Leveraging Community Information Exchanges for Equitable and Inclusive Data:
The CIE® Data Equity Framework

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We extend our appreciation to:

Introduction

The challenges associated with confronting and eliminating structural racism are extensive. Doing the critical work of addressing the pervasive public health, social, economic, legal, and educational crises that have occurred as a result of longstanding inequities requires institutions to do the hard work of engaging in uncomfortable discourse to reflect on and correct behavioral patterns, processes, and systems that have harmed and are currently harming the individuals and families they intend to serve. Otherwise, institutions risk perpetuating practices that produce poor health outcomes.[1]

We intend for this Data Equity Framework to guide institutions away from systems that perpetuate harmful practices and towards anti-racist systems that empower communities.

This work builds upon the following premises:

1. Racism

2. Do No Harm

3. Anti-racism

Racism

Racism is a social construct that operates on multiple levels: interpersonal, institutional or structural, and internalized. Interpersonal racism often manifests in stereotypes, individual discrimination, and forms of prejudice. Institutional racism is advanced through individual choices that provide or offer "differential access to goods, services, opportunities, by race." It is "normative, sometimes legalized, and often manifests as inherited disadvantage." Internalized racism is defined as "acceptance by members of the stigmatized races of negative messages about their own abilities and intrinsic worth."

Do No Harm

Do No Harm is a principle that recognizes that the realities of poverty, class, racism, past trauma, identity and other social inequities affect people's vulnerability to live a thriving life experience. Institutions that practice Do No Harm will:

- Acknowledge and address the real and tragic harm and danger that can be associated with the results of racial and social inequity experiences;
- Ensure that community members with said experiences have a real voice in the creation of programs and policies designed to serve them;
- Practice civic engagement and shared leadership within institutions and boards that are reflective of communities served; and
- Promote more inclusive and equitable data practices.

Anti-Racism

Anti-racism is a set of actions that respond to the systemic nature of racism. Anti-racism is a process that includes both unlearning and learning, abolition and building, divesting and reinvesting to create systems that advance racial justice. Practicing anti-racism offer 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.

Communities that are planning or have implemented multisector care coordination systems are forging new ground using their ingenuity as problem solvers. We call on these institutions to use this framework to understand the history of systemic racism and its ongoing effect on populations, reflect on past and current behavior and processes that harm individuals and communities, and engage community members to design a system that benefits all populations.

Institutional Racism:

Institutionalized racism manifests itself both in material conditions and in access to power. With regard to material conditions, examples include differential access to quality education, sound housing, gainful employment, appropriate medical facilities, and a clean environment. With regard to access to power, examples include differential access to information (including one's own history), resources (including wealth and organizational infrastructure), and voice (including voting rights, representation in government, and control of the media). It is important to note that the association between socioeconomic status and race in the United States has its origins in discrete historical events but persists because of contemporary structural factors that perpetuate those historical injustices. In other words, it is because of institutionalized racism that there is an association between socioeconomic status and race in this country.

Source: Jones CP. Confronting Institutionalized Racism. Phylon 2003; 50 (1-2):7-22.

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[1]Hardeman, Rachel R. Medina, Edward M. Boyd, Rhea W. "Stolen Breaths." N Engl J Med 2020; 383:197-199. DOI: 10.1056/NEJMp2021072.

Background

Historically, the way in which public health systems have gathered and interpreted data has created harms that are disproportionately born by communities of color. These harmful processes have contributed to a service delivery infrastructure that reinforces systemic racism and white supremacy by harming marginalized communities, exacerbating local resource inequities, and distorting the perceptions of populations who rely on public services. Communities have advanced innovative approaches to care coordination, but these systems are at risk of perpetuating inequitable practices unless institutions are willing to do the work to collaboratively design data systems that prioritize equity, inclusion, and person-centered care.

Historic and ongoing lack of transparency breeds community distrust. Additionally, several challenges around data collection and use threaten equitable care. First, because data has become the cornerstone of public health action and clinical care decision-making, in this evidence-based era the onus is on individuals to disclose information prior to being served. This practice subtly transforms a care process into a transaction contingent upon data acquisition, which at worst introduces coercive and extractive practices into the care necessary to serve clients' vital needs.

Second, in the social and health sectors, we have seen the prioritization of institutional goals above community needs, leading to a lack of transparency, and some may argue a disregard, for the humanity of people from marginalized groups and those who work with them across our health care systems. In many cases, these groups are often not included or respected as part of the SDOH intervention, and the lack of authentic community engagement, particularly among the most marginalized, has caused deep distrust of the institutions connecting individuals to resources and collecting data. As a result, these interventions run the risk of not being culturally sensitive, appropriate, or humble in implementation, which leads to a lack of acceptance and adoption of the SDOH intervention.

Third, in this era of competing narratives about data sharing and privacy, a lack of transparency around data collection, practices, exchange, and use processes significantly increases the risk that SDOH interventions will be unadoptable. We may have already begun to see the effects of the lack of honoring humanity in SDOH interventions as we see inconsistent results and outcomes in SDOH research found in medical journals.[3, 4, 5, 6, 7]

In contrast, a Community Information Exchange (CIE)® can support communities in shifting away from reactive, transactional models of care toward proactive, inclusive, person-centered care. A CIE® is a community-led ecosystem that delivers enhanced care planning through distinct processes that work together to support equitable, and inclusive information and data sharing practices.[8] At its core, a CIE® centers the community and aims to employ anti-racism practices that work toward achieving equity.

When developing a CIE®, community-serving institutions should approach the planning process with the goal of developing anti-racist systems that uplift and empower impacted populations by enabling equitable access to quality care. Practicing anti-racism—or the conscious dismantling of oppressive systems to design ones that are intentionally centered on the populations most impacted—requires introspection, uncomfortable discourse, and intentional efforts to build understanding and awareness at the individual, organizational, and systems levels. Anti-racist practices give communities the institutions[9] that serve them the opportunity to:

1. Name and dismantle interlocking systems of oppression that harm individuals and communities,

2. Reimagine ways of understanding and addressing human needs, and

3. Build practices for restorative justice to rectify the harm done to marginalized communities.

Absent an explicit commitment to equity and anti-racism, a CIE® plan runs the risk of developing a system that prioritizes the needs of the institution or a single sector, rather than the needs of the community and impacted populations. As a result, the system design could exploit historically neglected and underserved populations that should be guiding the direction of the CIE®, and harming— instead of uplifting—the community it serves.

[3]M. Tsega , C. Lewis, D. McCarthy, T. Shah, K. Coutts. Review of evidence on the health care impacts of interventions to address the social determinants of health. The Commonwealth Fund; July 1, 2019.

[4]Chang ET, Asch SM, Eng J, Gutierrez F, Denietolis A, Atkins D. What is the return on investment of caring for complex high-need, high-cost patients? J Gen Intern Med. 2021 Sep 10. doi: 10.1007/s11606-021-07110-y. Epub ahead of print. PMID: 34508291.

[5]Nuamah A, Opthof E. On my block: The impact of community resources on health outcomes and medical spending. CHCS Blog; May 1, 2020.

[6]Kangovi S, Mitra N, Grande D, Long JA, Asch DA. Evidence-based community health worker program addresses unmet social needs and generates positive return on investment. Health Aff. 2020;39(2):207-213. doi:10.1377/hlthaff.2019.00981.

[7]Schickedanz A, Sharp A, Hu YR, Shah NR, Adams JL, Francis D, Rogers A. Impact of Social Needs Navigation on Utilization Among High Utilizers in a Large Integrated Health System: a Quasi-experimental Study. J Gen Intern Med. 2019 Nov;34(11):2382-2389. PMID: 31228054. DOI: 10.1007/s11606-019-05123-2

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

[9]For the purposes of this framework, we define institution to broadly refer to any organization, intervention, or program that is providing direct health, human, and social services and/or participating in a care coordination system that connects individuals to services needed to improve health outcomes for populations.

How to Use the CIE Data Equity Framework

This framework is designed to serve as a strategic visioning tool for institutions and initiatives that are undertaking the critical work of creating more equitable, inclusive systems that support health outcomes. The hope for this framework is to better understand the design and key drivers to build a robust data system of care that honors the dignity of the people affected by the data gathering, sharing, and use processes.

1	First, this work requires these institutions, communities, and initiatives to acknowledge the past, reflect on the current state, and plan actionable next steps towards an equitable system.
2	Second, this framework intentionally engages the individual as integral to enacting change in communities that are beholden to powerful systems that have historically neglected populations.
3	Third, this framework challenges traditional approaches of measuring return on investment (ROI) while calling for stakeholders to intentionally articulate the benefit to the most marginalized groups while also naming the strategies deployed to both address and mitigate harm to the community. This differs from traditional approaches because it shifts away from a sole focus on institutional priorities and objectives.

This differs from traditional approaches because it shifts away from a sole focus on institutional priorities and objectives.

Reflection and Planning Tool, not a Blueprint
Use this framework to help facilitate conversations with key stakeholders, investors, and partners about the benefits of liberatory system design. There is not a clear map of how to realize a liberating model. Organizations will take different paths forward. Some may require rethinking and reconstructing current systems, which may look different for different stakeholders but ultimately creates accountability to anchor the work.

Starting Point
Upon reviewing the data system design types and reflecting on their relationship with community, institutions and their partners can identify areas for growth, and clearly define actionable next steps that support the establishment of anti-racist systems. Specifying anti-racism as a set of concrete actions, rather than just a set of values, is essential to moving from systems that benefit institutions towards systems that benefit and shift power to the community.

Evolution
We will need to continue to do intentional, ongoing, and meaningful work to move toward genuine impact on our communities.

Beyond Data
This template can be used beyond existing data systems and can be leveraged to support other institutions or systems within our society. Democratization of all systems of care is necessary to liberate humans from systems of oppression.

To guide this strategic visioning exercise, the **CIE Data Equity Framework System Design Reflection and Planning Worksheet** includes sets of questions for Institutional Reflection, Individual Reflection, and Plan for Action.

CIE® Data Equity Framework

The CIE® Data Equity Framework aims to help institutions and the communities they serve approach CIE® planning and systems change work from a place of anti-racism by:

- **Naming** how data system design reflects understanding of and participation by the intended beneficiaries of current programs and interventions;

- **Acknowledging** and documenting the effects of a spectrum of data system design types on oppressed populations and communities;

- **Identifying** strategies needed to eliminate the harm of current processes and practices;

- **Highlighting** the behavior change needed to rebuild or change the overall data system to better meet community needs across racial and ethnic populations; and

- **Adopting** practices that promote restorative justice, mitigate harm and exploitation, and address existing harm that has been committed towards the community.

Data System Design Types

What characteristics are essential to a data system that truly benefits the community? In the context of this framework, we have categorized data systems into six different design types according to the ways each orients the system toward the populations they intend to serve. We examined the categories of data use, client awareness and involvement, and accountability structures.[10]

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

Data System Design Type and Definition	Example of Community Engagement and Data Collection/Utilization
Predatory Engagement Profits from systems of oppression	• The data collected from a community program is treated as a commodity and used to demonstrate a return on investment to obtain more grants and contracts for the program. Profit drives data collection and exposes clients to harmful practices, such as predatory marketing and community surveillance. • Explicit lack of client consent processes. • Clients are not aware that data is being collected nor how the data is being used. • Reinvestment in clients and the community is not discussed, initiated, or incorporated into future programmatic plans. • No structures exist to hold the institution accountable.
Passive Engagement Ignores oppressed populations	• The institution collects data as a part of service, holds unnecessary data indefinitely, and uses it beyond the explicit purpose for which the client received services. • The data is collected without the client's knowledge. • Accountability structures are unclear.
Savior-Designed Engagement Exploits oppressed populations for secondary gain	• A program is designed to benefit an underserved population, but no individuals in the underserved group have been authentically engaged in its design or data collection methods. Institutional knowledge, also referred to as expert knowledge is esteemed above community expertise gained through lived experience. • Program data is collected with consent through screenings or extraction-based methods, often as a pre-requisite for services. The data is used to identify or diagnose surface-level needs to meet goals set by the institution. The program is evaluated based on the objectives and goals of the institution, rather than the community. • The accountability structure is set solely by the institution, but the community bears the responsibility for inputting data into the system. The community has no agency to hold the institution accountable for misusing the data or other potential abuses of power.
Ally-Designed Engagement Listens to community feedback to support institutional goals and objectives	• After implementing an intervention, community members are invited to provide feedback on program implementation with a focus on supporting the institution's evaluation efforts. Feedback will only facilitate change if the institution deems the change necessary or desirable. • The data narrative, or insights gleaned from the data analysis, is set by the institutional power, often highlighting the deficits of the community or patient population and can be used to perpetuate or reinforce systemic racism and inequities. • The institution establishes an accountability structure with feedback from the community.
Equity-Empowered Engagement Dismantles systems of oppression to primarily support the humans who are oppressed.	• A program has client-named goals and objectives, as well as names, acknowledges, and addresses systemic barriers. • Data collection is requested but not required for services, and clients have opportunity to easily understand how the data is being used. • The data is used by the community for advocacy to meet the needs of the most marginalized groups. Data collection, use, and analysis seek to address root causes of inequities and dismantle inequitable systems, processes, and practices. • Stakeholders engage in collaboration and authentic community engagement via community governance structures. • Clients have the power to hold systems responsible for outcomes and other accountabilities.
Liberatory Model Eliminates forms of systemic oppression as a means for the humans who have been oppressed to have power, self-determination, and reparation for past harms suffered	• A program enables collaboration with multiple stakeholders, authentic community engagement, and community ownership. • Data is requested but not required, and community members can opt in or out of contributing their data at any time. • The data is used to address community-identified problems and the community benefits most from data collection and usage. The program addresses resource gaps while calling for advocacy and policy change to address systemic barriers and root causes, like systemic discrimination, disparities, and racism.

Landscape of Data System Design

While every system type can intentionally or unintentionally cause harm, the response to the harm is what creates the lasting effect on the individual and the community. The mentioned system types converge at three axes:

Landscape of System Design: Axes

System Beneficiary
Who benefits most from the intervention (the institution creating the intervention or the most impacted population)? A simple way to denote the primary beneficiary is understanding which stakeholder(s) have decision-making rights and holds power in the intervention design.

Strategy to Address Harm
What are the intentions and strategy to reduce or address harm?

Impact on Oppressed Community
How is the community experiencing the starkest disparities experiencing and benefiting from the intervention? Are community members being exploited? Are they gaining influence and feeling empowered within the intervention? Is the oppressed community being exploited, or exercising autonomy?

Plotting each data systems design type along the three axes creates a landscape that characterizes the current state of systems, the impact on the community, and where institutions need to focus to work towards developing a system that benefits community, overrides structural racism, and empowers communities.

Guidance for Reviewing the Landscape of Data System Design

The Goal is a Liberatory Model

Liberatory models do not currently exist, but they offer a worthy goal for achieving more equitable, inclusive and outcomes-focused systems. A complete restructuring across public health, social services, economic, legal, and education systems is required for liberatory models to thrive.

Prioritizing communities requires breaking through structural barriers to move towards a Liberatory Model. Predatory, passive, savior-designed, and ally-designed system types are structured to uplift institutional values, goals, and priorities. As such, these system types run a greater risk of being more exploitative to oppressed groups and have a greater propensity cause harm. Although ally-designed systems are further along the X-axis (i.e., closer to community autonomy), this type of system design still prioritizes the institution over the most impacted communities.

Identifying Your Institution's System Type and Characteristics

An institution may be stewarding a system that has characteristics of more than one system design type. For example, an institution could lead a singular intervention that clearly has established processes that align with an ally-designed system type, but partner on or lead additional programs that reflect characteristics of an equity-empowered system. Institutions should use this framework to become more aware of current practices that could be harming the communities they intend to serve, and find a path forward to move towards system types that foster community engagement and input. (See Figure 1)

Reflecting on Your Individual Role Within the System

Systems or institutional change typically requires one or more individual champions. To effectively fulfill this role, individuals within systems or organizations must examine their personal experience, how they are situated within the system, and their role—even when unintentional—to perpetuating racism and to intentionally adopt anti-racism practices. The following diagram offers a similar framework and shifts the language to be inclusive of the interactions with those around them. (See Figure 2)

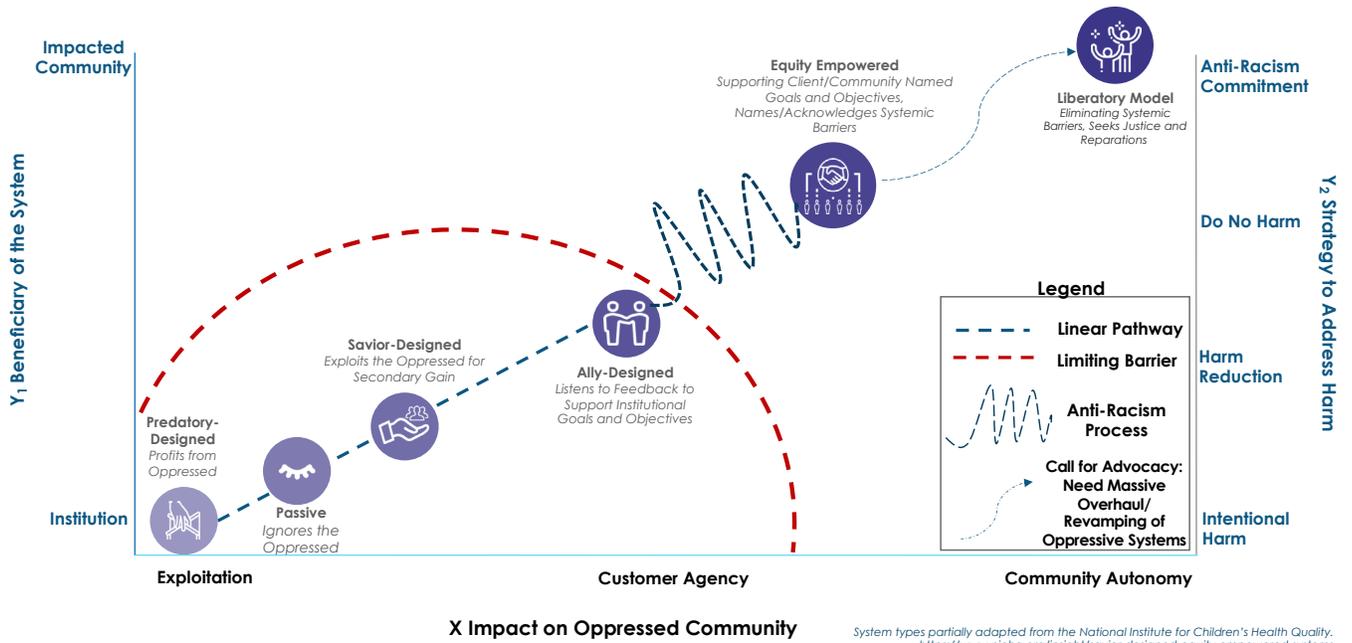## Continuous Reflection and Evolution

Advancing to systems that reflect the values and characteristics displayed in equity-empowered and liberatory system types requires practicing anti-racism—an active process of truth-telling, reconciliation with groups that have been and continue to be harmed, and justice as demonstrated through reparatory change.

Institutions can take a first step towards building systems that reflect the needs and values of their communities by committing to regularly reflect on how current processes and infrastructures can be improved. Use this Data Equity Framework and accompanying **CIE® Data Equity Framework System Design Reflection and Planning Worksheet** to revisit the current state of their systems and take actionable next steps to evolve the ways in which they engage and collaborate with communities. Institutions should also continuously revisit the best approach for building pathways that initiate and regularly enable community collaboration realized through shared decision-making and discourse designed to heal, empower, and uplift historically marginalized groups.

The Data Equity Framework pushes institutions to understand, acknowledge, accept, and act—moving towards continuous review and assessment of values, processes, and actions. An anti-racism commitment, which results from this continuous equity-oriented interrogation, should catalyze a desire to strive for models that facilitate liberation, or the ability of communities to be self-defined and self-determinant.
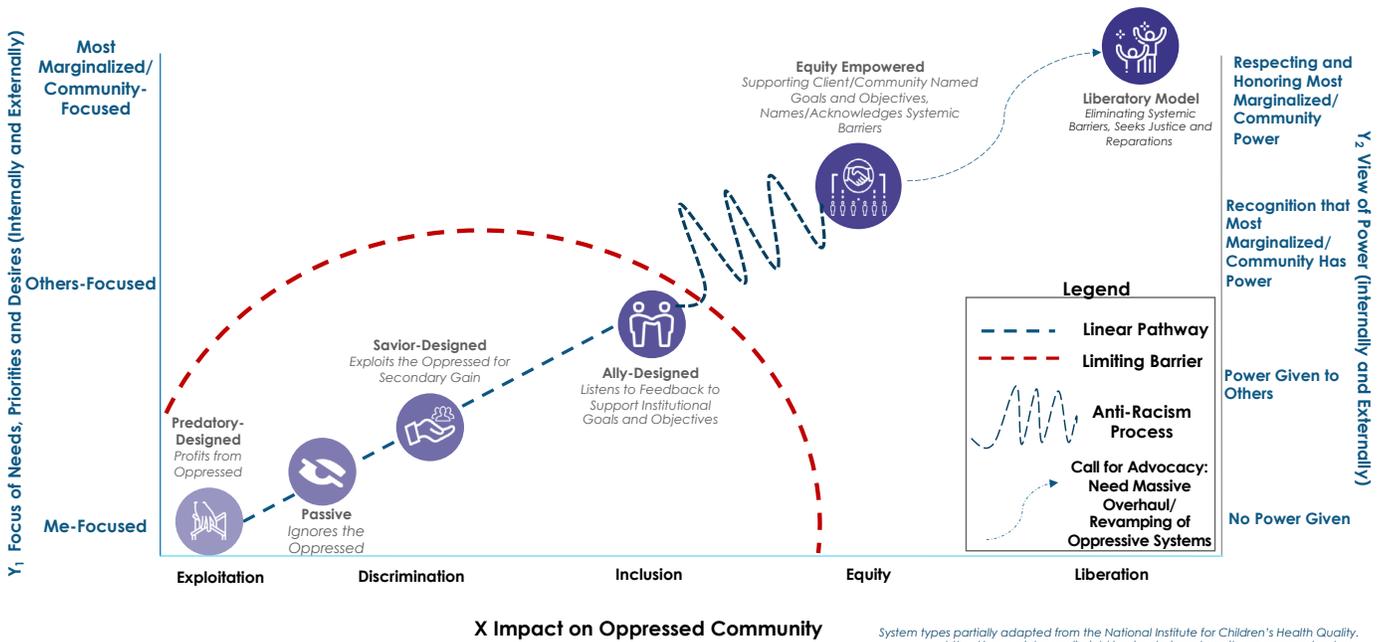
Landscape of System Design: Institutional Reflection

Figure 1

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

Liberatory Model
Eliminating Systemic Barriers, Seeks Justice and Reparations

Anti-Racism Commitment

Do No Harm

Harm Reduction

Intentional Harm

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

Impacted Community

Y_1 Beneficiary of the System

Institution

Y_2 Strategy to Address Harm

Exploitation — Customer Agency — Community Autonomy

X Impact on Oppressed Community

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

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

Figure 2

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

Liberatory Model
Eliminating Systemic Barriers, Seeks Justice and Reparations

Respecting and Honoring Most Marginalized/ Community Power

Recognition that Most Marginalized/ Community Has Power

Power Given to Others

No Power Given

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

Most Marginalized/ Community-Focused

Others-Focused

Me-Focused

Y_1 Focus of Needs, Priorities and Desires (Internally and Externally)

Y_2 View of Power (Internally and Externally)

Exploitation — Discrimination — Inclusion — Equity — Liberation

X Impact on Oppressed Community

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

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

Data System Drivers

To further understand the reach and impact of current practices, institutions should reflect on the design and function of each of the important components – or drivers – of data systems. The 11 system drivers defined below align with the primary elements and components of a Community Information Exchange (CIE®). Understanding how each driver functions within each system type helps institutions identify which practices are and are not being designed with an equity lens.

Driver	Definition
POWER, SYSTEM DESIGN & GOVERNANCE	Core stewardship and decision-making of a CIE®, including the different stakeholder perspectives that are represented and influence the system of care.
NETWORK ENGAGEMENT	Role in which participating organizations, community members, and institutions are engaged in quality improvement, workflows, and shared learning.
ACCOUNTABILITY & TRANSPARENCY	Role in which participating organizations, community members, and institutions are engaged in quality improvement, workflows, and shared learning.
INFORMED CONSENT & REFUSAL	Process in which a person's information is shared with others and the degree to which they are able to stop the use or sharing of information.
DATA STEWARDSHIP, COLLECTION & USE	Who leads and stewards the collection and use of data, and their role in data analysis and dissemination.
CARE COORDINATION & CLIENT AGENCY	Infrastructure and processes in place by institutions to support cross sector care for the individuals and families, including the client's direct involvement and influence on their care
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 communication.
OUTCOMES, IMPACT & ADVOCACY	Significance of the impact on individual/family, institutions and community and role with advocacy.
TECHNOLOGY & INTEROPERABILITY	The tool used to share information and its ability to integrate and exchange responsibly and ethically with other technology platforms.
SECURITY (ROLE-BASED PERMISSIONS & ACCESS)	The protection and partitions in place delineate who sees specific types of information and how information is accessed.
SUSTAINABILITY & MONETIZATION	Process through which technology and services are financed, including the initial investment, how cost-savings are allocated and who benefits/profits, and the process and responsibility for re-investment.

System Driver Functionality by System Design Type

Comparing system driver functionality and characteristics across system types helps institutions determine what changes can be made to move towards a system that strives to be more reflective of a liberatory model. The following tables provide examples of how each system driver functions within each system design type.

Predatory Engagement

Passive Engagement

Savior-Designed Engagement

Ally-Designed Engagement

Equity-Empowered Engagement

Liberatory Model

PREDATORY-DESIGNED SYSTEM

SYSTEM DRIVERS	FUNCTIONS AND CHARACTERISTICS
POWER, SYSTEM DESIGN, & GOVERNANCE	• Community representatives are not engaged and excluded from all decision-making • The protection and control of the institution are prioritized • Power structures that do harm and systemic racism are reinforced
NETWORK ENGAGEMENT	• No standardized inclusion of the people that are served by the institution of system, or opportunity to gather feedback or input
ACCOUNTABILITY & TRANSPARENCY	• The institution has not built adequate accountability to clients into its infrastructure and is able to omit and modify information in ways that protect the institution and reinforce racist practices rather than protecting the community it serves. • The institution is able to omit and modify information with no accountability measures in place.
INFORMED CONSENT & REFUSAL	• Client participation is involuntary and often unknown • Clients are required to share information to access services • Data collection primarily motivated by institutional needs rather than necessary to provide efficient care
DATA STEWARDSHIP, COLLECTION & USE	• Client data is controlled, owned, and misused in a way that causes harm to the client (eg. withholding service or sharing data for any reason unrelated to directly serving the client) • Data is treated as a commodity. • Profit drives data collection and exposes individuals to predatory marketing.
CARE COORDINATION & CLIENT AGENCY	• Disregards the connection of individual and population needs; lack of cultural humility; presupposes what is best for customers/ targeted population(s) I.e., biased data
SHARED LANGUAGE	• With an aim to exclude the community and organizations with less access to traditional power, communication infrastructure, including language used, developed by, and reinforced by institutions. Language is used to surveil and harm the most marginalized communities.
OUTCOMES, IMPACT, & ADVOCACY	• Exploiting--- only protects the system and not the people it is designed to protect, which could result in punitive outcomes for individuals. Exposure and vulnerability to carceral state and inaccessibility to resources for the most impacted.
TECHNOLOGY & INTEROPERABILITY	• Access is only with the institution. There is a lack of ethical standards or policy for which platforms/ organizations can be shared.
SECURITY (ROLE-BASED PERMISSIONS & ACCESS)	• There are no protections in place to assure personal information is kept secure or measures to define who the information is shared
SUSTAINABILITY & MONETIZATION	• Solely benefits the protected institutions and data invests back into established institutions, financial gain to sustain disenfranchised systems

PASSIVE SYSTEM

SYSTEM DRIVERS	FUNCTIONS AND CHARACTERISTICS
POWER, SYSTEM DESIGN, & GOVERNANCE	• The institution does not initiate nor does it actively engage in any process that reflects on or looks to change the existing decision-making structure or power dynamic.
NETWORK ENGAGEMENT	• Collaboration with community providers on shared initiatives is limited to situations in which the ROI provides significant value to the institution. • Community members and families are typically not included.
ACCOUNTABILITY & TRANSPARENCY	• Focused on maintaining the status quo. Does not think there is a need to be accountable or transparent because not part of mission. Accountability structures are unclear.
INFORMED CONSENT & REFUSAL	• The institution or system does not play an active role in obtaining consent for data collection, but is able to access data as part of service provision without a client's knowledge or any liability for protecting the data from misuse.
DATA STEWARDSHIP, COLLECTION & USE	• System governance values the ability extract information relevant to its values but is risk adverse and does not actively participate in sharing data. • The institution stores and uses client data that is unrelated or unnecessary to providing services to clients. • The institution derives power from data collection and usage.
CARE COORDINATION & CLIENT AGENCY	• Clients from marginalized groups are shamed and experience trauma for needing health/social support services.
SHARED LANGUAGE	• The communication infrastructure centers language and best practices developed and reinforced by institutions
OUTCOMES, IMPACT, & ADVOCACY	• The institution participates only if the network benefits specific institutionally-established goals and outcomes.
TECHNOLOGY & INTEROPERABILITY	• The institution uses a proprietary, siloed systems and relies on consumers to opt into multiple systems to access services.
SECURITY (ROLE-BASED PERMISSIONS & ACCESS)	• Access information to further self-interest.
SUSTAINABILITY & MONETIZATION	• Financial benefits/portfolio are driven by tax break. Institutional decision-making structures maintain a traditional position on capital gains.

SAVIOR-DESIGNED SYSTEM

SYSTEM DRIVERS	FUNCTIONS AND CHARACTERISTICS
POWER, SYSTEM DESIGN, & GOVERNANCE	• Utilizes an institutionally-driven governance model, that incorporates feedback from community members or community-based organizations. • Design structure is based on deficit or risk and institution is "rescuing" those not in power.
NETWORK ENGAGEMENT	• The institution prioritizes the adoption of a technology solution rather than community needs. • Changes workflows to accept referrals.
ACCOUNTABILITY & TRANSPARENCY	• Maintains only what is necessary to avoid legal and financial risks. • Accountability structure is set solely by the institution; often puts responsibility for inputting data on the community. • Community members have no agency to hold institution accountable for misuse.
INFORMED CONSENT & 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, often 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 internal, closed, institutional decision-making structures.
CARE COORDINATION & CLIENT AGENCY	• Focuses solely on use of and quantity of referrals to connect clients with resources, but falls short of following up to ensure care coordination occurred and the client benefited.
SHARED LANGUAGE	• Screenings aimed to assist clients are binary (yes/no - commonplace in a medical model setting) and have been developed, deployed, 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.
OUTCOMES, IMPACT, & ADVOCACY	• Measures and outcomes are determined by institutional decision-makers to benefit their narrative, 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 the most impacted population.
TECHNOLOGY & 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 input from impacted clients and community.
SECURITY (ROLE-BASED PERMISSIONS & 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.
SUSTAINABILITY & MONETIZATION	• Data is often used as a cost-savings mechanism, resulting in a no payment structure for CBOs or only through a medicalized care or administrative burden. • Philanthropic or institutional priorities and timelines drive investment, which is discontinued if institutional goals are not met • No or limited community reinvestment; community does not participate in how reinvestment occurs.

ALLY-DESIGNED SYSTEM

SYSTEM DRIVERS	FUNCTIONS AND CHARACTERISTICS
POWER, SYSTEM DESIGN, & GOVERNANCE	• Stewarded by a community-based organization, representative of the community's best interest, and is designed to incorporate voices and share power with a larger body of stakeholders that include the active participation of community members.
NETWORK ENGAGEMENT	• Actively engaged network of care with shared lessons learned, opportunities for collaboration are active through new initiatives or policies, addressing quality improvement and workflows to reshape intervention.
ACCOUNTABILITY & TRANSPARENCY	• Establishes avenues for transparency, accountability, and policies to ensure meeting expectations of larger community through governance. • Accountability structure is set by the institution with feedback from the community.
INFORMED CONSENT & REFUSAL	• Consent integrated into accessing community services, co-created with the network of healthcare/social services and fully able to remove data from system and control who can access information • Clients can revoke consent at any time.
DATA STEWARDSHIP, COLLECTION & USE	• Data ownership is with the community it serves or housed with community-based institution(s) that have earned community trust related to best interests for use. • The data is only used to improve outcomes for local community members. • Data is used to meet goals set by institutions with community feedback.
CARE COORDINATION & CLIENT AGENCY	• Institutions account for and prioritize clients based on trauma-informed lens. • Mutual understanding of individual /family needs and resiliency considered in care plan.
SHARED LANGUAGE	• Common language across health and social providers that account for variation of situational experience, trauma, etc. • With an aim to assist others, communication infrastructure, developed by and reinforced by institutions, seeks to understand how community interacts with infrastructure. • Language makes assumptions about communities but seeks to be culturally relevant and appropriate.
OUTCOMES, IMPACT, & ADVOCACY	• Outcomes focus on eliminating disparities, improving the systems of care for the recipients, and advocating for policy changes that benefit the larger community. • Data narrative is set by institutional power (often highlighting the deficits of the community or patient population) and can be used to perpetuate or reinforce systemic racism and inequities.
TECHNOLOGY & INTEROPERABILITY	• Community members are informed of and can weigh in on the applied standards of interoperability. • Individuals have access to information shared through user-friendly, human-centered apps.
SECURITY (ROLE-BASED PERMISSIONS & ACCESS)	• Community members are informed of "need to know" role-based security protocols and/or are provided with an opportunity to weigh in on the applied standards of "need to know" access.
SUSTAINABILITY & MONETIZATION	• Pays to support community-infrastructure and direct service providers. • Well-intentioned philanthropic or institutional investment that is flexible to meet the needs of the community; investment discontinues if institutional goals are not met. • Community provides feedback on how money is re-invested.

EQUITY-EMPOWERED SYSTEM

SYSTEM DRIVERS	FUNCTIONS AND CHARACTERISTICS
POWER, SYSTEM DESIGN, & GOVERNANCE	• Governing body is reflective of the community that the institution serves • Power is shifted to community members. • Reflects on points of privilege and oppression to inform additional perspectives needed at the table.
NETWORK ENGAGEMENT	• Network proactively stands up resources, responds, and invests based on needs of the community. • Programs shift as community needs shift. • Community members are active.
ACCOUNTABILITY & TRANSPARENCY	• System infrastructure is designed to center community voice and racial equity with the context of data integration and use throughout the data life cycle. • Power and leadership are shared. • Utilizes a Community Data Trust model, giving clients power to hold systems responsible for outcomes.
INFORMED CONSENT & REFUSAL	• Institution requests data from clients. • Processes are in place to protect the best interest of community members. • Clients have the agency to understand how data is collected and used. • Clients can customize and receive notification with regards to who, how, and why their information is accessed.
DATA STEWARDSHIP, COLLECTION & USE	• Data collection and use policies and protocols are established through community policy standards focused on data collection. • The community decides how data is used and how it is interpreted and shared with external stakeholders. • Community is active in data narrative. • Data is used to address community-identified problems and promote community and individual agency. • Data seeks to address root causes of inequities and dismantle inequitable systems, processes, and practices.
CARE COORDINATION & CLIENT AGENCY	• Ability to include family members and advocates as active part of care. • Care is inclusive of readiness and resilience. • Person-centered approach with collective responsibility to holistic needs of the individual/family.
SHARED LANGUAGE	• With an aim to promote equity, communication infrastructure, including language used, is driven by community in partnership with institutions. • Language is culturally relevant and appropriate and highlights resiliency, empowerment, and assets in the community. • Establishment of best practices affirmed by community. • Best practices are frequently reviewed and reassessed to ensure that they facilitate empowerment for community members, particularly those from the most impacted community.
OUTCOMES, IMPACT, & ADVOCACY	• Data is used for advocacy and provides agency for the most marginalized. • Data seeks to address root causes of inequities and dismantle inequitable systems, processes, and practices.
TECHNOLOGY & INTEROPERABILITY	• Community members have equal decision-making power in setting and defining standards for sharing of data sets between systems. • Platforms need not be industry-grade to participate and benefit from interoperability.
SECURITY (ROLE-BASED PERMISSIONS & ACCESS)	• Community members have an equal share of power to weigh in on what is "need to know" and to specify what roles should be authorized to see specific information. • Community members have comparable access rights to their individual personal information and aggregate data at the community scale. • Individual gets to define who gets access to your information including family members/advocates.
SUSTAINABILITY & MONETIZATION	• Braided funding model and continual re-investment in community, payment to direct services providers, sharing in cost-savings. • Funding aims to dismantle power constructs and center the voices of the community (particularly the most marginalized); continual re-investment to address community-identified needs or priorities.

LIBERATORY MODEL

SYSTEM DRIVERS	FUNCTIONS AND CHARACTERISTICS
POWER, SYSTEM DESIGN, & GOVERNANCE	• Power and governance structure center community perspectives, ensuring representation from historically underrepresented and underserviced groups are engaged and in leadership positions. • Designed to protect and support community members and institutions. • Community informs operations and investment.
NETWORK ENGAGEMENT	• Uses the Network to support prevention; responsive, continuous process and quality improvement; community member voice is incorporated in all aspects of feedback and insights.
ACCOUNTABILITY & TRANSPARENCY	• Uplifts community data ownership. • Community members also determine outcomes and risks. • Community determines how-to best secure funding that reflects community priorities. • Community Data Trust model: Data gives clients power to hold systems responsible for outcomes.
INFORMED CONSENT & REFUSAL	• Community-defined consent process. • Consent not required to access services. • Community members control who can/cannot access their information
DATA STEWARDSHIP, COLLECTION & USE	• Community Data Trusts and data sovereignty-- a commitment to ensure data acquisition is bi-directional. • Community owns data narrative, which is 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.
CARE COORDINATION & CLIENT AGENCY	• Care team defined by individual and family including a multi-generational understanding and perspective into care.
SHARED LANGUAGE	• 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.
OUTCOMES, IMPACT, & ADVOCACY	• Outcome/Impact measures defined by the community to support the ability to advocate and influence political, government and social service. • Infrastructure allows for integrated community-identified variables (quantitative or qualitative), system is analyzed to ensure that results are not discriminatory. • 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.
TECHNOLOGY & INTEROPERABILITY	• Interoperability standards center community needs and community access over industry or sector-based standards.
SECURITY (ROLE-BASED PERMISSIONS & ACCESS)	• Individuals have access to their own data with the choice of who accesses information, 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.
SUSTAINABILITY & 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 agencies for the most marginalized (i.e., reparations).