

Part One - Data Equity Framework: Designing Equitable and Inclusive Systems



Webinar Goals & Intentions

Webinar Goals

- Introduce the background & mindset of use of Data Equity Framework
- Reflect on system design and drivers through the Data Equity Framework
- Consider how to move sectors and organizations toward equitable systems; repair and redesign

Your Intentions

In the Chat:

- Name, Organization, Location
- What experience you bring to this session (I AM Statements)
- What knowledge you want to bring back to your community

Thank You



Robert Wood Johnson Foundation

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Key Concepts for Understanding & Awareness

Racism

- Racism operates at multiple levels – interpersonal, structural or institutional, and internalized.
- Interpersonal racism often manifests in stereotypes, individual discrimination, and forms of prejudice.
- Structural Racism is advanced through individual choices that provide or offer "differential access to goods, services, opportunities, by race." Structural racism often manifests as inaction in the face of need.

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

Do No Harm

- Recognizes that the realities of poverty, class, racism, past trauma, sex/identity based and other social inequities affect people's ability to live a thriving life experience.
- Will not minimize or ignore the real and tragic harm and danger that can be associated with the results of racial and social inequity experiences.
- Honor the data provided by our vulnerable populations by promoting more inclusive and equitable data practices.
- Increase civic engagement and shared leadership within institutions and boards that are reflective of communities served.
- Ensures that the community members have a real voice in the creation of programs and policies designed to serve them.

Anti-Racism

- A set of actions that respond to the systemic nature of 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 that is necessary to create CIE systems that advance racial justice.
- The benefits 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.



Strategic Visioning

Understand where you are on your journey to champion data equity and justice.

- See things for how they really are, not what you are aspiring to
- Understand how you are operationalizing or perpetuating harm

Set intentions.

- State what you intend to accomplish through your actions.
- Make a commitment to what you want the journey to be about as you move forward.
- Be in the moment: who you are, what you do, why you do it.



Mindset

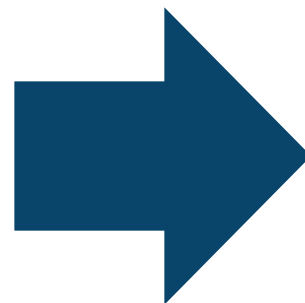


This framework is a reflection and planning tool, not a blueprint

- Help facilitate conversations with key stakeholders, investors and partners on the importance of system design within the work.
- Many organizations will have differing paths forward.
- Some may require breaking down and rebuilding much current systems may look different for different stakeholders.

- Better understand the design and key drivers to building a robust data system of care.
- We will need to continue to do intentional, ongoing and meaningful work to move towards genuine impact on our communities.

This framework is a starting point



This framework can be used beyond data systems:

- This framework can be leveraged to examine other institutions or systems within our society.
- Democratization of all systems of care are necessary to liberate humans from systems of oppression.

Landscape of Data System Design: Axes

Y₁: Beneficiary of the System

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

Impacted Community

Institution

Anti-Racism Commitment

Do No Harm

Reducing Harm

Intentional Harm

Y₂: Strategy to Address Harm

What are your intentions and strategy to reduce or address harm?

Exploitation

Customer Agency

Community Autonomy

X: 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 receiving more agency and feeling empowered in the intervention? Is the oppressed community being exploited, receiving agency, or exercising autonomy?

Landscape of Data System Design: System Types

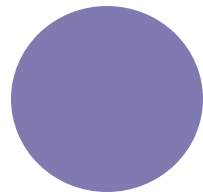
Each system's approach is differentiated by how it centers the community.

Every system or intervention has the ability to produce harm, but **the response to the harm is what creates the lasting effect on the individual and the community.**



Predatory

Profits from systems of oppression



Passive

Observes systems of oppression



Savior-Designed

Acknowledges systems of oppression



Ally-Designed

Confronts systems of oppression



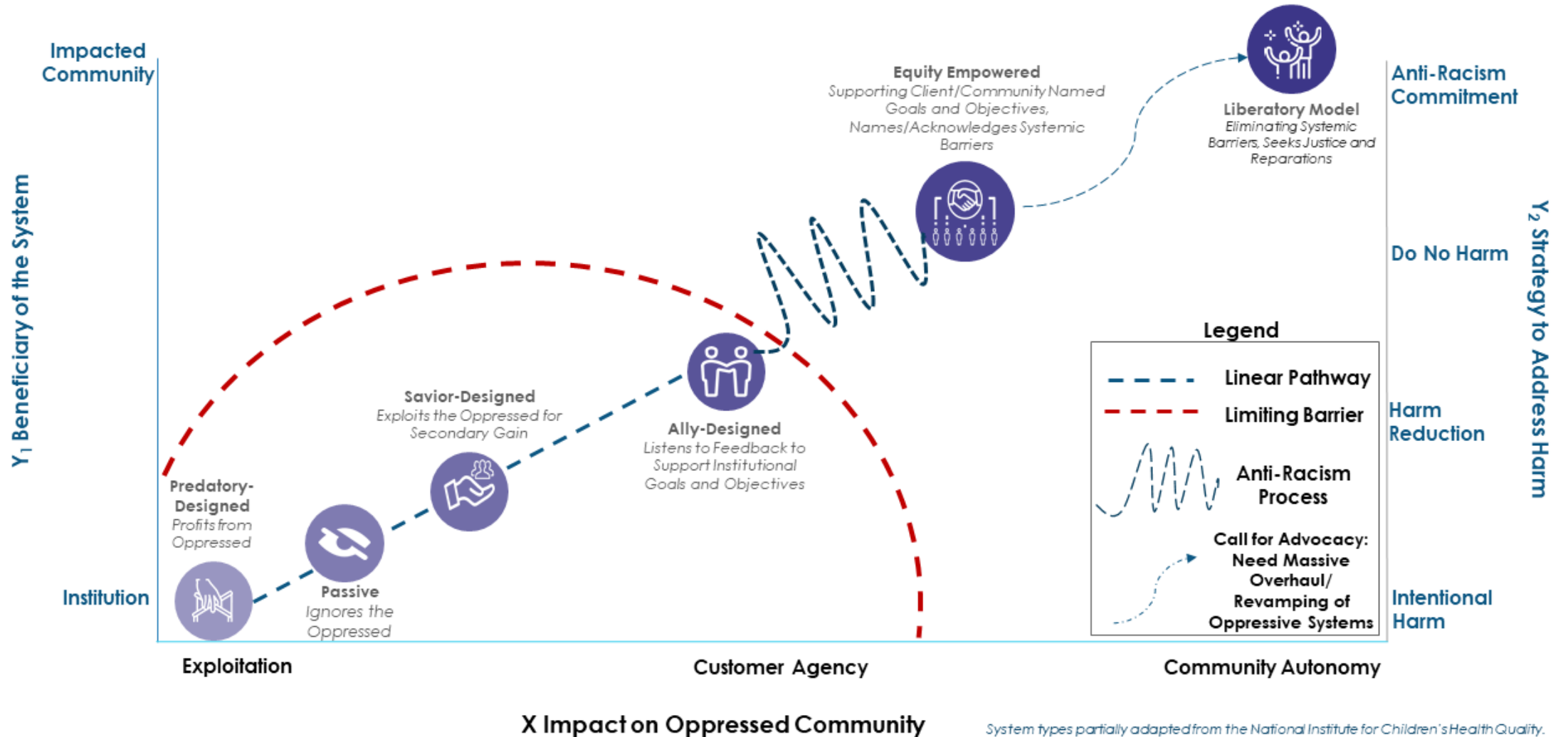
Equity-Empowered

Dismantles systems of oppression

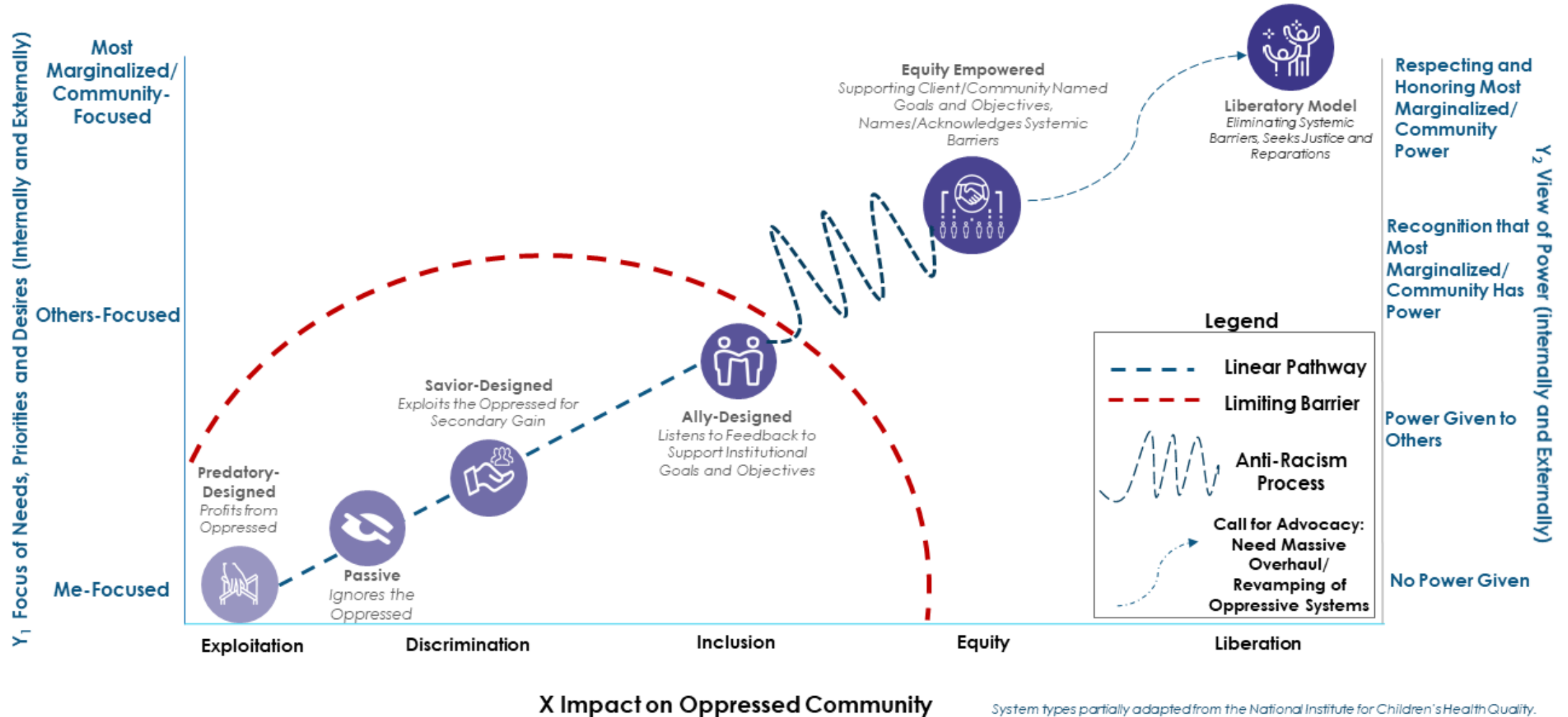


Liberatory Model
Eliminates systemic oppression

Landscape of Data System Design: Institutional Reflection



Landscape of Data System Design: Individual Reflection



Reviewing Landscape and System Design

The Goal is a Liberatory Model

Identifying Your Institutions System Type and Characteristics

Reflecting on Your Individual Role Within the System

Continuous Reflection and Evolution

Data System Drivers

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 leads 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/profitting, 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.

Example: Informed Consent



Predatory

- 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.



Ally-Designed

- 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.



Passive

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.



Equity-Empowered

- 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.



Savior-Designed

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



Liberatory Model

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

Audience: Q&A



Join Us for Part Two!



Data Equity Framework Reflection Worksheet: Applied in Action

December 2nd, 2021