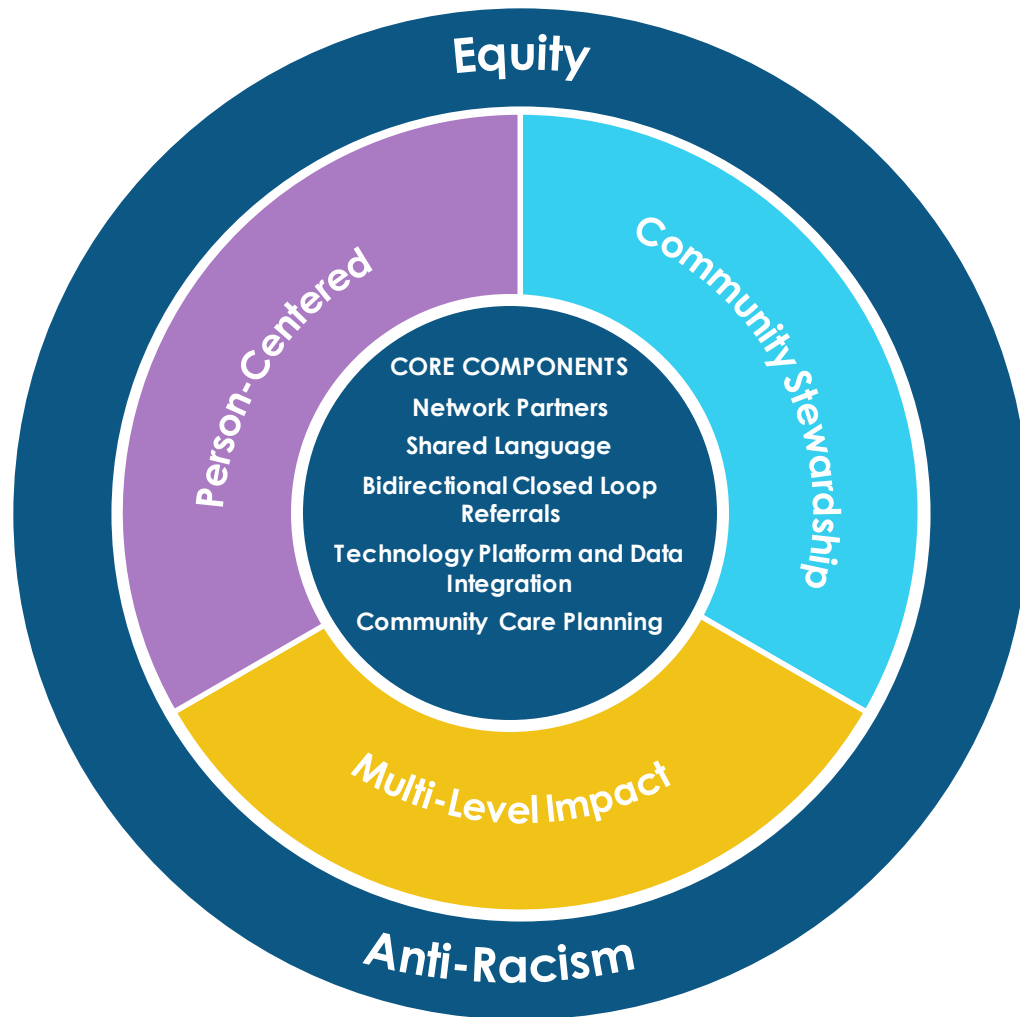
- **Equity:** The CIE ensures accessibility to all community members regardless of demographic or geography. It is rooted in equity-centered community design, which acknowledges and utilizes the role of people, systems and power when developing solutions to ensure a positive impact on the community.

- **Anti-Racism:** Anti-racism refers to the process required to achieve a liberating CIE system. This process includes both unlearning and learning, abolition and building, divesting and reinvesting necessary to create CIE systems that advance racial justice.

Fundamental Elements and Concepts

Person-centered	Community Stewardship	Multi-Level Impact
Cultivates trust and capacity within the community.	Enables cross-sector collaboration.	Drives systems change.
Cultivates individual agency and understands root causes of resource gaps.	Designed to uplift and assist in providing agency to the communities who experience the starkest disparities and inequities.	

Core Components

Network Partners

As a community-led initiative, the CIE is stewarded by multi-sector community-based organizations including healthcare and government entities who are involved in prioritizing community member's needs and allocation of resources. Partner engagement is guided by standard Participation Agreement, Business Associate Agreement, and participant consent with shared partner governance, ongoing engagement and support
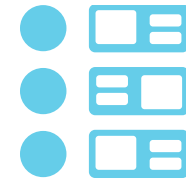
Aligned Language (SDoH)

The 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 the CIE. Bi-directional information sharing enable partner organizations to streamline the delivery of person-centered care, monitor individuals' progress, and capture outcomes in real-time.

Technology Platform and Data Integration

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

Community Care Planning

The 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.

Group Reflections

Group Reflections (10 minutes)

- What concepts resonated with you the most from the presentations and/or panel discussion that you want to continue talking about?

- What concepts would you want to continue discussing with other communities?

- What ideas or questions do you want to take back to your organization/community?

Charge/Intention

Charge/Intention:

In the chat, share key take-aways, reflections from "Group Reflections"

We are all users or collectors of Data.

Key Highlights:

- Recognizing Historical, Systemic and Structural Racism embedded into all of our systems (Harm has been done)
- Right people around the table (owning data narrative)
- Provide Data Sovereignty (CDC Foundation Principle)
- Using Data for Community Agency, Autonomy and Advocacy

Meagan Puzacke, Health Leads

Thank You!

- Are you attending the CIE Summit on September 8-10?

- What is something that struck you from this session and your breakout discussion?

- Remember to share your thoughts and feedback on the Discussion Board in Whova!