August 2023

Michigan Community Information Exchange (CIE) Task Force Final Report

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Letter from the Director

August 31, 2023

Michigan Community,

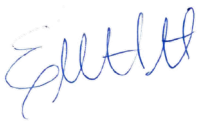
Community Information Exchange (CIE) is an emerging priority for the Michigan Department of Health and Human Services (MDHHS) because of the core role it plays advancing health equity in our state. Across Michigan, organizations use different technology systems to provide health, human, and social services to Michiganders. CIE closes barriers between people and technology by streamlining data sharing between health care providers and social care providers. Efforts to build CIE are happening across the state at the local level, but MDHHS recognizes the need for a development of a statewide strategy to support and align local efforts.

In August 2022, MDHHS established the Community Information Exchange Task Force to develop a statewide strategy to develop infrastructure, policies, and practices for the collection and use of social care data across communities. This report details its findings and a set of recommendations for the development of statewide strategy and roadmap for a CIE infrastructure in Michigan.

The development of a statewide CIE infrastructure will enhance health care and social care organizations ability to address the needs of Michiganders. In effectuating this report's recommendations, the department can make it easier for people to find services and address unmet needs of Michiganders.

This task force brought together representatives of community-based organizations, health care organizations, health payors, health IT, and governmental entities to understand the existing infrastructure of CIE activities in Michigan. I am grateful for their willingness to serve and their collaborative approach to create meaningful and lasting change. I view this strategy as a vital component of the future of addressing social drivers of health in Michigan.

Sincerely,



Elizabeth Hertel
Director
Michigan Department of Health and Human Services

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The Michigan Community Information Exchange (CIE) Task Force Final Report incorporates the expertise and experiences of many leaders. Thank you for your ongoing work to advance the health and well-being of our communities.

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Executive Summary

Community Information Exchange (CIE) capacities enable organizations using different technologies to share information while providing social care to people in need. CIE can also facilitate the aggregation of data about community resources, and communities' needs, to inform policy change that promotes more equitable and effective distribution of resources and programming. The Michigan Social Determinants Health (SDOH) Strategy, entitled "Michigan's Roadmap to Healthy Communities," includes CIE as an essential structural intervention for advancing health equity[1]. In the "Bridge to Better Health" report, the Michigan Health Information Technology Commission (MHITC) also highlights that the statewide development of CIE is a prioritized and actionable structural intervention that can support data standards.[2]

This report details the findings of the CIE Task Force and its recommendations for the development of a statewide CIE strategy. The CIE Task Force brought together representatives of community-based organizations (CBOs), health care organizations, health payers, health IT, and governmental entities to understand the existing infrastructure of CIE activities in Michigan, analyze the needs of various partners, assess the capacities of CIE that are needed in the field, and make recommendations for actions that the state government and other actors can take to support the information ecosystem of health, human and social service providers in Michigan.

The task force has put forth a set of recommendations with strong consensus alongside a high-level roadmap for implementation.

These recommendations include:

- Establish core technical capacities necessary to enable interoperability at a statewide scale – including standards for data exchange and identity management services.
- Establish a reliable supply of resource directory information to be provisioned as a public good.
- Establish a statewide framework for legal agreements that aligns with existing regulatory frameworks while addressing data collection in contexts that are not otherwise regulated; and establish an ethical framework in the form of a "Bill of Rights" for consumers and communities.
- Ensure that aggregation of longitudinal data about people and populations can occur with the informed consent of data subjects.
- Designate and support 'coordinating entities' in the process of facilitating activity among CBOs, government agencies, and healthcare institutions – and ensure that these entities uphold fiduciary responsibilities for the people and organizations that they serve.
- Establish federated systems of governance through which standards and policies are set statewide, while priorities and implementations can be decided and evaluated locally.
- Leverage a variety of financing mechanisms to build and sustain these capacities, including the capacity to provide more social services.

While there is broad consensus across healthcare, payors, government, and communities on the need for better data and information sharing to adequately address social drivers of health, in the absence of federal guidance and dedicated funding for states to promote CIE it is critical that Michiganders coalesce around core values and principles to promote equitable, effective, and interoperable social care data exchange. This report establishes a roadmap for Michigan to develop state-wide CIE infrastructure driven by the goal of health equity.

[1] Michigan's Roadmap to Healthy Communities: Phase Two [2] Michigan Health IT Roadmap Bridge to Better Health Report

Findings

The following table summarizes the thirty-three final recommendations developed by the task force. Recommendations are organized into seven domains. Analysis of domains and additional recommendation detail are described in the section addressing Objective 4 of this report.

Recommendations

Capacities for Data Exchange

- Adopt standards for data exchange to enable interoperability among many technology systems to ensure basic infrastructural capacities can be used by any compliant software system.
- Establish affordable and ethical statewide identity management services to enable information about people to be effectively shared across different systems.
- Establish shared terminology and translation capacities to ensure that different vocabularies used in different contexts can be effectively aligned.
- Establish a process of addressing these technical interoperability concerns over time.

Resource Directory Information Capacities

- Ensure that a reliable supply of resource directory information will be sustainably provisioned as a key component of CIE infrastructure.
- The CIE's resource directory information should be provided by a federated network of stewards, each of which have clearly defined areas of responsibility that accord with their respective expertise.
- Resource directory information must be provisioned as a public good.
- Service providers can be encouraged to ensure their own information remains up-to-date, through policy levers that incentivize such responsibilities.

Longitudinal Data Aggregation Capacities

- Enable collection of longitudinal data about clients' social needs, risks, service-related activities and results – contingent upon their informed consent.
- General standards for data collection, retention, and use should be set statewide; specific decisions over implementation and policies for usage should be made at the most locally appropriate level (in harmony with the statewide framework).
- Enable the longitudinal aggregation of anonymized data for sanctioned uses, subject to individuals' choice to opt-out of such aggregation when legally and technically possible.
- Leverage already-existing assets for data infrastructure when possible, and establish appropriate systems of governance for operation of any such infrastructure in contexts which aren't already regulated by HIPAA.

Legal and Ethical Framework

- MDHHS should establish a baseline policy framework and common structure for legal agreements for collection, exchange, and use of data in contexts not already governed by HIPAA, FERPA, or 42 CFR p2.
- The CIE task force will recommend a "Bill of Rights" for consumers and communities to be reviewed and formalized by a designated governing body.
- In all contexts not subject to existing regulatory frameworks, entities conducting CIE activities should ensure that data collection and use is subject to consumers' informed consent.
- Local communities and Tribal Nations should be able to build upon the baseline statewide legal framework with additional policies that address their specific needs and concerns.
- MDHHS should support and fund, where possible, processes for partnership development, workflow change management, auditing, and compliance with all of the above.

Coordinating Entities Capacities

- Activities associated with community information exchange can be conducted by 'coordinating entities' that assume fiduciary responsibilities for their partners in the community and for the consumers they serve.
- MDHHS can set standards and establish sustainable funding streams to support coordinating entities.
- Coordinating entities should both reflect the priorities of their communities, and be designed to facilitate collaboration across networks.
- Coordinating entities can formally represent their partners' and consumers' interests through equitable decision-making processes.
- Coordinating entities can be established within specific service domains, as appropriate on a local or statewide basis, to facilitate engagement of providers across their sectors

Governance

- CIE activities should be conducted by accountably governed bodies that are responsible for acting in the best interests of the people they serve.
- CIE governance should formally represent the interests of affected parties, especially those of consumers and service providers, in transparent and inclusive decision-making processes.
- CIE governance processes should clearly establish what use cases are permitted under which conditions, and should establish processes for monitoring, compliance, and conflict resolution to ensure equitable outcomes.
- Local CIE activities should operate as part of a federated network, with local representatives participating in the governance of a statewide entity that establishes baseline policy, standards, core infrastructure and conflict resolution processes

Sustainability

- MDHHS should expand the availability of funding for social services through Medicaid, by leveraging policies such as an 1115 waiver to examine the true cost of care for health related social needs social care interventions, taking advantage of the support recently signaled by CMS for "In-lieu of Services," and Community Health Worker reimbursement mechanisms that can include CBOs as Medicaid providers.
- MDHHS and commercial payers should create mechanisms to fund CBOs by leveraging existing use case participation incentive programs, like Physician Group Incentive Program (PGIP), Patient Centered Medical Home (PCMH), Pay for Performance (P4P), etc., to support tools, workflows, technical assistance, staff and other costs related to CIE.
- MDHHS should leverage Advance Planning Documents (APDs) where possible to offset the costs of information technology implementation and enhancements with federal matching funds. Medicaid Advance Planning Documents outline experimental, pilot, or demonstration projects related to health IT which are submitted by MDHHS to CMS to secure up to 90% federal match.
- recognizing the importance of social care as an essential component of holistic health and well-being, health systems, health plans, and hospitals should have established mechanisms for investing in social service delivery.
- The State should promote an equitable method of revenue-sharing among technology vendors who provide services in the CIE market, by which vendors collectively re-invest a percentage of revenue into core infrastructural services that support CBO activity in CIE processes, such as infrastructure maintenance and/or consumer engagement in
  governance processes.
- In the short-term, philanthropic funding can support the startup costs of CIE for CBOs, while in the long-term philanthropies can help sustain CIE by making 'program-related

investments' in CIE services that support their grantees' programs and inform their grantmaking processes.

- The State and key partners should advocate at the federal level for systematic investment in CIE, similar to the Meaningful Use Incentive program governed by the Office of the National Coordinator which incentivized providers to implement electronic health records and use them meaningfully. The criteria and stages of the Meaningful EHR Incentive program were essential to promoting interoperability and data sharing among health care providers. This guidance and support from the federal level is necessary to effectuate all of the recommendations.

The Community Information Exchange (CIE) Task Force

The Michigan Community Information Exchange Task Force is authorized by the Michigan Health Information Technology Commission's (MHITC) 2022 annual report, as per the Michigan Health IT Roadmap (Bridge to Better Health, February 2022), referred to as the MHITC Roadmap.\

Purpose

MDHHS has resolved to create and sustain statewide infrastructure to support the collection, exchange, and responsible use of information that can help address the social needs of Michigan's people and communities.

The CIE Task Force brings together CBOs, health care organizations, health payers, health IT, and governmental entities whose aligned work and interests are best served by a coordinated approach to Community Information Exchange. The task force is an advisory body that will make recommendations to both MHITC and the Michigan Department of Health and Human Services (MDHHS) on the development of capabilities for community information exchange.

Goal of the CIE Task Force

To promote health and social equity, and improve the well-being of all Michigan residents, CIE infrastructure can enhance capabilities for providers of health, human, and social services to coordinate care across sectors and technologies, by enabling information (such as information about people's needs, and the resources available to help them) to flow to the right people effectively and responsibly at the right time in the right context.

CIE Task Force Objectives

In service of the stated purpose, the CIE Task Force was tasked with:

1. Examining promising state, national, and global strategies, standards, metrics, and best practices that could accelerate, support, and improve CIE in Michigan.

2. Examining relevant perspectives from all interested parties and partners, with a focus on the priorities of communities that experience health inequities, the perspectives of CBOs that serve them, and the needs of people who have experienced the challenges of navigating these services.
3. Creating a knowledge resource in service of MHITC Roadmap (Bridge to Better Health) and MDHHS SDOH Strategy (Michigan's Roadmap to Healthy Communities).
4. Advising the state on the development of a CIE strategy, including recommendations as to prioritized capabilities, the appropriate balance between statewide and regional/local capacities and roles, prospective principles, and processes for governance, incentives and adoption support for CBOs, guidance for legal agreements, and a roadmap for implementation, among other critical considerations.
5. Articulating scenarios for pilot implementations of key use cases that enable cooperation among prioritized groups.

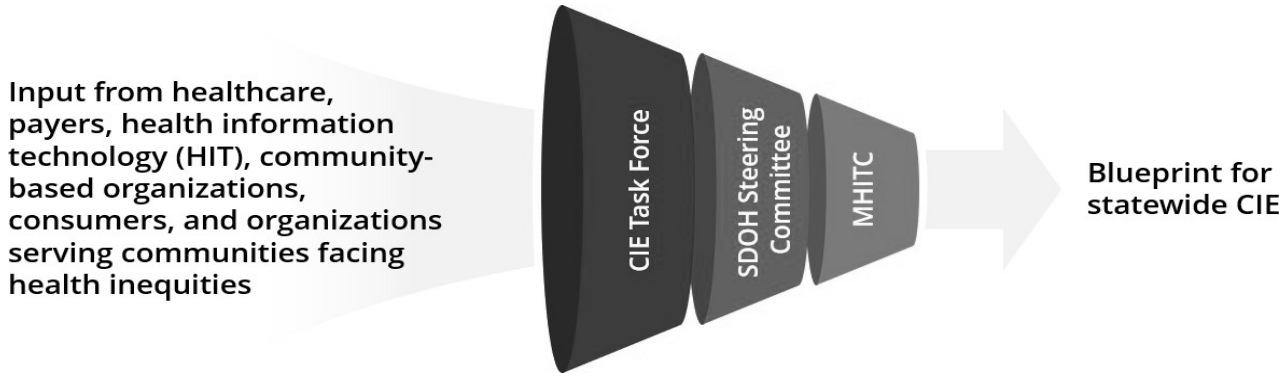

Figure 1. Input guiding the development of the statewide roadmap for CIE, with the CIE Task Force providing recommendations to the SDOH Steering Committee and the Michigan Health Information Technology Commission

Foundational Statements

Problem Statement
A wide variety of organizations provide health, human, and social services to Michigan residents, using a diverse array of data systems. These systems often do not share information easily, resulting in redundant processes for service users, duplicated efforts for service providers, barriers to critical resources, and gaps in service delivery – inhibiting our collective capacities to share information, coordinate care, and effectively meet people's needs to advance health equity.

Intended Result
By developing and promoting CIE infrastructure —including both technological and human capacities — the task force will enhance the potential for organizations in different sectors, using different technologies, to coordinate care for their patients and clients. The task force expects such CIE infrastructure will make it easier for people to find and access services by removing obstacles to care, building capacities for service providers to provide holistic care, and informing efforts to address unmet needs – to ultimately improve health and social outcomes for Michigan resid

Terms

What does the task force mean by Community Information Exchange?

In its first several meetings, the task force clarified what a CIE is not. For instance, a CIE is not a "closed-loop referral system," a phrase that typically refers to a software system; rather, a CIE is infrastructure that enables interoperability among different software systems. The Task Force has recognized two separate but non-conflicting definitions of a CIE and utilized these definitions to inform its deliberations.

2-1-1 San Diego CIE toolkit:
"A CIE is a **community-led ecosystem of multidisciplinary network partners** that use a **shared language**, **resource database**, and **integrated technology platforms** to deliver enhanced **community care planning**. 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."[3]

"Tackling Data Dilemmas in Social Care Coordination," (Bloom & Sorenson 2021):
"A [CIE] should encompass three elements of **primary infrastructure** that comprise a holistic ecosystem of health and social care: **Resource Data Exchange**, **Client Data Exchange,** and **Community Data Governance**. A CIE should facilitate the reliable flow of information about resources available to people in need to support service discovery and accessibility. A CIE should facilitate the responsible flow of information about clients as shared among various service providers to support cross-sector coordination of care. A CIE should ensure that the systems and activities associated with coordination of social care are equitably developed and implemented according to the expressed interests of stakeholders in a local community."[4]

[3] https://ciesandiego.org/what-is-cie/

[4] https://stldata.org/wp-content/uploads/2021/10/Social-Care-Data-Whitepaper-October-2021.pdf

Methodology

The CIE Task Force met monthly over the course of a nine-month period, during which members learned about existing initiatives in Michigan and across the country, prioritized topics for discussion, articulated values and principles to guide these discussions, and then engaged in facilitated small-group deliberations, breakout subgroups, and one-on-one dialogues. After each meeting, the executive committee—consisting of the task force co-chairs, MDHHS and MPHI support staff, and the group facilitator—summarized outputs from these discussions and shared back with the task force for members' review and suggested revisions. Task force members were encouraged to gather input from their respective communities on key topics between meetings.

In its dialogues and synthesis, the task force was asked to seek out and prioritize the perspectives of social service providers and historically disadvantaged communities. Notes were maintained in a running document on our group's SharePoint, and aggregated in a Miro work board where participants generated notes, identified patterns, and commented on each other's ideas in real-time. Task force members have access to previous iterations of the work board that are viewable through Miro, and all content is aggregated in SharePoint by the task force members.[5]

For each of the task force's final four meetings, the executive committee proposed recommendations that were intended to reflect the outputs from previous deliberations. Task force members were polled for their levels of agreement on these recommendations, and then discussed the results of these polls; recommendations were subsequently revised to address matters of concern articulated by task force members who were not supportive, and then re-polled. In total, the executive committee conducted four polls and arrived at a total of thirty-three final recommendations.

Each recommendation in this report received support from at least a majority of task force members—in most cases, a large majority—and no recommendation met strong objection from any members.

Objective 1: Conduct a Landscape Analysis

Examine promising state, national, and global strategies, standards, metrics, and best practices that could accelerate, support, and improve CIE in Michigan.
To address Objective 1, the CIE Task Force gathered insights by inviting experts from Michigan and across the country to share their subject matter expertise in CIE. The task force also reviewed several summary reports (included in Appendix G) and engaged State experts in CIE to understand the current state of CIE in Michigan.

Current State of the Michigan Landscape

This is a brief overview of initiatives that the CIE Task Force uncovered through a landscape analysis of existing social care initiatives in Michigan.

- **Michigan 2-1-1.** MI 2-1-1 provides connections to services, such as employment support, family support, housing, food, health, public benefits, and more. The MDHHS MI 2-1-1 state office coordinates a network of seven regional contact centers that help people in need of assistance access services. Notably, Michigan 2-1-1 utilizes an application program interfaces (API) to house

its resource directory (with over 30,000 resource referrals) to allow third-party partners access to its database of resources, including MiBridges and the Michigan Hope Portal (www.MiHopePortal.com).

- **MI Bridges.** MI Bridges utilizes the MI 2-1-1 API to provide resource navigation to local and state resources, as well as benefit programs. MI Bridges is an online platform where residents can explore potential eligibility for services, apply for Food Assistance, Medicaid, Child Care Subsidy benefits, apply for state emergency relief, view their case information, or report changes to their MDHHS Specialist.
- **No Kids Hungry Project.** In 2022, MI Bridges launched the closed-loop referral pilot program - the No Kids Hungry Project - with the Food Bank Council of Michigan and several food banks across the state to improve community partners ability to support Michiganders facing food insecurity. Through the No Kids Hungry Project, MI Bridges Navigators and referral partners, as well as the client, can initiate requests for services that lower the incidence of food insecurity.
- **Connect4Care:** Connect4Care is a southeastern Michigan CIE, supported by United Way for Southeastern Michigan (UWSEM). In August 2021, UWSEM and the MI 2-1-1 regional contact center initiated a CIE with Henry Ford Health (HFH), Gleaners Community Food Bank for Southeastern Michigan, and the Health Alliance Plan (HAP). Through this CIE, HFH and Gleaners act as initial spokes, connecting through APIs to bidirectionally process and serve patients who have been identified through screenings at HFH facilities as food insecure. HFH and UWSEM are also utilizing data to better connect people with basic needs assistance and other support, improve health and social outcomes, and lower costs for health systems. Since this initial use case, the CIE's capabilities have expanded to provide automated connectivity for real-time appointments for tax preparation services, transportation assistance through a ride management broker service to Uber and Lyft, and childcare eligibility tests and subsidy application processing and submission to childcare providers across Wayne County.

- **Michigan Community Network.** In 2021, Healthify, a private entity working with managed care organizations to address SDoH, initiated a CIE with Blue Cross Blue Shield of Michigan to coordinate nonclinical care for members. Healthify works on a closed-loop referral model to increase interoperability among formalized partners to the project.

- **Genesee County Community Health Innovation Region (CHIR).** In 2019, the Genesee County CHIR began working with providers to promote an SDoH screening tool. The Genesee County CHIR then began housing results in a central SDoH Repository to aggregate and analyze screening results to identify population-level SDoH needs. In addition, the CHIR implemented a Community Referral Platform (CRP) that provides closed-loop referrals between participating providers the CHIR Hub organization - the Greater Flint Health Coalition - and community/social service agencies.

- **Riverstar Community Care Hub - Jackson County CHIR.** In Jackson County, the Jackson County CHIR began working with the IT solutions company Riverstar to launch a virtual hub that hosts a SDoH screening tool. The application rolled out in Jackson County utilizes the MI 2-1-1 API to provide resource navigation to individuals in Jackson County. As of January 2020, the Care Hub has provided more than 80,000 SDoH screenings and provided more than 11,000 referrals.

- **Northern Michigan Community Health Innovation Region (NMCHIR).** The NMCHIR serves 10 counties in the northwest Lower Peninsula of Michigan. The NMCHIR developed and implemented a web-based, tablet-based screening and referral platform that screens patients

for SDoH, refers patients for service navigation, and coordinates care between community services and clinical providers.

- **Livingston-Washtenaw Community Health Innovation Region - MI Community Care.** In 2015, the Livingston-Washtenaw CHIR launched a free community-wide care coordination program in Livingston and Washtenaw counties. The program offers integration with regional medical providers, including Michigan Medicine and Trinity Health, as well as shared consent forms and protected messaging through an IT platform.

Physician Group Incentive Program (PGIP) Blue Cross Blue Shield of MI

Blue Cross Blue Shield of Michigan (BCBSM) is focusing efforts on the Provider Group Incentive Program, also known as PGIP to create the path for physicians and payers alike to better understand how social drivers of health impact health care outcomes.

In early 2022, BCBSM partnered with MiHIN to gather domain focused aggregated SDoH data from physicians' offices across the state. This partnership allows for providers to receive funding from the payer as they begin to transform health care screening practices in their offices. The current incentive offers infrastructure development funding to participating PGIP practice units. By late 2022, SDoH data informed the need for community health workers. Community Health Workers (CHW) are considered boots on the ground workers when it comes to taking care of the patients. BCBSM launched an initiative to cover the cost of training for CHWs for participating PGIP organizations.

The current initiative offers funding to cover the cost of training to PGIP participating practice units. BCBSM is currently analyzing data and developing a strategy to further address health care disparities that impact members and the community.

Payor Involvement

Several payors in Michigan currently incentivize the collection of SDoH data from health care providers in a multitude of ways. The Michigan Payor Group has summarized the incentives in a table and made that available to providers on their website, and also made the information available to the 42 Physician Organizations/Physician Hospital Organizations (POs) who act as fiduciaries of the funds to their physician provider members.[6] The incentives are available to hospitals, physicians, and in some cases advance practice providers. The Centers for Medicare and Medicaid Services have begun to incorporate social care screening requirements and reporting into their Conditions of Participation for inpatient facilities with 2024 being the first year it is required.

These incentives encourage providers to utilize screening tools to assess social care needs, partner with CBOs, make referrals to those organizations, and track and report on the referrals. Some of these incentives are paid directly to the providers, while others are distributed through the POs for them to enhance and support infrastructure provided to their members. Managed Care Organizations themselves, in some instances, are currently required to collect and report SDoH data, such as social care screenings and number of patients screened.

Michigan Health Information Network (MiHIN) Legal and Data Framework MiHIN was established by the State of Michigan Health Information Technology Commission in 2006 to serve the state's health information exchange needs. While it serves as the statewide Health Information Exchange (HIE), there are regional HIEs that operate in respective geographical areas and send data to MiHIN. Providers and organizations can participate in the HIE by signing on to specific use cases, like Admission, Discharge

and Transfer (ADT) notifications. Organizations must first agree to a Master Use Case Agreement, then the Active Care Relationship (ACRs) use cases to establish patient/provider relationships and exchange data. Patient data is captured by the health care provider within the electronic health record and shared with other providers or organizations who are responsible for the care, treatment, or payment of those healthcare services as defined by HIPAA.

MiHIN was initially funded in part by federal funding from the Electronic Health Record (EHR) incentive program. That program had three stages. Stage One paid incentives to hospitals and eligible providers for adopting a certified electronic health record. Stage Two continued incentives to hospitals and providers for adopting a certified EHR and expanded the incentives for hospitals and providers that promoted "meaningful use" use of EHRs. The EHR Incentive Program established objectives for providers to demonstrate "meaningful use" that specified the functionality of the EHR necessary to access incentives. Stage Three transitioned the EHR Incentive Program to the Promoting Interoperability (PI) Program that introduced requirements for participation including objectives for coordination of care through patient engagement, HIE, and public health reporting. The standards formed are the guardrails for EHR adoption as well as the requirements that hospitals and providers must meet to receive incentives and avoid CMS penalties.

[6] Michigan Multipayer Initiatives (mimultipayerinitiatives.org)

Lessons Learned from the National Field

Community Information Exchange is still a new concept with few examples to reference in the field. To gather insights from experiences elsewhere, the task force spoke with Alana Kalinowski, a representative from CIE San Diego. CIE San Diego is the first instance of a CIE, holders of the trademark for the term, and conveners of the National CIE Community Network. The task force also reviewed multiple reports from a range of implementations of "closed loop referral platforms," and several summary reports that compile findings from the field of "community informatics. A few of examples are listed below in greater detail. The task force compiled references below in a set of common themes; citations and links are available in a bibliography in Appendix G.

- Few precedents for success so far; signs of underperformance. This is a long-term challenge with few apparent models for sustainability.
  2-1-1 San Diego's CIE has shown some initial signs of success in facilitating community care planning that reduces hospital readmissions, as well as efforts to build capacities for data-driven advocacy. This is the one apparent precedent for successful CIE that the task force has found. Their infrastructure, however, took more than 10 years and more than $10 million to develop.

  Meanwhile, implementations of "closed loop referral systems" – one of the primary points of reference for many in the task force, and a major topic in the processes that preceded its formation – have generally reported disappointing results. A report from the "Highlighting and Assessing Referral Platform Participation" (HARP), produced through a partnership with the Trenton Health Team and Social Interventions Research and Evaluation Network, found that "Trenton CBOs value the up-to-date searchable community directory, but the value of electronic referrals is less obvious," and that "financial incentives to use community referral technology do not seem to motivate CBOs."[7]
- Technology is not a solution in and of itself. Effective CIE implementation needs to build trust and capacity, which requires investments in governance process change management and organizational and human resources.

The report observes that "pre-existing referral systems and processes" conflict with attempts to start from scratch with a new software system. A report from HealthierHere in King County, Washington also found that a new closed-loop referral software system actually created "additional work to document referrals across multiple platforms."[8]

The HealthierHere report echoes findings from Data.Org's "ReCODE" assessment of the field of "community data ecosystems" which unexpectedly rejected common assumptions about the needs of communities for more technology to collect more data. The ReCODE report – which compiled interviews from more than 500 community leaders in surveys, interviews, and a Learning Council – sums up its findings with this statement: "We were wrong."

"More data doesn't mean better outcomes," the ReCODE report states.[9] "Throughout interviews and workshops, we heard over and over again that this work requires trust, transparency, empathy, and humility. When those with power don't share it, nothing changes. Until data systems are overseen and owned by community, the systems who have power over these data ecosystems must begin to share and cede power back to that community."

- Closed-loop referrals are not the only use case for CIE (and not always appropriate). Other use cases involve anonymous referral, care planning and coordination, and benefits assistance.

  The HealthierHere report is very explicit on this front: "Using technology to send electronic referrals is not appropriate in all care coordination situations." They point to the wide range of instances in which social services are delivered anonymously – or, at least, without data collection – in ways that reflect important social and cultural contexts that ought to be preserved. Other situations like crisis response might actually be burdened by complex referral processes that obstruct other more direct and relational methods of coordinating care among providers.

  CIE San Diego also cited a range of examples in which community information exchange supports coordination of care among providers without a "closed loop referral" ever being made – such as assistance in applying for benefits and care planning among providers.

  One of our task force members summed up this theme in the following way: "a closed-loop referral is a two-dimensional idea in a three-dimensional world."
- Interoperability as a core principle can reduce burden, decrease costs of change, and enable many efforts to be complementary not siloed.

  HealthierHere, notably, has shifted away from its initial strategy of a referral software platform, and instead is developing interoperability capacities to enable exchange of information among systems. Interoperability as a core principle can address the challenges faced by the Trenton Health Team (as reported on by the HARP project mentioned up above in lesson #1) and other initiatives that found that simply implementing a new software system actually creates additional work and even erects new barriers to care. Instead of a new "centralized system" that inherently must compete with already-existing systems, community information exchange capacities ought to be designed to enable existing systems to work together.

  In a paper commissioned by the Robert Wood Johnson Foundation's Data Across Sectors for Health program, Bloom and Sorenson outline a set of interoperability objectives that face CIE initiatives – such as enabling resource directory information to be shared among multiple systems; enabling identities to be matched across multiple systems; enabling personal data to be securely exchanged among systems; and managing permissions across systems.[10]

  This paper observes that the same architectural design decisions that determine the structure of HIEs also are relevant for CIE: such infrastructure can be "centralized" (in that data from multiple systems is aggregated in a shared database) or "decentralized" (in which data is exchanged among multiple systems but not centrally

aggregated) or “federated” (a hybrid approach in which data is exchanged among decentralized systems and some data is centrally aggregated). The paper further outlines a range of governance questions that face communities considering these options.

- **Incentives are not naturally aligned, and power is imbalanced**. CBOs are typically not opting into resource referral systems, in part because of an absence of apparent benefits, a range of apparent risks, and a lack of trust. Virtually all of the reports reviewed observe that there are significant prospective costs, and known risks, posed to CBOs by participation in data-sharing initiatives – whereas the prospective benefits are hypothetical, long-term, or otherwise uncertain. There is a clear need to engage in trust-building efforts that ensure CBOs and the people they serve develop capacity to participate, agency to make decisions, accountability for outcomes, and trustworthy institutional contexts.

- [7] https://trentonhealthteam.org/reports/harp-research-findings/
- [8] https://healthierhere-org.webflow.io/our-work#connecting
- [9] https://data.org/reports/recode-report/

[10] Social-Care-Data-Whitepaper-October-2021.pdf (stldata.org)

Objective 2: Examine Input from Impacted Parties

Examine relevant perspectives from all interested parties and partners, with a focus on the priorities of communities that experience health inequities, the perspectives of CBOs that serve them, and the needs of people who have experienced the challenges of navigating these services.

To address Objective 2, the CIE Task Force identified three primary types of impacted parties[11] whose interests should be centered in the design of CIE capacities: 1) individuals and families in need; 2) community-based organizations; 3) and communities. The task force also identified a range of secondary types of impacted parties- government agencies, healthcare payers and providers, and research institutions.

For each of these impacted parties, the task force analyzed needs, prospective benefits, and potential harms associated with this work. The task force continuously engaged perspectives from individuals representing these groups to guide recommendations, including prioritization of CIE capacities. The task force conducted an additional round of qualitative interviews with task force members, specifically oriented towards task force members' commitment to the implementation of the recommendations. The task force also disseminated a survey to Michigan's federally recognized tribes to capture the distinct CIE needs of Michigan's tribal nations. Finally, the task force worked with the Promotion of Health Equity Project learning network and the Michigan Health Information Network Community of Practice (CoP) to gather insights on the final recommendations and on protections for consumers essential to effective CIE.

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[11] Previously, Objective 2 was entitled "Stakeholder Analysis." The task force would like to acknowledge a movement away from the term "stakeholder" in this report in accordance with guidance from the Centers for Disease Control. The CDC notes the term "stakeholder" can come to be indicative of a power differential between groups, specifically with tribal partners. The task force resolves to utilize language that is discrete and specific to the group in reference. https://www.cdc.gov/healthcommunication/Preferred_Terms.html

The following is a summary of the analysis for each type of impacted party:

People (Individuals and Families)

The task force is guided by the goal of improving data sharing between health care and social services providers to address the needs of people and families. CIE that successfully serves people and individuals must facilitate better information about what services are available and, more importantly, how to access those resources in a direct way. In addition, people want to know what information is being collected about their health and social needs, what entities have access to it, and how their information is being utilized, including how it is being changed or removed.

Successful CIE capabilities would support many technologies that accommodate individuals with differing abilities, diverse languages, and a variety of social needs. Individuals and families should be able to access health and social records, change and/or update health record information, and, if desired, opt-out of data collection and/or exchange. In turn, people will have a system they can trust and is responsive to their needs and concerns.

Establishing trustworthy systems is critical because people fear a lack of transparency of data practices, and the potential for improper disclosure of sensitive information can ultimately put people at risk. Apprehension about surveillance might disincentivize people from seeking help. Multiple requests for more or redundant information from different service providers reinforces distrust and is cumbersome to individuals.

Community-Based Organizations

CBOs need to know what services are available in their local community and how to access those services in order to share that information with their clients. CBOs vary in degrees of reach, scope, and capacity. The primary focus of local CBOs is to meet people where they are and meet their needs. Some work in partnership with other local CBOs to do this work. In addition, CBOs want access to aggregated, population- level data to demonstrate their program's effectiveness and justify needs for additional funding.

A critical capacity for CIE is appropriate levels of funding to train and support CBO staff in processes of collecting, assessing, sending, and using information in new ways that are relevant to their organizational mission. Social service providers want to be able to seamlessly coordinate care for individuals without burdensome worry that the individual will be lost in the system or unable to access the service they are directed to. CBOs also want to be able to convey actionable information about the benefits of individuals' participation.

Organizations are concerned that a lack of sustainable funding to meaningfully collect data, and establish the technical capacities to share client data, will result in more costs and burdened, overworked, and underpaid staff. There is concern that CBOs might lose the agency to choose what technologies, tools, and workflows will work for their organization and the community they serve. There are also concerns about conceptual mismatches between social care organizations, healthcare institutions, and their clients; for instance, the question of when a need has been effectively "met" may be answered very differently by a healthcare provider, social care provider, and a client. Without ways

to account for differences in meanings across contexts, system integration and automation could yield unintended inequitable outcomes.

Diverse Communities (Population-Level Analysis)

CIE must also support healthy and diverse communities. Communities and their leaders need access to information about the resources available, to whom they are available, and resource capacities and restrictions. More importantly, communities need access to information about the gaps in resources specific to their communities to understand where there are unmet community needs.
Successful CIE would provide timely and relevant information to support community-level and culturally competent interventions that improve health outcomes and socio-economic well-being and reduce inequities while respecting the values and safety of the community.

Mistrust in communities might yield unequal or nonexistent buy-in, siloing resources and perpetuating inequities in care and disparities in outcomes. To build trust, CIE must be flexible in supporting the varied needs of diverse communities. Without such commitment to meeting diverse communities where they are, and addressing their unique needs, CIE initiatives might result in uneven participation that perpetuates inequities.

One example of a risk that community leaders are concerned about is the unaccountable use of algorithms in predictive analytics; for example for processes like risk adjustment. Without accountable data systems that are monitored for bias and undesirable outcomes, flawed data could result in inequitable access to resources and funding.

Health Payers and Providers

Health payers - such as health plans, Medicare, and Medicaid - and providers utilize patient data to coordinate with service agencies and target social drivers of health. Health payers and providers want to know what services are offered by CBOs in their local community. At an individual level, they want real-time understanding of a patient's existing referrals and treatment plans, and a patient's ongoing needs (i.e., from patient records or screening results), risks, and treatment priorities.

Through effective CIE, health payers and providers could reduce the amount of duplication in the administration of assessments at the client-level and duplication of referrals. Health payers could access aggregated data about the effectiveness of supporting social drivers of health and utilize that data to reimburse social care providers. Finally, health payers and providers could support individuals in accessing coordinated, holistic care.

Without effective CIE strategies, health payers and providers can only access incomplete data on individuals, which limits effective care management. At a systems level, lack of systemwide buy-in and participation could lead to health payers and providers being forced to maintain old processes while implementing siloed efforts to incorporate social care. The absence of coordination on the community side leads to inconsistency in the identification and services to address social needs across providers,

payers, and health systems, which can increase costs and undermine patients' well-being.

Government Agencies

Government agencies can support local CIE to become more efficient and equitable through funding support, resource allocation, and strategic guidance. To allocate resources, government agencies need information about the availability of services, gaps in services, redundancy of services, as well as demand for services and unmet needs. More importantly, government agencies need to understand the successes and failures of its resource allocations.

CIE should support government agencies in defining "Who is accessing services? Who is not? Why not? How much does it cost to provide specific services - e.g., housing vouchers in this community?" In turn, government agencies should be able to identify systemic issues and support frontline CBOs in closing gaps and addressing unmet needs. The role of government agencies is to utilize CIE data to influence policy, funding, and programming, including at the state and federal level.

Government agencies also play a key role in alleviating population and organizational concerns about privacy of data. Government should provide clear and ongoing guidance on data-sharing. More importantly, government agencies have an opportunity to effectuate clear guidance by providing information technology (IT) solutions for CBOs to ensure affordability and promote interoperability. That includes ensuring that terminologies are standardized across sectors, such as for definition of "needs met."

Finally, government agencies play a role in equipping CBOs with the tools to do this work. In addition to funding and data guidance, government agencies should support with standardized trainings for staff, capacity building, guidance on using and sharing data for organizations, and access to guidance on IT solutions. Ultimately, wherever a person is entering a system, information should be available to meet their needs, and government agencies play a key role in cutting through silos to promote access to needed data.

Government agencies face limitations in supporting CIE work. They must maintain compliance with complex federal rules and regulations (e.g., 42 CFR pt. 2, HIPAA). The scope of CIE work happening across the system creates complexity that dissuades meaningful state participation. In addition, government agencies must maintain the role of neutrality and empower community-level leadership; that is most difficult with reluctant on-the-ground partners. Requirements to demonstrate positive health and financial outcomes from CIE projects detracts from addressing system-level CIE concerns leading to unsustainable or time-limited funding. Lastly, there continues to be a lack of sustainable funding models to support CIE.

Feedback from Task Force Members: Qualitative Interview Key Findings

To address Objective 2, the CIE Task Force conduced two rounds of 30-minute qualitative interviews with members of the task force to understand their experience participating on the task force as well as to gather perspectives on the level of engagement of task force members moving forward.

Round 1: Qualitative Interviews Findings

In January and February of 2023, MDHHS conducted 30-minute qualitative interviews with members of the task force to understand their experience participating on the task force, assess perceptions on the application of equity, the effectiveness of organizational tools and facilitation methods, progress on task force objectives, and the overall vision for the work.

Key Findings:

- **Expand efforts to engage diverse impacted parties.** Task force members acknowledged positively the diversity of representation on the task force, one member noted representation from "frontline staff to Vice Presidents from big organizations," yet task force members did identify additional parties that could be engaged in the conversation around CIE, notably:
    - CBOs in rural areas of the state
    - Local on-the-ground organizations doing client-level work, particularly CBOs serving populations that experience health disparities (for example, organizations representing immigrant populations, communities of color, and/or indigenous populations)
    - Direct consumers of services
- **Improve processes of the task force.** Task force members identified structural and technology process improvements for the task force to better streamline feedback and increase active engagement across membership.
- **Structure:** The CIE Task Force convenes in 2.5-hour meeting sessions led by the Executive Committee, which consists of the two co-chairs, MDHHS staff, MPHI administrative support, and the facilitator. Task force members recognized the limitations of longer meetings to foster continued engagement and suggested opportunities to create more individual small groups to consult on specific task force objectives.
    - Additionally, task force members noted opportunities to increase engagement outside of meeting times, through tools like direct surveying or shorter targeted meetings between the full convenings of the task force.
- **Technology:** Beginning in 2022, the task force began working in the visual collaboration platform, Miro. Task force members noted positively that it creates a real-time virtual space for all members to participate (through tools like live sticky notes, etc.) which is a particular challenge during virtual meetings. Task force members also felt the Miro board provides a high-level visual of the work done.

    - Task force members also noted the SharePoint site pairs well with the Miro board as a secondary resource for materials. Task force members did identify the need for technical support when implementing a technical tool, like the Miro board, such as

tutorial videos or Frequently Asked Question guides, before implementation.

- **Build consensus on operationalizable recommendations as to actions that the state can take to support local activities.** Task force members were solicited to provide feedback on the most important work of the task force to accomplish. Consistently, task force members noted the need to finalize recommendations that will support the state of Michigan in its work to develop a state CIE strategy that supports the range of existing and emerging activities on a local and regional basis.
    - Task force members noted the opportunity provided by the diversity of impacted parties convened through the task force and recognized that this group must provide guidance on the most critical considerations of a state CIE strategy. Task force members noted key areas that the recommendations should offer critical guidance on:
        - The legal challenges around privacy and consent (i.e., clarity on 42 CFR and DHHS-1555 Authorization to Release Confidential Information, etc.).
        - The appropriate balance between statewide and local/regional capacities and roles, especially in processes relating to governance.
        - The need to support CBOs role as the infrastructure of people who provide connections to services on-the-ground.
          The role of the state designated HIE in supporting CBOs, and the ability of these organizations to maintain autonomy from a health data exchange infrastructure.
          The challenges facing the Michigan workforce that impact CIE work.

Round 2: Qualitative Interview Findings

In May and June of 2023, MDHHS conducted 30-minute qualitative interviews with members of the task force to gather perspectives on the level of engagement of task force members moving forward, progress on final recommendations and feasibility of implementation, and the overall impact of the task force on the CIE landscape.

Key Findings:

1. **Majority of task force members want to remain involved in the work.** Task force members see their role as engaging and informing their communities of resources available and advocating on their behalf to continue to connect resources with people who need social care services. Most of the members would like to continue to remain engaged with MDHHS efforts around CIE, whether that's as members of a subcommittee of the HIT Commission or as advisors within their regions as subject matter experts.
2. **Task force members want to make CIE concepts and participation easier for CBOs and partners to understand through clear guidance and support from MDHHS.** Members expressed the need for clear and measurable goals as a way of tracking success of the recommendations. They agreed that while lack of federal standards and guidelines for CIEs may hinder some work, MDHHS' approach to creating accessible infrastructure is ideal to accommodate future modifications.
3. **Task force members recognize the recommendations are ambitious and may take several years and concerted effort to implement.** Members were generally proud of the work they had completed and the rapid pace at which the recommendations were developed. The group expressed appreciation to the state of Michigan for recognizing the needs of community-based organizations, convening the task force, and for quickly delivering on the stated goals and objectives of the task force.

Tribal Community Information Exchange Needs and Barriers Survey and Qualitative Interviews

To address Objective 2, the task force disseminated a survey to Michigan's federally recognized tribes to gain a better understanding of the needs, hopes, and concerns of Michigan's tribes as they relate to the collection and sharing of information about Tribal members' social needs to inform policy development and planning for statewide CIE infrastructure. The task force worked with Lorna Elliot-Egan, Tribal Services Manager, and Tribal representation on the task force to distribute the survey.

There are ten federally recognized Indian tribes in the state of Michigan. These federally recognized tribes have sovereign governments and provide various physical and behavioral health services to their members, they also provide services to meet members social needs, including housing, food, transportation, education, and access to healthcare.

The "Tribal Information Exchange Needs and Barrier" survey received responses from two federally recognized tribes in Michigan; the Nottawaseppi Huron Band of the Potawatomi located in the Southwest region of the state and the Match-E-Be-Nash-She-Wish Band of Potawatomi Indians (Gun Lake Tribe) located in West Michigan. Survey respondents included elected officials and directors of social services for their respective tribes. The survey also received responses without submission of contact information. Additionally, the task force engaged the Match-E-Be-Nash-She-Wish Band of Potawatomi Indians (Gun Lake Tribe) in a qualitative conversation regarding tribal CIE needs. The Gun Lake Tribe emphasized the need for recognizing tribal data sovereignty as well as a need for resources to support better alignment between tribal data systems and state data systems to better access aggregate data for grant opportunities.

All respondents indicated struggle in accessing information for social care needs, including food, housing, mental health and substance use resources, employment, childcare, and transportation, as well as medical care needs. Specifically, respondents noted struggles with reentry support following release from incarceration and recovery support following return from inpatient treatment services.

Survey respondents also indicated the need to access aggregated information about social needs across their respective tribes. On an individual level, respondents indicated the need for information about referrals for social services and information about public benefits a member is receiving, specifically respondents indicated the need to have better access to information about child welfare records for cases where Tribes and MDHHS collaborate to coordinate care services.

Respondents also noted the need for CIE to recognize tribal sovereignty and the need to apply data sovereignty principles to all aspects of CIE planning and implementation. CIE must recognize the roles and responsibilities of tribal leaders to its members to create genuine partnerships and collaboration. An effective tribal community information exchange between tribal and state partners must ensure patient health information is protected, private and secure, and is used in a culturally sensitive and appropriate way.

Additional Workgroup Feedback

To address Objective 2, the task force sought additional input during the process of developing recommendations from various groups supported by MDHHS funding, including the Promotion of Health Equity Project Learning Network (the "learning network") and the Michigan Health Information Network Community of Practice (CoP).

Promotion of Health Equity Project Learning Network

The Promotion of Health Equity project (the "health equity project") is supported through Advance Planning Document (APD) Activity 34 funding provided to MDHHS. This project seeks to build infrastructure and support entities seeking to develop and connect medical providers and CBOs through SDoH screenings and referral tools. The work is split between the Michigan Health Information Network (MiHIN) and the University of Michigan (U of M), with multiple subsidiaries under U of M. One subsidiary, the Centers for Healthcare Research and Technology (CHRT) serves as a backbone organization for one of the Community Health Innovation Regions (CHIR) and as a coordinating entity for several other CHIRs and Regional Health Collaboratives (RHC). RHCs in the learning network, representing eleven Michigan counties, have created networks of health and social care partners within their respective geographies to work collectively to identify and address factors that affect the health and lives of their residents. They convene the groups monthly to participate in the learning network for the purpose of sharing information and policies related to technology, training, and building infrastructure.

The task force asked the learning network to provide feedback on several recommendations related to the governance and sustainability of CIE and on the Consumer Bill of Rights. The meetings were facilitated by Janée Tyus, co-chair of the task force and preexisting participant in the learning network, and expert facilitator of the task force, Greg Bloom. This subgroup met several times over the course of two months to refine the general recommendations and provide feedback on the Consumer Bill of Rights. The Consumer Bill of Rights can be found in Appendix D.

The task force also consulted the learning network to analyze a range of potential risks posed by CIE activities, including risks to individuals (of sensitive data used in inappropriate contexts in ways that cause harm) and risks to communities (in which aggregated data is used in ways that amplify inequities in access to care and allocation of resources). In light of these risks, task force recommended the drafting of a Consumer Bill of Rights as a normative foundation for this work.

Michigan Health Information Network Community of Practice (CoP)

The Michigan Health Information Network (MiHIN) Community of Practice (CoP) is also supported through Advance Planning Document (APD) Activity 34 funding provided to MDHHS. In 2022, MiHIN convened a group of social care vendors to create a CoP. In spring 2023, MiHIN added representatives from MiBridges and Michigan 2-1-1. At its foundation, this group of social care vendors signed an interoperability pledge, committing their organization to sharing information about their systems to demonstrate their willingness to work together in areas like interoperable referrals.

The task force asked the CoP to review the initial set of recommendations related to data standards and governance. The draft language was sent to the group in advance of their meeting. The discussion of the recommendation language was facilitated by MiHIN, and the group provided their insights and feedback related to data standards and oversight. They also expressed an interest in engaging more with the task force's implementation efforts of the recommendations and agreed to serve as subject matter experts on questions related to data standards, identification and matching, and general data governance questions related to social care data.

Feedback from Local Health Departments

The task force solicited feedback from local health departments (LHD) receiving funding to support CIE work on the final recommendations. In response, they emphasized that effective CIE needs to account for the tensions between state and local government funding, and local CBO engagement. They emphasized that each region and community have diverse and complex needs and are not structured in the same way, therefore it is essential that CIE remains flexible to the needs of different communities. The local health departments also emphasized a need for state level partners to explicitly state what they can support through funding and to elevate data protection (i.e., Consumer Bill of Rights, clarifying HIPPA/FERPA compliance standards for social care data). Further, the LHDs noted it is important to acknowledge best practices, examples, and frameworks to success within the state, especially where it relates to successful precedent set by the Northern Michigan CHIR leveraging LHDs as CIE hubs

Objective 3: Create a Knowledge Base

Create a knowledge resource in service of Michigan Health Internet Technology (HIT) Commission five-year HIT Roadmap (Bridge to Better Health) and MDHHS Social Determinants of Health (SDoH) Strategy (Michigan's Roadmap to Healthy Communities)

To address Objective 3, the CIE Task Force developed a "Knowledge Base" of compiled materials from programs across the state of Michigan along with findings from across the field of health and human services, as well as general guidance for data system integration processes. These materials have been variously reviewed by task force members to inform deliberations, and key themes are reflected in the findings above and recommendations below. The materials in the Knowledge Base are listed along with links to publicly available documents in an index which can serve as a centralized repository for collateral materials about CIE in Michigan and beyond. This Knowledge Base Index can be found in the Appendix G.

Additionally, the task force undertook a process of articulating two CIE use cases, a CBO referral to a CBO use case, and a CHW referral to community-based services use case. The task force reached several important conclusions through analysis of these use cases.

- Encourage or require vendors to enable interoperability by using common standards for data exchange so that different organizations using different tools can still coordinate with each other.
- Invest in a workforce for care navigation that is trained, supported, and familiar with community resources. The "care navigation" workforce should be closest to the people seeking help and embedded within a community.
- Invest in the production of comprehensive and interoperable resource directory information maintenance and coordination. Ensure that this capacity is responsive to local needs and knowledge, such that input from providers and coordinators and users is promptly received and acted upon. Also ensure that the resulting data can be made accessible in any information system where people might make use of it.
- The state should provide support to coordinating entities that can shoulder the cost and risk of this work. Costs include convening and facilitation for governance and mediation processes, as well as investments in technical infrastructure, security, legal agreements, and monitoring. Another form of support is regulatory and legal – standardized Business Associate Agreements (BAA) and consent processes that give organizations an established path through which they can do this work.
- Health plans should pay for the cost to hire and train care navigators through reimbursement, as well as the costs of administration thereof. However, task force members cautioned against the prospect of health plans assuming entire responsibility, and setting all criteria for, care navigation work.The CIE use cases and analysis can be found in Appendix E.

Objective 4: Develop Recommendations

Advise the state on the development of a CIE strategy, including recommendations as to prioritized capabilities, the appropriate balance between statewide and regional/local capacities and roles, prospective principles, and processes for governance, incentives and adoption support for CBOs, guidance for legal agreements, and a roadmap for implementation, among other critical considerations.

To address Objective 4, the CIE Task Force analyzed the needs and perspectives of prioritized impacted groups—especially service providers who might use a variety of software systems, and the consumers and communities that they represent—to understand the potential benefits and risks associated with CIE.

The task force then generated, reviewed, revised, and approved a set of recommendations pertaining to each identified set of priorities and risks. Every recommendation in this report received support from at least a majority of Task Force members—in most cases, a large majority—no recommendation was met with strong objection from any member. In total, the task force produced with consensus thirty-three final recommendations.

This section of the final report includes a summary of the task force's analysis, followed by recommendations and references, across a prioritized set of topical areas.

Analysis and Recommendations

Capacities for Data Exchange

Analysis

Many kinds of software tools are already used to connect people to resources across Michigan's health, human, and social service sectors. Some software systems are purpose built to meet the needs of a single organization; some are required by policy to be used by specific organizations as a condition of funding. Some software systems have been designed specifically to enable coordination of care among specific networks of organizations. For the most part, these software systems are siloed off from each other.

Many assume that the right solution to the problem of fragmented siloed software systems is to build one new centralized system that everyone would use, but the task force has found no evidence of success from such a strategy. The needs of Michigan's communities and service sectors are too diverse to be effectively met by a single software interface. Instead, a CIE (such as the CIE developed by 2-1-1 San Diego) should be designed to enable already-existing systems to coexist and interoperate as part of the same ecosystem and to make it easier for organizations to develop new software systems that achieve specific purposes without becoming siloed off from the broader landscape.

The task force has identified a core set of technical capacities that can be established at scale to enable community information exchange among the many systems already in use in Michigan. Task force members conducted this analysis by describing ideal scenarios for collaboration among different organizations using different tools and considered what would need to be true if different technologies are to effectively work together.

In order for a user of any given information system to effectively exchange personal information with someone using any other information system, the following capacities must be established and accessible to all: 1) each software system must use structured protocols (such as data standards) for publishing and consuming data; 2) a person's identity must be consistently recognizable by each involved system; and 3) the people using each system must either use the same words to refer to the same concepts, or be able to translate across different vocabularies that are used in different contexts. When these three conditions are in place – along with all of the attendant means of security, legality, etc. – CIE can occur among many different information systems.

There are already existing and emerging standards for secure transmission of personal data, some of which are already required by federal policy (such as Fast Healthcare Interoperability Resource (FHIR), for use in Medicaid and Medicare systems). MDHHS, and the various institutions represented in CIE, can further level the playing field in the market for coordination software by requiring the use of standards and non-proprietary data exchange protocols through procurement policy that ensures all software can be expected to interoperate with other software in common baseline functionality.

Through consultation with CIE experts at 2-1-1 San Diego, the task force has recognized that the availability of reliable and affordable identity-matching services is a core infrastructural capacity that ought to be established at a state-wide scale. Such identity management services are a key precondition for many of the objectives identified by CIE, such as "warm referrals" with "closed loops," as well as person-centered control over access and use of consumers' personal information. That said, CIE efforts should recognize various constraints associated with identity management especially in the social sector. First, identity matching is inherently prone to false positives and false negatives that may result in confusion or even harm for consumers and providers. Also, task force members acknowledge that social service delivery often is conducted under conditions of anonymity, sometimes for important reasons; task force members from the social care sector have urged the task force to assume that identification may not be universally possible or appropriate in all social care contexts.

Finally, the task force has observed that many potential value propositions for CIE hinge upon the ability for different actors to share information across different contexts in which different vocabularies may be used to describe the same concepts.
For example, screening and referral processes involve articulation of social risks and social needs for which there are established clinical terminologies (i.e., ICD-10 z-codes and LOIN codes for people experiencing homelessness or elder abuse) that may not directly correspond with established vocabularies in other sectors (such as the terms used by HMIS systems for reporting to HUD or the terms used by Aging and Disability Resource Systems to report under the Older Americans Act). For another example, government partners have informed the task force that the definition of "needs met" tends to vary across contexts in ways that could have problematic implications for consumers' access to care. To succeed at scale, CIE requires the use of controlled vocabularies – and the capacity to align those vocabularies, when possible, translate between vocabularies when necessary, and resolve conflicts between meanings when identified.

These capacities pose significant potential value as well as significant risks to affected parties across the state – and successful implementation will require ongoing care and adjustment over time. The CIE task force recommends the establishment of a dedicated process of technical governance consisting of subject matter experts, operating within a broader institutional governance system, to ensure effective and equitable implementation of these information exchange capacities over time.

References

MiHIN's Interoperability Pledge: https://mihin.org/2022/07/six-of-the-nations-leading-social-care-companies-sign-trailblazing-interoperable-referrals-pledge/

"Tackling Data Dilemmas in Social Care Coordination," Greg Bloom and Paul Sorenson for DASH: https://stldata.org/wp-content/uploads/2021/10/Social-Care-Data-Whitepaper-October-2021.pdf

"A Framework for Cross-Organizational Patient Identity Management," The Sequoia Project: https://sequoiaproject.org/resources/patient-matching/

Capacities for Data Exchange Final Recommendations

Capacities for Data Exchange Recommendation #1:

Adopt standards for data exchange to enable interoperability among many technology systems to ensure basic infrastructural capacities can be used by any compliant software system. MDHHS should support policies that require adoption of nonproprietary protocols and standardized APIs for data exchange by any vendor contracted by a participating organization. These policies will ensure organizations can choose which technologies they use, while preserving their ability to exchange information with any other organization in the CIE network – and minimizing their dependency upon software vendors for custom integrations.

Capacities for Data Exchange Recommendation #2:

Establish affordable and ethical statewide identity management services to enable information about people to be effectively shared across different systems. Alignment of identities across different information systems is a necessary precondition to implementation of other CIE priorities; such identity management services should be accountably governed and universally accessible to all participating organizations. Task force members also note that the paradigm of social care is often different than healthcare, in that people are not necessarily identified in the course of service delivery, sometimes intentionally; these values may be important to preserve in some cases.

Capacities for Data Exchange Recommendation #3:

Establish shared terminology and translation capacities to ensure that different vocabularies used in different contexts can be effectively aligned. Standardized terminologies should be established and promoted for use within the CIE ecosystem. A system of shared vocabulary should reflect national standards that are in use within the state (such as the 2-1-1LA taxonomy or LOIN codes) and support localized extensions and applications of these terms.

Capacities for Data Exchange Recommendation #4:

Establish a process of addressing these technical interoperability concerns over time. A working group, focused on the technical process, trust, and policy aspects of data exchange standards, vocabulary management, and identity management, could be formed to help inform and support this work. The group should include members from the CIE task force as well as those from the MiHIN's Community of Practice social care vendor group.

Resource Directory Information Capacities

Analysis

Resource directory information is a public good – public information that should be accessible. This information is a critical element of CIE infrastructure – enabling people to know what resources are available to whom and how to access them. Directory info should be comprehensive and reliable. The task force has prioritized improved access to and usability of this information as one of the primary benefits of CIE.

Task force members observe that different partner groups need to access this information in different ways. Some task force members articulated a desire for “everyone to access all this information in one place," but others observed that a single website cannot effectively meet the diversity of needs among all communities and organizations that serve them. For instance, people seeking help need information expressed in simple terms; service providers might need more complex info to provide precise assistance. Task force members also recognized that different communities may have different priorities – in terms of what kinds of services should be included, what kinds of information should be collected, and how services should be curated and prioritized in search results. Also, various communities need this information in multiple languages. A statewide resource directory information service should be able to accommodate services across a range of various “inclusion criteria” that respond to diverse communities’ needs, and it should also enable different users to set their own “exclusion criteria” in the process of filtering results of tailored search and analysis in accordance with localized and/or specialized priorities.

It is possible to meet such diverse needs by enabling the same data to be used in different ways; but such a resource data supply chain would require a significant amount of human capacity for collection, standardization, curation, and quality assurance.

Currently, there are many different resource directory information systems serving many different needs in the state of Michigan. Task force members expressed concern that the proliferation of siloed, purpose-specific resource referral systems might end up recreating health care’s problematic model of “narrow networks” of providers. On one hand, community anchor institutions like hospitals should be able to develop specific networks of known and trusted service providers whose information can be specially promoted to users for specific health and social care objectives; at the same time, users should still be able to access information about all service providers beyond those narrow networks. Task force members observed that when resource directory information is provided by many different organizations in siloed, fragmented systems, there will be varying levels of awareness and trust of any given channel – as well as confusion and inefficiency across all systems – which can yield various inequitable outcomes.

If different people and organizations are going to use different information systems – call centers, case management systems, care coordination systems, MiBridges– then *the same information should be accessible in many places*. The same information should be accessible through various devices, various software systems, and even simply published on the web with standardized markup so it can be easily found through search engines, like Google.
Information about local services is usually known best by local people. It is important to have local

capacities for maintaining information about local services. That said, without common standards and protocols, and sufficient funding, the quality and usability of available resource information might vary across communities in inequitable ways. Many communities might struggle to sustain the labor of directory information on their own, so enough funding for directory information maintenance should be established statewide. Many services are provided statewide, so some amount of resource directory information should be centrally provisioned for all of Michigan. The right balance may involve a mix of local information management with statewide capacity for coordination and quality assurance to ensure consistency and reliability.

The task force recognizes most communities have individuals in their area who may not be formally recognized CBOs or a 501c3 but provide vital resources. These individuals should not be excluded from resource directories; local/regional directory stewards should have the discretion to include them as needed.[12]

[12] Though resource directory information is generally *public* information, there are some examples of kinds of information that are sensitive and therefore should have carefully restricted access. For instance, the addresses of some kinds of services for vulnerable people – like domestic violence shelters – should not be publicly accessible to protect the safety of clients. Also, some kinds of contact information managed in an information-and-referral provider's resource database – about specific staff available for specific purposes – might need to be withheld outside of the context of a specific partnership. These decisions require care and management capacity to manage responsibly.

References

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"Tackling Data Dilemmas in Social Care Coordination," by Greg Bloom and Paul Sorenson for DASH: https://stldata.org/wp-content/uploads/2021/10/Social-Care-Data-Whitepaper-October-2021.pdf

Resource Directory Information Capacities Final Recommendations

Resource Directory Information Capacities Recommendation #1:

Ensure that a reliable supply of resource directory information will be sustainably provisioned as a key component of CIE infrastructure. MDHHS should ensure that directory information about services is reliably maintained and easy to use by many different systems for various purposes. This will entail allocating sufficient resources for maintenance and quality assurance.

Resource Directory Information Capacities Recommendation #2: The CIE's resource directory information should be provided by a federated network of stewards, each of which have clearly defined areas of responsibility that accord with their respective expertise. The CIE's supply of reliable resource directory information should leverage assets that already exist in Michigan. This entails partnerships among multiple organizations – statewide, local, tribal, domain-specific. These partnerships should form a 'federation' – a collaborative network of designated responsibilities, anchored and coordinated by a single entity that upholds bottom-line stewardship responsibilities for synthesis and quality assurance (like a 'utility'). This partnership model should be developed in phases, expanding in size and scope through iteration, under the accountable oversight of an entity authorized to set CIE standards and policy.

Resource Directory Information Capacities Recommendation #3: Resource directory information must be provisioned as a public good. This resource directory information should be considered a public good, freely accessible to Michiganders (with responsible exceptions made for sensitive and/or privileged information that must only be shared among a closed network of partners). Such data should be available in standardized machine-readable formats, via API, so that it can be used through any information system that might help Michigan residents. This data should remain a public good that cannot be enclosed and resold for profit by third-party vendors.

Resource Directory Information Capacities Recommendation #4: Service providers can be encouraged to ensure their own information remains up-to-date, through policy levers that incentivize such responsibilities. MDHHS (along with other government agencies and institutions that allocate resources to service delivery) can explore the potential to promote efficiency and effectiveness in resource data management by advocating for policy levers that incentivize human service organizations to reliably submit updates about their own services. For instance, human service agencies contracted by the government can be required to provide reliable updates about their services to the designated directory information steward. However, the CIE should not depend upon this tactic to eliminate the need for data stewardship capacities; resources for monitoring, compliance, and curation will still be necessary to ensure reliable information at scale.

Longitudinal Data Aggregation Capacities

Analysis

Longitudinal data collection entails aggregation of information about people's social context, care activities, and results over time. Data can be aggregated longitudinally about individuals, like in a shared client record used for "community care planning." This can remove the burden for a client who might otherwise have to make multiple requests with redundant application processes to get help for a persistent social need. Data can also be anonymized for longitudinal aggregation of population-level data. Aggregate longitudinal data can enable reporting, analytics, and evaluation of community needs or program effectiveness. This can enable data-driven awareness of community needs, and support more equitable resource allocation to meet such needs.

Task force members observed that statewide infrastructure for longitudinal data collection already exists – and could be better leveraged for care coordination. Social care data is especially important for payers to meet reporting requirements, but there may be tension between payers' interests in collecting more data and clients' interests in privacy, dignity, and agency. However, some kinds of information might be aggregated locally with less risk than at the state level (for example, information regarding immigration status).

A client may divulge information that providers/payers want for data completeness, but the client may not want that info shared beyond their local CBO. Longitudinal data collection does pose various risks for a community and individual people. Often risks are framed in terms of bad actors having access to information they shouldn't have; but the task force identified a range of other undesirable outcomes that could result from such aggregation.

On a community level, longitudinal data collection can be used for algorithmic processes of risk stratification and rate adjustments that can yield inequitable allocation of resources. There are many known instances of such undesirable outcomes from the use of aggregate data to automate decision-making about access to care.

On an individual level, the collection and preservation of data about social needs can unintentionally result in stigmas and inequitable outcomes – for individuals and for their family members – as data is used over time in ways that may not have been anticipated. For instance, clients can unexpectedly lose insurance coverage or benefits eligibility if certain kinds of information are collected and shared through automated systems. People should be able to not only see but correct or remove information about themselves. They should have the ability to decide which information should be shared with what entities. People not only need to be able to do this – they need to know that they are able to do this, with established channels for monitoring, complaint, and redress. The task force observes that even methods of eliciting consent for such data collection are not reliably ethical, as some vulnerable clients might feel pressured to give information to receive access to services, and others might lose access to care if they do not wish to be surveilled.

To mitigate the risk of inequitable outcomes, there should be guardrails around the permitted uses of aggregated data – such uses should be proposed, reviewed, and sanctioned through an accountable

governance process (such as an internal review board).

References

“Yes, no maybe? Legal and Ethical Considerations for Informed Consent in Data Sharing and Integration,” AISP: https://aisp.upenn.edu/resource-article/consent-brief/

“Integrated Data Systems Governance: Setting up for Ethical and Effective Use," Actionable Intelligence for Social Policy, Expert Panel Report: https://aisp.upenn.edu/wp-content/uploads/2016/07/Governance.pdf

“Community Bill of Rights,” Full Frame Initiative: https://www.fullframeinitiative.org/resources/the-community-bill-of-rights/

Longitudinal Data Aggregation Capacities Final Recommendations

Longitudinal Data Aggregation Capacities Recommendation #1:

Enable collection of longitudinal data about clients' social needs, risks, service-related activities and results – contingent upon their informed consent. Given adequate consumer protections, and informed consent processes (i.e., opt-in consent practices) longitudinal collection of personal data when conducted over a reasonable period of time with clear standards for retention, management and use, can yield significant benefits that can improve coordination of care and build capacities for needs assessment and quality improvement when utilized in a de-identified and aggregate way; however, such collection also poses significant risks. In settings that are not subject to HIPAA, collection and retention of personal data should be subject to the informed consent of individuals seeking services.

Longitudinal Data Aggregation Capacities Recommendation #2:

General standards for data collection, retention, and use should be set statewide; specific decisions over implementation and policies for usage should be made at the most locally appropriate level (in harmony with the statewide framework). Decisions about longitudinal collection of personal data (i.e., clients' information) may need to be made at different scales by different actors in different contexts and for different uses. Rather than a centralized system that collects all data about everyone, the Task Force recommends developing these capacities in ways that enable longitudinal data collection to occur in specific contexts for specific purposes under specific conditions. MDHHS should develop capacities for partners to assess the risks of various kinds of data collection and use, make decisions about what is supported and allowed, and field any complaints that might emerge as it relates to consumer data. Standards for data preservation, use and retention should be established statewide; implementation should be governed locally.

Longitudinal Data Aggregation Capacities Recommendation #3:

Enable the longitudinal aggregation of anonymized data for sanctioned uses, subject to individuals' choice to opt-out of such aggregation when legally and technically possible. By enabling CIE across shared infrastructure for data exchange, the longitudinal aggregation of anonymized population-level data should be possible. Such aggregation should be subject to careful scrutiny of both the methods of anonymization and the purpose of use – recognizing that some kinds of uses (such as risk adjustments and automated algorithmic decision-making) may yield inequitable outcomes and need to be sanctioned. The aggregation of such data should be aligned with statewide and /or national standards and practices. These conditions should be articulated in a manner that is easy for individuals to understand and should provide a clear and easy process for individuals to opt out of sharing and collection to the extent that is legally permissible and technologically feasible.

Longitudinal Data Aggregation Capacities Recommendation #4:

Leverage already-existing assets for data infrastructure when possible, and establish appropriate systems of governance for operation of any such infrastructure in contexts which aren't already regulated by HIPAA. Capacities for longitudinal data aggregation may already exist in Michigan. A designated body empowered to set CIE policy and standards should assess the appropriateness of such capacities for the purpose of equitable aggregation and management of non-clinical data about social needs and risks, and consider whether any new infrastructure might still be needed to achieve its objectives. For either already-existing or new capacities for longitudinal data aggregation and analysis, this designated entity will need to develop systems of accountable decision-making, monitoring, and sanctioning to ensure that such aggregation is conducted ethically and equitably.

Legal and Ethical Framework

Analysis

Regulatory frameworks establish guardrails for data usage that can protect people.

But…

Existing legal frameworks don't offer clear guidance for important cross-sector exchanges involved in use cases of CIE. Furthermore, different regulatory frameworks might be difficult to align across sectors – i.e., HIPAA and FERPA have requirements that differ and may even conflict. For another example, there is confusion about the requirements of CFR 42, which inhibits action around mental /behavioral health.

This compounds the challenge of organizations' legal compliance, which is necessary if they are going to engage in significant data collection and exchange. There's a high cost of legal frameworks (MiHIN spends $2-3m per year on legal services). There are also high costs for compliant security, in ways that might conflict with the culture of social care organizations (i.e., locked access, etc.). In general, the prospect of data collection and exchange poses significant risks to orgs of unintentionally breaking the law.

Finally, legal compliance tends to stand in for ethics by default; however, there are various bad outcomes that might result from actions that are legal but not ethical.

And…

Expectations are largely localized – and vary across communities. Most implementation capacities need to be local. And trust is best established locally, through local institutions.

But local communities don't have funding or legal capacities to establish complex legal frameworks for data exchange themselves. Even if they did, it would be challenging – perhaps unworkable – for statewide institutions to develop unique legal agreements with every locality that does things in a different way. To some extent there needs to be consensus across communities to establish a baseline framework that can work for the state.

Task force members noted that there is a provisional agreement that the state should work to develop a baseline legal framework for social care data exchange. The framework should align with the already-established 'umbrella' legal framework for health data exchange; it should also accommodate the differing interests, needs, and capabilities of state and local entities across social service sectors. The framework should reflect both the necessary conditions for regulatory compliance, and ethical principles that sufficiently address the interests of social care groups.

To initiate this process, the CIE Task Force engaged social care sector partner groups in a process of deliberation around an ethical framework – i.e., a 'Bill of Rights' – that establishes normative principles for data collection, exchange, and use among social service providers. (See Appendix D.)

Outputs from this “Bill of Rights” process should be synthesized with the outputs from other, already-underway processes to develop legal frameworks for data exchange, such as those being conducted by both the Health Equity Project’s Learning Networks and the Michigan Multi-Payer Alliance.

Further engagement of CBOs is necessary to consider the operational challenges associated with both legal requirements and ethical principles. In this process, various scenarios should be described in easy-to-understand language that paint the picture of what's possible in terms that are not too legal or technical. The process should consider a range of scenarios, including:

- Healthcare entity shares personal data with CBO.
- CBO shares personal data with healthcare entity.
- CBO shares personal data with another CBO, or a group of CBOs.
- CBO shares data with government agency (health care)
- CBO shares data with government agency (public health)
- Government agency shares data with other gov agency (i.e., healthcare to public health)

For each scenario, partners should articulate kinds of outcomes that should not happen involving specific kinds of actors, actions, and data types. Given these criteria, the state can initiate the development of a legal framework that should specify what methods of consent solicitation and permissions management must be established for each primary scenario of data exchange. The framework should further specify how these rights will be upheld. The framework should be drafted and reviewed with CBO leaders through rounds of input and revision until a sufficient threshold of agreement is reached.

The result should yield a templatized “CIE Services Agreement,” which should serve as a baseline standard framework for all business agreements associated with a CIE. Extensions to this baseline agreement can be developed locally and/or across service domains (i.e., behavioral health, education) through modular agreements that establish additional conditions or exceptions, to be submitted and reviewed through an accountable governance process.

Through this framework, and alongside other processes of capacity building, the state should empower and support ‘backbone agencies’ that can assume the risks of liability and hold responsibilities for coordination of associated activities on behalf of entire networks of CBOs. These local data aggregators (i.e., CHIRs) can facilitate partnership development, use case design, compliance, ethical oversight, and quality assurance.

State government should establish and fund processes for auditing, monitoring, and compliance of legal frameworks. In pilot phases, the state government should seek funding to support organizations' legal and operational costs, including evaluation, change management, and assessment.

The task force recognizes a set of open questions that must be addressed through governance processes, notably:

- How will conflicts be resolved (i.e., between local and statewide priorities, between actors in different domains, etc.)?
- How will the rights established in an ethical framework be adjudicated?
- How will the framework be evaluated and revised over time?

References

"Is that even legal? A guide for builders experimenting with data governance in the United States," Mozilla Foundation: https://foundation.mozilla.org/en/research/library/is-that-even-legal/usa/

"Data Sharing to Build Effective and Efficient Benefits Systems: A Playbook for State and Local Agencies." Benefits Data Trust: https://bdtrust.org/data-sharing-to-build-effective-and-efficient-benefits-systems_january-2023.pdf

"Finding a Way Forward: How to Create a Strong Legal Framework for Data Integration," AISP: https://aisp.upenn.edu/resource-article/finding-a-way-forward-how-to-create-a-strong-legal-framework-for-data-integration/

Legal and Ethical Framework Final Recommendations

Legal and Ethical Framework Recommendation #1: **MDHHS should establish a baseline policy framework and common structure for legal agreements for collection, exchange, and use of data in contexts not already governed by HIPAA, FERPA, or 42 CFR p2.** MDHHS should develop policy guidance for cross-sector sharing of social care data that originates in a community-based setting, using HIPAA as a baseline and establishing harmony with other regulatory frameworks as needed.

Legal and Ethical Framework Recommendation #2: The CIE task force will recommend a "Bill of Rights" for consumers and communities to be reviewed and formalized by a designated governing body. MDHHS should convene a process through which partners, comprised of consumers and CBO representatives, draft a "Community Bill of Rights" which articulates consumer protections for the use of an individual's social care data to protect privacy and promote ethical data use.

Legal and Ethical Framework Recommendation #3: **In all contexts not subject to existing regulatory frameworks, entities conducting CIE activities should ensure that data collection and use is subject to consumers' informed consent**. A designated governing body should establish policies outlining specific requirements for solicitation and preservation of informed consent and associated consumer protections, especially for interaction not already governed by existing regulatory frameworks.

Legal and Ethical Framework Recommendation #4: Local communities and Tribal Nations should be able to build upon the baseline statewide legal framework with additional policies that address their specific needs and concerns. Policies established by the designated governing body should permit local communities and Tribes at various levels of government to build upon the established baseline legal and ethical frameworks in a way that supports each community's unique needs with additional requirements intended to protect social care information not regulated by existing law.

Legal and Ethical Framework Recommendation #5: MDHHS should support and fund, where possible, processes for partnership development, workflow change management, auditing, and compliance with all of the above. MDHHS should ensure CBOs' ability to participate by supporting education and outreach on existing regulatory requirements (e.g., HIPAA, FERPA, 42 CFR pt. 2) to better equip CBOs to participate in data sharing across sectors. Special consideration and funding should be given to entities, like Tribes, in need of additional capacity building. This funding should be designed to support the braiding of other funds from philanthropy, local, state, federal, and Tribal agencies.

Coordinating Entities Capacities

Analysis

Most CBOs lack the capacity to establish the necessary legal frameworks, technical integrations, and associated coordinating capacities that would be necessary to benefit from CIE – or to assume the liabilities associated with the risks of data collection and exchange. By enabling CIE activities to be facilitated through local or regional coordinating entities, a certain baseline of access to CIE services could be offered to all CBOs.

New coordinating entities might struggle to handle these responsibilities themselves if they have limited experience or have not demonstrated success in the role. For this to be realistic and not burdensome, there need to be a clear financing model in place, with opportunities to build capacity to participate, such as subsidies from MDHHS, and/or cost recovery strategies for coordinating entities. Funding would need to be established statewide as it relates to incentives and training. Through this funding, the state can establish a baseline scope and focus of coordinated entities, standards, and rules of engagement between the coordinated entity and CBOs, minimum functional requirements, and capacity-building processes to train would-be coordinating entities for the role. Additional levels could be established locally.

Some CBOs already are a part of coordinating networks, so new coordinating entities could misalign with their commitments, and cause more competition and fragmentation. This could result in further inequities to people and communities. For coordinated entities to be able to function successfully, MDHHS should encourage domain-specific statewide networks – such as the statewide food bank council – to facilitate participation of their local partners in developing relationships with local/regional coordinating entities of broader scope.

A one-size-fits-all approach will not work in this case and certain roles and responsibilities should be managed locally. CBOs should be able to choose which coordinating entity they work with, or to become a coordinating entity themselves. Even in communities where a coordinating entity functions as a backbone for a given network of organizations, there should be a “no wrong door” approach, ensuring people are not cut off from organizations that are not in the coordinating entity’s network.

Additional things to consider are potential conflicts of interest involving access to information for the CBOs and coordinating entities. This is again why the scope of coordinated entities would have to be well-defined, and rules clearly established, with monitoring and evaluation processes clearly defined.

References

"Community Care Hubs: Making Social Care Happen" by the Partnership to Align Social Care. https://www.partnership2asc.org/wp-content/uploads/2022/12/CCH-Primer-Final.pdf

Coordinating Entities Capacities Final Recommendations

Coordinating Entities Capacities Recommendation #1:
Activities associated with community information exchange can be conducted by 'coordinating entities' that assume fiduciary responsibilities for their partners in the community and for the consumers they serve. Activities associated with CIE – from contracting, to implementation, to billing, to monitoring and decision-making – could be enabled through 'coordinating entities' (i.e., "care hubs") that are designated, trained, and resourced to support community-based organizations and represent their interests. These hubs could also assume fiduciary responsibilities on behalf of their members' clients. CBOs should be able to choose which coordinating entity they work with and should have the option to assume such fiduciary responsibilities themselves.

Coordinating Entities Capacities Recommendation #2: MDHHS can set standards and establish sustainable funding streams to support coordinating entities. The state could establish clear baseline criteria, requirements, and standards for such coordinating entities, as well as funding streams and programs for training and quality assurance of such entities. There should be clear cost-recovery models in place to enable these entities to scale and sustain.

Coordinating Entities Capacities Recommendation #3: Coordinating entities should both reflect the priorities of their communities, and be designed to facilitate collaboration across networks. A one-size-fits-all approach will not work in this case. There should be a "no wrong door" approach, ensuring people are not cut off from organizations that are not in a given coordinating entity's network. Competition among coordinated entities should be healthy.

Coordinating Entities Capacities Recommendation #4: **Coordinating entities can formally represent their partners' and consumers' interests through equitable decision-making processes.** Coordinating entities could be conduits for governance. The entities should establish accountable governance processes through which their members' interests are represented in the hub's decision-making. There should be grievance and mediation policies in place to address conflicts and negotiate tradeoffs among interested parties.

Coordinating Entities Capacities Recommendation #5: Coordinating entities can be established within specific service domains, as appropriate on a local or statewide basis, to facilitate engagement of providers across their sectors. **MDHHS could encourage domain-specific statewide networks – such as the statewide food bank council – to facilitate participation of their local partners in developing relationships with local/regional coordinating entities of broader scope.**

Governance

Standards and protocols set statewide with support for implementation, monitoring, and evaluation.

To promote alignment with our values and principles, a designated governing body should first set standards for CIE program design and implementation, especially regarding data collection practices and consent processes. Programs should be audited to ensure adherence to these standards. One form of this monitoring can be surveys of consumers that elicit their feedback on the effectiveness of programs and clarity of the terms of their participation. These surveys can generate organizational metrics which enable evaluation of the effectiveness of processes and equitability of outcomes. In the case of inadequate assessment, coordinating entities should receive supplemental training and support to improve the equitability and effectiveness of processes.

Use case development, proposal, review and approval

Use cases should be proposed, reviewed, and approved. Use case authorization should not be open-ended and requests for information should include specification of secondary uses. Uses of data should be formally proposed, evaluated as to benefits and risks to partners, and permitted through processes that represent and involve interested groups. Generic 'types' of use cases should be established with policy frameworks statewide. Specific implementations can be implemented and governed locally.

Processes for consumer concerns, complaints, and/or grievances

There should be designated channels through which consumers can request help and/or express concerns. Through the process of eliciting consent, it should be made clear to consumers which entity is responsible for addressing their interests. Consumers should be made aware of their rights, and the mechanisms by which they can assert those rights. There should be written procedures that specify how consumers can talk to a designated person about what's happening; there should be clear and easy processes through which that person can address consumers' concerns.

If a consumer's rights have been violated, the CIE may need to take corrective action upon the data flows and/or the program itself. Consumers who have experienced material harm may deserve restorative action. To assess the situation and determine a course of action, a grievance process initiated by a consumer's complaint should assign a designated representative for the consumer and establish representation for other responsible parties. Responsible parties may include the data collector, data aggregator, and any relevant third parties who have accessed and used the data. This process may involve an ethical review and/or mediation. If mediation fails to result in an outcome that is accepted by all parties, the issue should be escalated to a statewide body and, if necessary, brought to court.

Analysis of Governance Scenarios

The task force's values call for a high degree of accountability about the way personal information is collected, managed, and used. This entails both clear processes of establishing standards in program design, and careful attention to the actual outcomes. To center the interests of the people served, CIE needs to establish trustworthy mechanisms by which consumers' concerns can be heard and satisfactorily addressed. Without these processes, this work might result in situations in which consumer access to services becomes contingent upon invasive collection of data with other harmful repercussions (like loss of benefits, stigma, etc.).

The process considered here would establish the means for all parties to consider themselves accountable. CBOs will need to be able to capture a certain threshold of data to effectively participate in this process. Without a record of care, there cannot be an effective grievance process. The data collection involved, and the process of monitoring and enforcement may be extremely burdensome to CBOs. Evaluations must be supportive to consumers first, rather than punitive to CBOs.

There will also need to be capacity to respond to the sources of grievance to avoid future incidence, such as training, at a minimum, and perhaps policy change processes. This points to the need for 'coordinating entity' capacity, such as fiduciaries.
Enforcement may require an independent body. It would have to be trusted by the CBOs, too. Such a coordinating entity would need to have a governing board that authentically represents multiple kinds of affected parties.

One solution to consider would be an ombudsman's office. Local governing bodies would need to operate under oversight of an overarching statewide governing body which can establish baseline policy frameworks. Local bodies should be represented in the governance of this statewide body. It would need to be able to draw the line between what issues need to be dealt with internally to an organization, versus a local network and what would need to be dealt with across the CIE.

Standards should be consistent across the state; local implementations should have the ability to adapt their approach within a standardized framework. Too much centralized control will restrict the ability for diverse communities to meet their specific needs. On the other side, too much local variation in rules could overly complicate processes from design to implementation to governance.

For data that's not clearly governed by state or federal law, there will need to be a means of enforcement. For instance, funding could be lost, and/or an organization could be removed from a CIE network. There is often a lack of trust in the justice system, so the task force does not assume that the right answer will be found in the courts.

While trying to design these systems, we must not imagine that there will be no problems; the systems need to be designed to cope with problems.

Governance Final Recommendations

Governance Recommendation #1: CIE activities should be conducted by accountably governed bodies that are responsible for acting in the best interests of the people they serve. Duties of care and loyalty – also known as fiduciary responsibilities – should be upheld by organizations responsible for aggregating, managing, and sanctioning the use of data collected in a social care setting. This entails, for instance, that at any point in the lifecycle of data collection and use, a consumer should know how to get in touch with a human who is responsible for addressing their concerns. It also entails that such activities are designed and conducted by entities that have an accountable governance process through which consumers' interests can be articulated and addressed.

Governance Recommendation #2: CIE Governance should formally represent the interests of affected parties, especially those of consumers and service providers, in transparent and inclusive decision-making processes. Such governing structures might take the form of a consumer council or review board, ombudsman office, juries, or other mechanisms that formally represent the interests of affected parties, and assess the equitability and sustainability of CIE activities in light of these interests.

Governance Capacities Recommendation #3: CIE governance processes should clearly establish what use cases are permitted under which conditions, and should establish processes for monitoring, compliance, and conflict resolution to ensure equitable outcomes. CIE governance should establish a set of processes by which standards are set, policies are created and changed, compliance is assured and outcomes evaluated, and conflicts are identified and resolved in accordance with the values and principles articulated by the CIE Task Force. Decisions should be made at the most locally appropriate level. Violations should be addressed through measure that escalate in accordance with the context – such as warnings, corrective training, sanctioning, and even removal from the CIE, or legal action when necessary.

Governance Recommendation #4: Local CIE activities should operate as part of a federated network, with local representatives participating in the governance of a statewide entity that establishes baseline policy, standards, core infrastructure and conflict resolution processes.

This should involve a federated network in which many different entities that serve many different communities across the state. A statewide governing body – such as a Commission – could set minimally-required standards; develop baseline frameworks for legal agreements and privacy protocols; vet and set policy for generic use cases involving the collection, exchange, and use of personal information in social care settings; and provide support for local implementation and adoption. Options for a statewide governing body could include:

- Establish a CIE subcommittee within the HIT Commission
- Revise the charter of the HIT Commission, to encompass social care on par with healthcare, and to manage CIE alongside HIE
- Establish a new CIE commission to oversee information exchange among social care organizations
- Support decentralized community governance across self-directed local structures.

These options are not mutually exclusive, meaning that, there are ways for a governance structure to include elements of one or more of these in one model.

Exploring Governance Recommendation #4: The Structure Question

In developing and analyzing governance scenarios for CIE, the task force acknowledged an overarching, ongoing question:

What body or bodies will be designated to design and implement CIE policies and strategies?

The task force identified options for a statewide governing body. To gather the feedback of the task force, members were asked "Of the following options, which do you think would be the most effective for statewide CIE governance?"

- Establish a CIE subcommittee within the HIT Commission
- Revise the charter of the HIT Commission, to encompass social care on par with healthcare, and to manage CIE alongside HIE
- Establish a new CIE commission to oversee information exchange among social care organizations
- Support decentralized community governance across self-directed local structures.
- Other

The task force analyzed the different options below. These options are not mutually exclusive, meaning that, there are ways for a governance structure to include elements of one or more of these in one model. Additionally, two or more of these models may start to develop concurrently and/or start with one model and build into another. The local, regional, and/or domain-specific entities that conduct CIE activities should themselves be represented in a statewide governance body. Operating under and in harmony with this statewide framework, local entities can govern the process of setting local priorities, approving specific use cases, implementation and evaluation.

Option 1: Establish a CIE subcommittee within the HIT Commission

A clear benefit of this option is it would be easier to achieve. Currently the MHITC is not independent of the state, MDHHS supports the work of coordination and facilitation. Conversely, there is concern that it lacks a mechanism for social care providers and consumers to be effectively represented in an accountable process. Further, it is unclear if the MHITC has an effective way to mitigate the ongoing tension between social care prerogatives and healthcare incentives.

Option 2: Revise the charter of the MHITC, to encompass social care on par with healthcare, and to manage CIE alongside HIE.

This option would establish parity between healthcare and social care, establishing something akin to the Health and Human Services Information Technology Commission. It would work within the structure of what already exists, and build on established authority and capacities, while evolving to address the broader concerns of social care sectors.

Similarly to the first option, there are concerns that social care parties would not be equitably represented, especially comparatively to healthcare institutions. It is also unclear if the needs of HIT/HIE and social care data exchange are similar enough to be governed by a single body.

Option 3: Establish a new CIE commission to oversee information exchange among social care organizations.

The option would establish a body dedicated to social care sectors concerns, entirely comprised of social care representatives. CIE overlaps with HIT but it is not encompassed by HIT. A joint commission would allow both social care and healthcare sectors to be represented. Additionally, it could support coordination between HIT and CIE commissions.

Notably, this is an intensive solution. In addition, it is unclear how much authority and capacity a new commission would have if it is separate from a HIT commission. Potentially, there could be an opportunity for a joint commission with the MHITC.

Option 4: Support decentralized community governance across self-directed local community governance structures.

This option places power closest to the need and supports the facilitation of work by the community. It is also more likely to create innovative models. Conversely, this option takes significantly more time to stand up. It requires investment in governing bodies that a funder would not control, and it is unclear how to establish sustainable long-term funding mechanisms, through federal tools like Medicaid, without a consistent statewide framework. It is also likely that the creation of decentralized community governance would result in siloing, potentially creating redundant and confusing access processes for consumers. It also presumes that community members have the interest or capacity to participate in governance structure and could result in inequity in communities without capacity for self-organizing. Lastly, decentralized community governance creates little incentive for interoperability between systems.

The task force was surveyed to gain an understanding of the governance scenario with the most support from this group. While this report remains agnostic, the survey found task force members were most in agreement with supporting a decentralized community governance structure across self-directed local structure. There was also support for establishing a CIE subcommittee with the MHITC. Although, there no option received majority support underpinning the ongoing need for discussion of CIE governance.

Sustainability

Analysis

A fundamental limitation on the effectiveness of any CIE strategy in Michigan is a lack of resources and capacity in the existing network of social services. The task force recognizes that the value of improvement in access to information about services is limited when service providers are already unable to meet existing demand. Given the lack of community-based services in many regions, but especially rural regions in Michigan, increasing the flow of information without increasing the supply of resources may only exacerbate capacity constraints. CBOs need sustainable funding streams to support service delivery and to incentivize them to build technical and organizational capacities to participate in CIE. It is an essential priority of Michigan's CIE sustainability strategy to build capacity for social service delivery. This strategy will require a multi-pronged approach and involvement from multiple partners.

The task force has identified the following costs associated with CIE activities – both for CIE infrastructure, and for the CBOs who would participate in it.

CIE infrastructure funding needs:

- Resource directory information stewardship
- Identity matching services
- Vocabulary management (terminology/translation)
- Monitoring and compliance processes
- Legal agreement development, onboarding, and management
- Governance processes
- Coordinating entities to facilitate local implementation of all of the above

CBOs funding needs:

- Program capacity to meet increased demand for services
- Staff capacity for coordination of care
- Administrative and/or infrastructure needs, including tools, workflows, and billing (i.e., administrative support)
- Participation in CIE system design, evaluation, and decision-making processes.

Medicaid

The most significant actions that MDHHS can take to expand opportunities for funding of social care are through Medicaid policy. Key Medicaid policy levers include 1115 demonstration waivers, which many states have used to test innovative approaches to addressing social needs among Medicaid beneficiaries. Currently in Michigan, Medicaid health plans support some social service delivery through their administrative budgets which are very limited and more restricted than other funding. Other states, like California, have successfully leveraged 1115 waivers to allow for more flexible funding to contract with community-based service providers to provide temporary housing and other social services. In the absence of an 1115 waiver, Medicaid can still capitalize on CMS' increased support for 'in lieu of services' (ILOS) policies which allow managed care Medicaid health plans flexibility to address social needs in lieu of other medical services. ILOS are often used to fund housing or access to healthy foods for Medicaid beneficiaries, and could be expanded to cover other kinds of social services as per recent guidance from CMS (SMD 23-001 - ILOS (medicaid.gov). ILOS could be structured to require engagement with CBOs, thereby increasing the pathways for CBOs to access funding for services. Another key Medicaid policy lever with the potential to expand resources for CBOs is a Medicaid state plan amendment, currently under development, to establish Medicaid reimbursement for Community Health Worker (CHW) services.The policy is slated to go out for public comment concurrently with this report. Task Force members have observed that a key component of ensuring that this policy is leveraged for maximal effect in promoting social service delivery, and by extension, CIE is to allow CBOs to enroll as Medicaid providers to support the reimbursement of CHWs in community-based settings. While a CHW's primary role is to engage individuals in their community, they are often a key conduit for collecting and communicating data on social needs, providing capacity to CBOs to participate in CIE.

HIE Incentives

Health Information Exchange (HIE) Incentives are designed by payors to entice and reward organizations and providers to participate in the exchange of health care information for the purpose of better care coordination, reductions in duplicate services, and overall patient safety. Patients often are mobile in their care and can see multiple providers at multiple organizations. By sharing the information with an HIE, providers with an active care relationship can see across health systems to better serve their patients. HIE incentives are paid by multiple payors in Michigan through different programs, usually by measuring participation in a specific HIE use case such as Admission, Discharge, or Transfer (ADT) notifications.

Currently, there are programs that incentivize Provider Organizations (PO) to provide data, through HIE Use Case-based incentives and Z-code based incentives, or incentives based on claims data using diagnosis codes which identify social needs, to different initiatives. These include the MSHIELD Collaborative Quality Initiative (CQI), which is focused on promoting health equity by leveraging data on social need to inform care delivery across CQIs targeting various chronic conditions, and the Blue Cross Blue Shield of Michigan (BCBSM) Provider Group Incentive Program (PGIP) which distributes money to providers for participation in SDoH use cases through POs. These programs could be structured to reimburse CBOs for their role in care delivery and associated CIE activities.

Commercial payors currently incentivize primary care providers and specialist providers through the Patient Centered Medical Home/Neighborhood certifications.
This certification for specialty and primary care practices makes them eligible for special payments or uplifts through value-based care programs through commercial payors. The incentive for this program is paid to POs as the certifying body for the practices, and to providers directly through Value Based Reimbursement via claims. These designated providers are required to engage with CBOs, make those resources available to their patients, and demonstrate a process for closed loop referrals to CBOs. This capability could be updated to require or incentivize the referral process to be completed through CIE versus manual processes, to encourage greater adoption of the technology by CBOs, facilitating a more efficient process.

Current programs, such as Blue Cross Blue Shield of Michigan Physician Group Incentive Program, incentivize health care providers to send information to the state's HIE, including social needs screening data through the SDoH use case. Other incentives are provided for Z-Code submission on claims. These incentives, when paid to health care providers, currently have no expectation or acknowledgement of the work of the CBO in receiving and processing a referral. Incentive programs related to the use cases of SDoH and closed loop/interoperable referrals should establish mechanisms to incentivize CBOs to participate in CIE in their design given their critical role in addressing social needs.

Revenue Sharing and Reinvestment Strategies

The task force also discussed the potential for revenue sharing strategies among the technology vendors that serve the market for CIE activities. If MDHHS takes action to develop a CIE ecosystem, it will make it easier for vendors to find and acquire customers for their products. Furthermore, building up state CIE infrastructure (such as, resource directory information, identity management services) benefits vendors by alleviating costs and liabilities they would otherwise have to take on individually. Given the state's commitment to the value of equitability in establishing CIE, this set of profit-making incentives can be balanced by revenue-sharing agreements among vendors which can reinvest funding into the community that they serve. This might involve a certification fee or percentage-based profit-sharing arrangement. The task force can recommend a process of engaging vendors and interested partners in discussion about equitable arrangements in which a fair amount of reinvestment from vendors can be allocated to CIE priorities that benefit the entire market, especially the CBOs involved.
In that same light, the task force observed that non-profit hospitals are expected but not required to reinvest their revenue for community benefits, and the effectiveness of current reinvestment patterns are in doubt; advocates are increasingly calling for corrective action to ensure that non-profit hospitals are meaningfully re-investing surplus revenue in community benefit strategies. Michigan is one of few states that does not have community reinvestment required through legislation.

Additionally, MDHHS can leverage Medicaid health plan contracts to require reinvestment in community-based services. As with any reinvestment policy, it is important that there are guardrails to ensure these investments are made with input by the community. This may include requiring the establishment of a community advisory board or council to help direct funding in alignment with community needs.

Advocacy for Federal Support of CIE

The task force recognizes without federal guidelines and funding, implementing the recommendations will be difficult. A CIE sustainability strategy should leverage infrastructure established by regional and statewide Health Information Exchanges (HIE). HIEs were created primarily with funding from the federal government when adoption and meaningful use of electronic health records were a priority for the Centers for Medicare and Medicaid Services (CMS) following the Health Information Technology for Economic and Clinical Health (HITECH) Act, under the American Recovery and Reinvestment (ARRA) Act of 2009.

Under HITECH, there was funding available to the HIE itself, and there was funding available to incentivize the use of HIE. Funding was structured to pay for meeting different milestones. States were responsible for administering the Medicaid incentives and ensuring compliance with the program. HIEs were funded specifically to serve providers and the state in exchanging health care data. Hospitals and providers were then incentivized to use the HIEs to exchange the data.
The Office of the National Coordinator for Health Information Technology (ONC) is responsible for oversight and certification of Certified Electronic Health Records. The third stage of Meaningful Use is known as “Promoting Interoperability” part of a broad effort to move toward value-based payment. Incorporating the social service sector into health information exchange is a key component to promoting interoperability. As such, the ONC is well suited to offer states guidance on the implementation of CIE.

The CIE Task Force recognizes without federal guidelines and funding, implementing the recommendations will be difficult. While the comparison between HIE and CIE is not apples to apples, engagement and participation in any CIE effort by a CBO would benefit specifically from the clarification and guidance regarding:

1. Privacy and Security for non-covered entities
2. Certification and Standards for Social Care Vendors
3. Funding for CBOs to provide incentive to engage and participate in CIE

The Role of Philanthropy

Another promising avenue for regional sustainability is active participation and funding from both philanthropic organizations, including various foundations across the state, as well as corporate sponsors. The task force has noted that there are active discussions taking place in several regions between CIE pilots and regional foundations, many of whom see alignment between their mission(s) and what CIEs hope to achieve. Similarly, several industry sectors including automotive and energy are also discussing collaboration or funding to either augment or expand the reach of their existing assistance efforts for low-income customers or employees, or general community investment where they have a significant employment presence. Task Force members have observed that the role of philanthropy is especially important with respect to CIE investments independent of healthcare. While much of the impetus behind CIE comes from increasing recognition by payors and providers of the importance of addressing health related social needs to improving outcomes and reducing costs, investment in connections and referral among community-based organizations is essential to a robust CIE ecosystem.

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Sustainability Final Recommendations

Sustainability Recommendation #1: MDHHS should expand the availability of funding for social services through Medicaid, by leveraging policies such as an 1115 waiver to examine the true cost of care for health-related social needs social care interventions, taking advantage of the support recently signaled by CMS for "In-lieu of Services," and Community Health Worker reimbursement mechanisms that can include CBOs as Medicaid providers.

Sustainability Recommendation #2: MDHHS and commercial payers should create mechanisms to fund CBOs by leveraging existing use case participation incentive programs, like Physician Group Incentive Program (PGIP), Patient Centered Medical Home (PCMH), Pay for Performance (P4P), etc., to support tools, workflows, technical assistance, staff and other costs related to CIE.

Sustainability Recommendation #3: MDHHS should leverage Advance Planning Documents (APDs) where possible to offset the costs of information technology implementation and enhancements with federal matching funds. Medicaid Advance Planning Documents outline experimental, pilot, or demonstration projects related to health IT which are submitted by MDHHS to CMS to secure up to 90% federal match. Match is determined with respect to the impact on the Medicaid program and its beneficiaries. These funds are able to support up-front costs related to IT improvements and enhancements, including staff time and training.

Sustainability Recommendation #4: Recognizing the importance of social care as an essential component of holistic health and well-being, health systems, health plans, and hospitals should have established mechanisms for investing in social service delivery. This may include requirements in health plan contracts, or statute requiring the reinvestment of profits into community-based services. There should be established guardrails on these investments to ensure alignment with needs of the community and are under community direction.

Sustainability Recommendation #5: The State should promote an equitable method of revenue-sharing among technology vendors who provide services in the CIE market, by which vendors collectively re-invest a percentage of revenue into core infrastructural services that support CBO activity in CIE processes, such as infrastructure maintenance and/or consumer engagement in governance processes.

Sustainability Recommendation #6: In the short-term, philanthropic funding can support the startup costs of CIE for CBOs, while in the long-term philanthropies can help sustain CIE by making 'program-related investments' in CIE services that support their grantees' programs and inform their grantmaking processes.

Sustainability Recommendation #7: The State and key partners should advocate at the federal level for systematic investment in CIE, similar to the Meaningful Use EHR Incentive program governed by the Office of the National Coordinator which incentivized providers to implement electronic health records and use them meaningfully. The criteria and stages of the Meaningful Use Incentive program were essential to promoting interoperability and data sharing among health care providers. This guidance and support from the federal level is necessary to effectuate all of the recommendations.

Prioritization of Recommendations

The final recommendations were further reviewed by the task force to support implementation planning. Task force members completed a survey related to the overall priority of each recommendation and its level of urgency. As a result, thirteen recommendations surfaced as essential for early implementation by most survey respondents (more than 50%). Four of the thirteen essential recommendations were further identified for immediate implementation by a strong majority of survey respondents (more than 65%).

The following table summarizes recommendations by priority. The task force may leverage opportunities to accelerate recommendations not prioritized and/or to revisit prioritization during the implementation phase, as necessary.

Priority	**Recommendations**
Highest	Capacities for Data Exchange: Adopt standards for data exchange to enable interoperability among many technology systems to ensure basic infrastructural capacities can be used by any compliant software system.
Highest	Legal and Ethical Framework: MDHHS should establish a baseline policy framework and common structure for legal agreements for collection, exchange, and use of data in contexts not already governed by HIPAA, FERPA, or 42 CFR p2.
Highest	Sustainability: MDHHS should expand the availability of funding for social services through Medicaid, by leveraging policies such as an 1115 waiver to examine the true cost of care for health related social needs social care interventions, taking advantage of the support recently signaled by CMS for “In-lieu of Services,” and Community Health Worker reimbursement mechanisms that can include CBOs as Medicaid providers.

Priority	Recommendations
Highest	Sustainability: MDHHS should leverage Advance Planning Documents (APDs) where possible to offset the costs of information technology implementation and enhancements with federal matching funds. Medicaid Advance Planning Documents outline experimental, pilot, or demonstration projects related to health IT which are submitted by MDHHS to CMS to secure up to 90% federal match.
High	Longitudinal Data Aggregation Capacities: General standards for data collection, retention, and use should be set statewide; specific decisions over implementation and policies for usage should be made at the most locally appropriate level (in harmony with the statewide framework).
High	Longitudinal Data Aggregation Capacities: Leverage already-existing assets for data infrastructure when possible, and establish appropriate systems of governance for operation of any such infrastructure in contexts which aren't already regulated by HIPAA.
High	Legal and Ethical Framework: MDHHS should support and fund, where possible, processes for partnership development, workflow change management, auditing, and compliance with all of the above.
High	Coordinating Entities Capacities: MDHHS can set standards and establish sustainable funding streams to support coordinating entities.
High	Coordinating Entities Capacities: Coordinating entities should both reflect the priorities of their communities, and be designed to facilitate collaboration across networks.
High	Governance: CIE activities should be conducted by accountably governed bodies that are responsible for acting in the best interests of the people they serve.

High	Governance: CIE Governance should formally represent the interests of affected parties, especially those of consumers and service providers, in transparent and inclusive decision-making processes.
High	MDHHS and commercial payers should create mechanisms to fund CBOs by leveraging existing use case participation incentive programs, like Physician Group Incentive Program (PGIP), Patient Centered Medical Home (PCMH), Pay for Performance (P4P), etc., to support tools, workflows, technical assistance, staff and other costs related to CIE.

Priority	Recommendations
High	Sustainability: The State and key partners should advocate at the federal level for systematic investment in CIE, similar to the Meaningful Use EHR Incentive program governed by the Office of the National Coordinator which incentivized providers to implement electronic health records and use them.

Objective 5: Articulate Prospective Pilot Scenarios for CIE

Articulate scenarios for pilot implementations of key use cases that enable cooperation among prioritized groups.

CIE pilots should involve health, human, and social service providers who use different technology systems to deliver care to Michigan residents and agree to work together as designated lead implementers of new or expanded CIE capacities. The pilot collaboration should involve more than two organizations who may each articulate their own specific objectives yet share a goal of improving outcomes by enabling information to be exchanged across multiple technologies. Lead implementers will designate staff who directly provide services to participate as partners in each phase of the lifecycle, and these staff will also participate in strategic engagement with designated client representatives to elicit feedback on the priorities, outputs, and implications of the pilot.

Pilots should establish a specific set of technical objectives for which information exchange capacities can be designed, tested and evaluated in iterative cycles – with results reviewed in each phase of the lifecycle by the lead implementers and the designated CIE governing body. Pilots should specifically designate responsibilities for stewardship of the design, implementation, and evaluation processes; pilots can identify one or more technical partners who will support implementation of these information exchange capacities.

To achieve their stated objectives, it is preferred that pilots be designed to leverage data infrastructure that already exists in Michigan. If it is demonstrably evident that already-existing data infrastructure is not fit for the pilot project's purpose, the pilot should at least demonstrate the ability for any new infrastructure to eventually become interoperable with relevant statewide infrastructure.

In the concluding phase of the pilot, the stewards and lead implementers will work together to develop a final report which will include at least one proposal for future development

Prospective objectives for pilot projects:

1. Matching identities of clients across platforms to ensure individuals can be securely identified from one service context to another (i.e., health care patients who might also receive care from social service providers), among heterogeneous information systems.
2. Exchanging sensitive personal data across platforms such that the various information systems used by participating providers can securely and effectively transmit and receive data for purposes such as screening, making referrals, sharing information about service delivery, and monitoring results.
3. Aligning vocabularies across systems such that diverse and context-specific terminologies – such as LOIN codes and SNOMED-CT, and social care terminologies like the 2-1-1 Taxonomy – can be reliably translated and accountability clarified over time.
4. Share resource directory data across systems in support of service discovery and cross-platform referral coordination.

Any pilot proposal should:

1. Apply the shared values and principles, and uphold the rights of consumers and communities, as articulated by the CIE Task Force. Documented legal agreements and operational protocols will be considered key outputs of the pilot.
2. Articulate a method by which program capacity for service delivery will be expanded among participating CBOs.
3. Use replicable workflows and/or standardized protocols for data exchange that can be implemented beyond the pilot by other organizations using different technologies, to ensure that the pilot yields interoperable outputs that are not dependent upon any one vendor.
4. Actively elicit and uphold consent such that individuals, service providers, and communities have agency in the process of data collection, exchange, use and re-use – upholding rights to understand, refuse, revoke, and seek redress for harmful outcomes.
5. Establish systems of evaluation and governance for all of the above, ensuring that representatives of key groups of impacted parties – including consumers themselves – will contribute consequential input each phase of the lifecycle of CIE programs, such that feedback from consumers and service providers is received and fairly addressed in all design and development processes.
6. Develop proposals for sustainability of the involved information exchange infrastructure beyond the timeframe of the pilot.

Conclusion

This report details the actions of the CIE Task Force to realize its goal of advising a state CIE strategy. The CIE Task Force has brought together CBOs, health care organizations, health payers, health IT, and governmental entities to align work that are best served by a coordinated approach to CIE. To that end, the task force has produced thirty-three recommendations actions that the state government can take to support the information ecosystem of health, human and social service providers in Michigan.

The task force has put forth a set of recommendations with strong consensus alongside a high-level roadmap for implementation. These recommendations include:

1. Establish core technical capacities necessary to enable interoperability at a statewide scale – including standards for data exchange and identity management services.
2. Establish a reliable supply of resource directory information to be provisioned as a public good.
3. Establish a statewide framework for legal agreements that aligns with existing regulatory frameworks while addressing data collection in contexts that are not otherwise regulated; and establish an ethical framework in the form of a “Bill of Rights” for consumers and communities.
4. Ensure that aggregation of longitudinal data about people and populations can occur with the informed consent of data subjects.
5. Designate and support ‘coordinating entities’ in the process of facilitating activity among CBOs, government agencies, and healthcare institutions – and ensure that these entities uphold fiduciary responsibilities for the people and organizations that they serve.
6. Establish federated systems of governance through which standards and policies are set statewide, while priorities and implementations can be decided and evaluated locally.
7. Leverage a variety of financing mechanisms to build and sustain these capacities, including the capacity to provide more social services.
8. Creating an effective CIE remains a challenge in the state of Michigan. It remains clear that any CIE must prioritize interoperability among different software systems, capacity to participate among partner groups, and systems of accountable governance to ensure equitable process and outcomes.

Successful implementation of the recommendations will require strong leadership from the Michigan Department of Health and Human Services, the Michigan Health IT Commission, and leaders across healthcare, social care, payers, and in communities. These recommendations serve as a guide to the department for the implementation of CIE in the state of Michigan that, if done correctly, will promote health equity and lead to improved health and social outcomes for Michiganders.

Appendix A: Glossary of Common Acronyms and Terms

Term	Definition
Community Information Exchange (CIE)	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. 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. Source: 211 San Diego CIE Toolkit
Community Information Exchange (CIE)	A [CIE] should encompass three elements of primary infrastructure that comprise a holistic ecosystem of health and social care: Resource Data Exchange, Client Data Exchange, and Community Data Governance. A CIE should facilitate the reliable flow of information about resources available to people in need to support service discovery and accessibility. A CIE should facilitate the responsible flow of information about clients as shared among various service providers to support cross-sector coordination of care. A CIE should ensure that the systems and activities associated with coordination of social care are equitably developed and implemented according to the expressed interests of partner groups in a local community. Source: "Tackling Data Dilemmas in Social Care Coordination," Bloom and Sorenson 2021

Term	Definition
Health Equity	Health equity means that 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. Health equity also means reducing and ultimately eliminating disparities in health and its determinants that adversely affect excluded or marginalized groups. Source: Robert Wood Johnson Foundation
Social Drivers of Health	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. These forces and systems include economic policies and systems, development agendas, social norms, social policies and political systems. Social determinants of health refer to macro patterns pertaining to population health that are observable in aggregated data. Source: "Meanings and Misunderstand ings: A Social Determinants of Health Lexicon for Health Care Systems," Milbank Quarterly

Term	Definition
Infrastructure	The underlying systems and resources that are required for public works [and associated activities]. Source: Dictionary
Stewardship	The careful and responsible management of something entrusted to one's care. [as distinct from ownership]. Source: Dictionary

Term	Definition
Governance	The process of establishing and ensuring the freedoms, constraints, and incentives that determine how two or more parties agree to conduct their behavior. Source: Sage Networks on Data Governance
Resource Data	Information about the health, human, and social services that are available to those in need, including the organizations that provide them, the locations at which they are available, and associated types of information about the accessibility thereof. Source: "Tackling Data Dilemmas in Social Care Coordination," Bloom and Sorenson 2021

Term	Definition
Federated HIE	Enables sharing of data among systems, given common patient identifiers; does not hold data itself, data remains locally stored. Source: "Tackling Data Dilemmas in Social Care Coordination," Bloom and Sorenson 2021
Centralized HIE	Maintains a single shared 'clinical data repository' to which all member systems contribute. Source: "Tackling Data Dilemmas in Social Care Coordination," Bloom and Sorenson 2021

Term	Definition
Hybrid HIE	Some shared clinical data is stored in an HIE which facilitates exchange among a network of local data sources. Source: "Tackling Data Dilemmas in Social Care Coordination," Bloom and Sorenson 2021
Application Programming Interface (API)	A set of software code, protocols and tools that enable developers build applications that interact with a database. APIs do not have a user interface; rather, they offer instructions that enable software developers to embed interactions with the given database through their software programs. Source: Office of the National Coordinator APIs 101, 4/2021

Term	Definition
Closed-loop Referral Platforms aka Social Health Access Referral Platforms (SHARPs)	Software designed to enable care coordinators to screen for social risks, needs, and protective factors, connect members to community resources to address social health and then understand the impacts on members' clinical health outcome – with the shared aim of enabling health care organizations to identify and refer patients to social service organizations more easily. Source: UCSF Social Interventions Research & Evaluation Network (SIREN), April 2019
Service Request	http://www.hl7.org/fhir/servic erequest.html

Term	Definition
Identity matching capacities	Capacity to associate records about a given person in one system with records about the same person in another system. Source: https://sequoi aproject.org/re sources/patien t-matching/
Consent and/or Permissions management	The processes by which users agree to collection, sharing and use of data about themselves, and the related processes by which third parties are permitted to conduct such activities.

Term	Definition
Data Exchange Capacities (APIs, etc.)	Enable the transmission of data between different actors at different organizations using different technologies.
Terminologies and translation capacities	Enable the standardization of vocabularies across contexts, and/or translation between different vocabularies to support semantic interoperability.

Term	Definition
Consent and/or Permissions management	The processes by which users agree to collection, sharing and use of data about themselves, and the related processes by which third parties are permitted to conduct such activities.
Data Exchange Capacities (APIs, etc.)	Enable the transmission of data between different actors at different organizations using different technologies.

Term	Definition
Terminologies and translation capacities	Enable the standardization of vocabularies across contexts, and/or translation between different vocabularies to support semantic interoperability.
Longitudinal data collection	Aggregation of information about people's social context, care activities, and results over time. Data can be aggregated longitudinally about individuals, like in a shared client record used for "community care planning." Data can also be anonymized in longitudinal aggregation of population-level data for reporting, analytics, and evaluation of community needs, program effectiveness, etc.

Term	Definition
Normalization	Organizing data entries to ensure they appear similar across all fields and records.
Aggregate reporting and analytics	The ability to combine data across organizations to look at overarching social care trends for a population of community.

Term	Definition
Anonymization	Organizing data entries to eliminate personally identifiable information.
CIE Network	A network of partners bidirectionally sharing data to connect people to health care and social care services.

Appendix B: Membership of the Task Force

Membership includes 15 representatives of entities or communities with a stake in CIE, up to two designated liaisons from the Michigan HIT Commission, and no less than two consumers.

Members of the task force can make recommendations for expansions to the membership, for consideration and approval by the MDHHS SDOH Steering Committee.

Name	Title	Organization
Ammar Alzuad	Community Health Worker	Medicaid Health Plan
Bob Kreha	MI 2-1-1 Technology Consultant, Principal & Co-Founder, BrightStreet Group	Michigan 2-1-1
Dawn Opel	General Counsel and Director of Research & Strategic Initiatives	Food Bank Council of Michigan
Ed Worthington	President/Owner	Advanced Technology Health Solutions/NMCHIR
Janée Tyus	Senior Director, Mid-Michigan Community Health Access Program	Greater Flint Health Coalition
Joyce Fetrow	Project Director	Northern Michigan Opioid Response Consortium (NMORC)
Julia Aronica	Director of Plan Initiatives	Blue Cross Complete
Kelly Stupple	Program Manager and Child Health Advocate	Washtenaw Health Plan

Name	Title	Organization
Marissa Ebersole-Wood	VP, Regulatory Implementation and Data Governance	Blue Cross Blue Shield of Michigan
Nadeem Siddiqi	Executive Director, Technology, Development and Data Strategy	Wayne Metro CAA
Patrick McNeal	Director	North Flint Neighborhood Action Council
Renee Smiddy	Sr. Director, Policy	Michigan Health & Hospital Association
Sarah Kile	MI 2-1-1 Director of Outreach	Michigan 2-1-1
Steven Grulke	Chief Information Officer	Mid-State Health Network
Tim Pletcher	Executive Director	MIHIN
Tyler LaPlaunt	Tribal Council Member	Sault Ste. Marie Tribe of Chippewa Indians

Appendix C:

Values andPrinciples The CIE Task Force convened by Michigan DHHS has articulated a set of values that should guide all activities associated with the collection, exchange, and use of personal data through social care processes: accessibility, accountability, equitability, and responsibility.

Values

Accessibility

- CIE intends to facilitate the connection of people and resources through methods that are both efficient and effective. This entails the development of accessible interfaces, understandable information, and accessible institutional processes in which interested partners are able to participate.
- In promoting accessibility, CIE programs and strategies should prioritize interoperability (to the extent that interoperability is responsible and appropriate) to ensure that new technologies do not create new barriers to care.
- The accessibility of data on individuals and services should enable a trauma-informed approach to care that supports the whole individual.

Accountability

- Accountability entails transparency – decisions and rationales should be knowable and understandable by all interested partners; it also means that decisions and outcomes are subject to evaluation of and feedback from partners.
- Criteria for data collection and use should be clearly articulated, understandable, and subject to challenge by interested partners. Coordination, collaboration, and trust among community members and the sectors that serve them is key to ensuring accountability.
- When appropriate, the CIE should yield aggregated and disaggregated data back to community organizations and members for interpretation and use for advocacy.
- We monitor for any unintended consequences and commit to creating a process to address any harm that occurs.

Equitability

- CIE should prioritize the removal of barriers to service, and in that effort we center the perspectives of people who commonly face exclusion due to social, economic, demographic or geographic situations – and who are most impacted by our work.
- We commit to both equitability of process – which entails inclusive and fair decision-making – and equitability of outcomes. When processes and/or outcomes are found to be inequitable, we commit to rectifying this imbalance.
- The work of CIE is collaborative, inclusive, and intentionally and equally distribute power across all sectors and the impacted community.

Responsibility

- We design systems to value the best interests and protect the safety of community members.
- Information about individuals is stored securely and there are clearly established governance processes in place to determine who can access the information, what they can do with the information, what should happen when things go wrong, and who is ultimately responsible for these decisions.
- Uses of aggregated data, even when de-identified, should be vetted through accountable processes to anticipate the range of possible impacts thereof.

Interconnectedness

- We recognize the interrelatedness of people with each other – i.e. CIE doesn't just serve individuals but families, caregivers, communities as a whole.
- We recognize the relationships between health and social factors, and promote holistic approaches to care coordination that address people as a complex whole.
- We recognize that technology systems and organizations should work together (to whatever extent is responsible and accountable) to meet common goals. A primary purpose of CIE is establishing interoperability among systems.

Principles

Learn together

- In our work, we should clearly state our assumptions, articulate the logic guiding our decisions, test these assumptions, and revise as we learn.
- We define measurable criteria and metrics, and engage all relevant partner groups in gathering data, analyzing data, and evaluating outcomes.
- We commit to continuous, iterative quality improvement processes. Center impacted parties in both design and decision-making.
- Our processes and products should be people-centered, prioritizing the perspectives and prerogatives of those who have most at stake in this work – primarily people in need, community organizations, and diverse communities as a whole.
- Diverse perspectives should drive decisions, with an emphasis on the perspectives of people most impacted
- We strive for consensus when possible, and consent always; we invest in conflict resolution.

Build and maintain trust

- Treat all with dignity and respect
- Work with compassion and build trust Serve

Common interests

- Commitment from network partners to think beyond their individual programs and services
- Willingness to re-engineer business processes in support of a shared vision for healthier communities
- Work across silos – break down barriers while maintaining important boundaries.

Anticipate, mitigate, reduce, and redress any possible harms

- We uphold not only the privacy of individuals – meaning, their right to decide what they share – such that the specific context of their permission to share is accounted for and respected.
- We recognize that there are potential harms that can come to people and communities from the use of aggregated, de-identified data, and we assess the risks of those harms and take action to mitigate or if necessary redress them.

Appendix D: Consumer Bill of Rights

CIE task force recommends the drafting of a Consumer Bill of Rights as a normative foundational tool for this work. This recommendation stems from work done by the Promotion of Health Equity Project's learning network that analyzed a range of potential risks posted by CIE activities, including risks to individuals (of sensitive data used in inappropriate contexts in ways that cause harm) and risks to communities (in which aggregated data is used in ways that amplify inequities in access to care and allocation of resources).

The learning network has articulated this first set of rights that can protect consumers and ensure equitable processes and outcomes when effectively upheld through principled decision-making processes.

Consumer Bill of Rights

1. Consumers have a right to understand the purpose and conditions for collection, sharing, and use of data about themselves – and to refuse such data collection, sharing, and use on both general and specific bases, to the extent permissible by law, and with possible exceptions for matters of urgent public interest such as infectious disease outbreaks or other public health emergencies. The specific context of consumers' consent must be accounted for and respected.
2. Consumers have a right to clear and accessible processes through which they can request information about, corrections to, and if need be revocation of data about themselves, to the extent that is advisable by practice and permissible by law.
3. Consumers should be able to withdraw from automated processes in order to engage with a human who can quickly consider and remedy any problems they have encountered.
4. Consumers have a right to object to processes that use data about themselves or people like them in ways that they believe are unfairly discriminatory. Such challenges should be heard through an accessible and transparent process, and remediated through measures that repair the harm caused and take action to avoid such future harm.
5. Consumers' access to care should not be contingent upon collection of any information other than that which is minimally required by transparent and consistent policies.
6. Consumers have a right to bring data about themselves with them from one provider/organization to another, regardless of which technology any given provider uses.
7. Consumers should be able to designate an individual who may act on their behalf, or have such a designation made in their best interest. Consumers should also be able to challenge and request an update of such a designation in the event that they believe decisions are not being made in their best interests.
8. Consumers have a right to articulate their own goals and objectives for health and well-being. In so doing, consumers should have agency in the process of care planning and coordination, to whatever extent permitted by law and relevant policy.
9. Communities should have established processes through which their members can propose, review, and sanction any uses of data about people within the community.
10. Communities should have the right to collectively refuse to be subject to surveillance. Technology systems operate with a social license that is revocable.

On Community-based Organizations

The task force recognizes that the interests of CBOs should be clearly articulated and respected in CIE systems. There is no consensus as to whether these interests should be expressed as rights on par with the rights of consumers and communities – or whether they should simply be codified through CIE-related policies. To inform future deliberation, we are including this proposed set of freedoms for CBOs.

In CIE systems, CBOs should be able to:

1. Choose the technology they use.
2. Choose the organizations with whom they wish to partner.
3. Request corrections to directory information about their services.
4. Respond to grievances raised against them, and receive a fair hearing.
5. Raise grievances about policies or actions that they consider to be inequitable – for the CBO, their clients and/or community – as well as propose changes to policies, and receive a fair hearing.

Appendix E: CIE Use Cases

The task force undertook a process of articulating two CIE use cases, a CBO referral to a CBO use case, and a CHW referral to community-based services use case.

Use Case #1: Referral from a referring CBO to a servicing CBO

This use case illustrates a referral from one CBO to another CBO. The example involves a senior citizen working with an agency for seniors, which is the referring CBO. We'll call them the Senior Agency. The Referring CBO submits a service request for housing assistance to the CIE which is routed to a housing assistance network, the Serving CBO. We'll call them the Housing Agency. The Senior Agency also receives notification that the family has/has not received assistance.
In this use case, the client or the community member is the ultimate beneficiary, who receives services from the serving CBO. The referring agency, that is a community-based organization, is the primary party. In this example the referring agency is the senior agency. They initiate the action by describing how the Housing Agency can assist the client, gaining consent, and ensuring that the client's data is entered into the CIE as a service request. The senior agency also expects to receive data about outcomes for the clients they refer through the CIE. The CBO that receives the service request the CIE forwarded on behalf of the client and the referring agency is the actor in this process, it is the serving community-based organization, their job is to fulfill social care needs through the programs and services they provide.

The referring agency's goal is to transmit a client's specific need to a specific serving agency that can meet the client's needs. A secondary goal is for the referring agency to receive confirmation and details regarding how the client's needs were/were not met. In this use case, the client (community member) must consent to their need/data being sent into the CIE. In addition, the CBOs (referring agency and servicing agency) need to be listed in resource directory, preferably with up-to-date program, location, and eligibility information. Finally, this use case requires a pre-established routing rule for domain-specific (in this case housing) needs from the referring agency has been configured in the CIE.

The basic flow for this use case is the referring CBO access the client profile in their system. The servicing CBO administers an assessment of their choice to understand the client's situation. The referring CBO documents the specific observations (e.g., housing need) in their system. In discussions with client, the referring agency recommends housing providers to the servicing CBO to the client to assist with the housing need. The client consents to share their data (profile and observations and consent for a service request to be created) with the CIE for routing to housing services. The referring CBO then electronically submits a service request, on behalf of the client, to the CIE (the referral agency could also manually submit a service request using a default, community-wide referral form for this step). Based on pre-defined triggers and rules the service request is routed by the CIE to housing provider.

Within the service request, the CIE includes relevant client data (profile and observations) as well as referring CBO details to the housing provider. The Housing provider receives a client service request notification as well as the client's service request data (profile and observations/needs) in their integrate system. Alternatively, the housing provider could receive a client's service request notification as well as the client's service request data outside of their system, such as through secure email notification).

The servicing CBO then reviews and accepts the service request or, alternatively, the servicing CBO determines they cannot accept the service request and notifies the CIE and/or the referring agency.

If the housing provider can service the client, they then create a client profile, or accesses client's information already in their system. The housing provider then contacts the client, alternatively, the client may contact the housing provider (through phone, email, or in-person). The housing provider performs the intake process, which might consist of an eligibility evaluation and/or a needs assessment and/or documenting additional observations (e.g., In addition to housing assistance, the client needs transportation assistance and legal assistance). This data stays in the housing provider's system and is not shared back into the CIE unless the housing provider chooses to submit a service request for these needs and has the client's consent to do so.

The next step is the intervention when the housing provider provides the client with assistance. The housing provider documents the intervention (e.g., assistance in progress) in their system. It sends data electronically to the CIE regarding the intervention, using a client unique identifier. The referring agency receives updates on their specific client's service request status and met/unmet need(s) per a pre-established agreement on what status(es) are meaningful to the referring CBO. It is likely that the housing provider could detect additional client needs and decide to create new service request(s) in the CIE for additional assistance. In this case, the housing provider becomes the referring CBO and this process starts again.

Analysis

This is a use case that involves coordination of care among two CBOs – a referring agency and servicing agency. Organizations in this use case must have information systems that can send and receive data securely. Additionally, they must have the capacity to: uniquely identify the client across different databases; the ability to route data between systems; the ability to standardize and/or translate the terminologies used by each system to describe clients and processes; and monitoring and assurance for all of the above. There also need to be clear policies for the client to consent for their data to be collected, shared, and stored.

The task force noted that many – perhaps most – of these capacities already exist in Michigan, through MiHIN and/or Michigan 2-1-1. However, it still takes funding and work to implement each of these integration capacities with any given organization. The task force noted that the referring agency needs capacity to perform the labor of screening, and the service agency needs to have capacity and ability to contact the client, as well as to conduct and document a more thorough assessment.

Relatedly, this use case further reveals the tremendous complexity within a closed-loop referral. Housing, for instance, is one of the most critical needs in Michigan communities, but this need cannot simply be met by a referral to a housing assistance program. A successful housing referral requires structured process and staff time to place an individual into housing, potentially in addition to intermediate interventions along the way.

There are also many different kinds of housing (such as, recovery housing) that are not all supported by government subsidizing. It is important to not close off pathways to forms of assistance that are not supported by one institution (such as, the government). The task force recognizes that any strategy that generates more referrals without addressing the need for more resources, like housing, is incomplete.

Notably, no healthcare providers are involved in this use case. This prompted questions among task force members for which there were not answers with clear consensus. Some task force members posited that there could be benefit from making information gathered by the referring agency available to other providers through some sort of shared client record. Therefore, data from this interaction could be used to preempt the need for other providers to conduct redundant screenings and could be used to help other providers address other gaps. However, other task force members expressed concern about this prospect – observing, for instance, that some of the data collected in this interaction could, if shared elsewhere, negatively affect a client's access to other benefits and programs. Beyond such specific risks, these task force members expressed on principle that social circumstances should be considered short-term, not permanent labels that could "blemish" a person and even other people in their family. Also, we noted that the client might not even have a primary care provider with whom this data could be shared.

In summary, it might sometimes be appropriate and good to share the kind of data collected in this use case with other providers outside of the two featured, but also such sharing might sometimes be inappropriate and bad. There is general agreement that data about these interactions should be longitudinally collected in an aggregated, anonymized format – to enable research and advocacy for data-driven decision-making that can affect systemic change, such as increased funding for housing. As for sharing personal information outside of the interactions described here, we observed potential tradeoffs between the potential efficiency of centralization and concerns of human dignity and agency – tradeoffs need to be carefully managed through equitable governance processes.

Use Case #2: Referral from a Community Health Worker to community-based services, Greater Flint Health Coalition's Mid-Michigan Community Health Access Program (CHAP)

In Flint and Genesee County, there are a variety of small and mighty CBOs that provide resources to the community with limited technological, funding, and staffing capacity. A local coordinating agency helps people connect to health care services and community-based resources. The coordinating agency uses Apricot, a Client Management System, to internally manage all information about each person it serves; it also uses findhelp, a community resource referral platform, to receive and send referrals for clients to other community organizations that use findhelp.

For instance, a local church operates a community outreach center that can provide home delivered meals to people in need for emergencies and on an ongoing basis. They can also provide food boxes that are tailored to the person's needs. They will not conduct medical verification of diabetic needs themselves; rather, they can meet the needs of a person who is referred to them through a trusted intermediary. They use findhelp to receive such trusted referrals.

A scenario involving community information exchange capabilities could involve the following steps: A Community Health Worker working at the coordinating agency (i.e. the Hub) receives a referral, through findhelp, from an Educator at a school-based health center, for a diabetic student, after receiving consent from the caregiver. The CHW connects with the student's family and interviews them to assess and identify their health-related social using an internal social determinants of health screening tool and documents the results of the screener in Apricot. The CHW enters this information into Apricot, which also includes historical data about the student's medical history and past engagement with the hub.

Reviewing these records received through participating health care providers and health plans, the CHW observes that they might need specialized food support. Within the Apricot CMS, the CHW performs a search for diabetic meal services and receives a list of options, delivered from the 2-1-1 resource database, to which the patient can be referred, including the local community outreach center. The 2-1-1 directory record for the outreach center indicates that it is accepting referrals via findhelp.

The CHW asks the caregiver if they would like to receive this kind of specialized food assistance. When the person says yes, the CHW asks if they can share information about the family with the CBO including the local church. The caregiver is presented with a set of specific options describing what kind of information will be shared with whom and for what purpose. The caregiver consents to have their information shared with the community outreach center and information about the student and their needs is sent from the CHW's Apricot, via API, to the findhelp platform, where it can be directly accessed by a staffer from the CBO.

The CBO staff will respond to the referral and contact the family directly for further assistance. The CBO operates their own home-grown system to track inventory and client requests; they extract patient details from findhelp and add it into their home-grown system for record keeping and processing purposes. The CHW at the hub will check in with the community outreach center through the findhelp platform and confirm that the appropriate information was received by the caregiver and meals will be delivered.

The next week, the CHW at the hub sends a text message through the hub's texting platform to confirm that needs were met and the case is closed. The patient replies yes. The CHW logs this information in Apricot, then sends an update to findhelp that updates the client's status and alerts the referring agency (the Educator at the school system) that the student's needs were met. The CHW produces a final confidential feedback form in Apricot and sends it from Apricot to findhelp to be added to the student's household record there, so that the referral sources knows all that was addressed. (This form normally is exported out of findhelp and uploaded into the patient's EHR.) Upon confirmation from all parties, the CHW produces a final case closure form in Apricot that is then shared through findhelp and ultimately ends up within referring agency's case management system.

In an alternative scenario, the family might need access to a resource provided by an organization that does not use the findhelp platform. For instance, St Luke Presbyterian Church provides food support and manages intake through their own home-grown internal system. With CIE capacity, the CHW can find information about St Luke's programs from the CIE's resource directory information service – *even though St Luke does not use findhelp*. According to the 2-1-1 posted criteria that covers Genesee County, organizations (such as churches, social clubs, etc.) which offer a service to the community at large, not just to their own members, may be included. They can still refer their patient directly to St Luke Presbyterian Church, through partially manual processes that can still be effectively recorded in Apricot and the referring agency's case management system. The CHW would obtain consent from the caregiver and connect the client via three way call to the church for pick up dates and times. The CHW indicates the referral and result in their Apricot system, which then sends an update to the referring Educator's case management system.

Analysis

Task force members appreciated that this use case demonstrates a "no wrong door" principle. The systems involved are flexible and integrated – different CBOs use different tools, but they can still work together to share information, and remain aware at every step. This enables both "warm" referrals that involve more than just handing a client a phone number, yet also enables loops to be "closed" by multiple methods – in order to meet people where they are, rather than expecting each party to come use a new system, while still getting feedback to the referring source.

Task force members observed that this isn't animated by a "payment first" mentality. There is a wide availability of services in the community, with different paths to success.

Task force members observed that the effectiveness of the use case reflects the role of Community Health Workers (CHWs) and other care navigators who are closest to the people seeking help, as they are embedded within a community. This value of local, embedded human resources – and their training, supervision, and support – should be prioritized in funding strategies.

Task force members observed that this interaction does reflect lots of work that's already happening in communities in informal ways, among organizations that don't have capacities for handling complex technical and legal processes – such "grassroots" work should be supported, not marginalized. HIPAA-compliant data gathering and exchange may be important to enable reimbursement for services, but may be too much of an obstacle for a church or other community-based organization to adopt themselves. FERPA requirements for consent may also be relevant if this data is collected and shared within an educational system, but the school has to have processes in place for these situations.

Task Force members acknowledge that, today, existing resource directories often fall short in comprehensiveness, especially with regard to capturing hyper-local, seasonal, time-limited resources, and resources offered by religious institutions or informal associations which are often essential for filling gaps. Sometimes, CHWs are tasked with updating resource directories themselves, especially for these smaller scale resources; there is no consensus as to whether this is efficient or effective. In any case, CHW's tend to have local knowledge of services that is at least as useful as resource directories. Improved resource directory information maintenance and coordination would presumably bolster and benefit from – not replace – this local knowledge, ensuring local coordination and feedback that will be promptly addressed, and ensuring that this information is equitably distributed and consistent across systems. This entails funding for maintenance and coordination of resource information.

Task force members acknowledged that CHW training is not standardized, which may reflect important realities that different models of delivery have different needs for different capacities – CHWs may not be one-size-fits-all.

Task force members wondered what it would take to make this kind of interaction scalable. There needs to be various processes in place to ensure that data is collected and shared in standardized formats. There also needs to be some standardization of workflows and reporting templates to ease entry for smaller organizations into partnerships like this – balanced against some need for specialization to meet particular community needs. That said, there was not a clear consensus as to whether this feedback process needs to be entirely standardized for all. Task force members observe that “loop closing" can be conducted in ad hoc, even informal ways; sometimes this may be more appropriate than more formal methods. For some, standardization was considered more of a nice to have but simply supporting entities to collect and share data in any way was more important.

There needs to be Business Associate Agreements (i.e., BAAs – legal agreements) for collecting and sharing this data, especially with regards to developing, overseeing, securing consent and establishing insurance against liability. For this purpose, the state can leverage the expertise of its regulatory infrastructure, developing and sharing standardized consents like the DHHS-5515 form for sharing information that is protected by 42 CFR part 2.

Ideally, the state should provide support to coordinating entities to address the cost and risk of this work. This arrangement minimizes risk for smaller CBOs working with the hub and for the state and payors who can coordinate with the hub rather than having data sharing agreements with each organization separately. Costs include convening and facilitation for governance processes as well as investments in technical infrastructure, security, and legal agreements. This could be organized through coordinated grants by state in partnership with philanthropic organizations, such as the Michigan Health Endowment Fund (MHEF).

Ideally, the state should provide support to coordinating entities to address the cost and risk of this work. This arrangement minimizes risk for smaller CBOs working with the hub and for the state and payors who can coordinate with the hub rather than having data sharing agreements with each organization separately. Costs include convening and facilitation for governance processes as well as investments in technical infrastructure, security, and legal agreements. This could be organized through coordinated grants by state in partnership with philanthropic organizations, such as the Michigan Health Endowment Fund (MHEF).

Health plans can pay for the cost to hire and train CHWs through reimbursement, as well as the costs of administration thereof. However, task force members cautioned against the prospect of health plans assuming entire responsibility – and setting criteria for – CHW work. In this case, the preferred payment model for the CHW may be per member per month, although other organizations may not prefer this.

Task force members discussed a potential complement or alternative to the hub model that would reproduce Physician Organizations (POs) in service of CBOs (rather than clinical providers). POs act as fiduciaries, and distribute incentives and grants to physicians and clinics from payors. They act as the coordinating certifying bodies for programs like the BCBSM Patient Centered Medical Home for primary care providers. They also serve providers and clinics by helping with administrative burden, identifying opportunities for more revenue, and complying with mandates. Most of the forty-two recognized POs in Michigan also offer other services to their members, such as Care Management for patients, population health registries, and participation in health information exchange like submission of Active Care Relationship Services (ACRS) files which allow providers to access the protected health information for those with whom they have an active care relationship. CBOs not affiliated with a large health system or backbone organization may struggle with many of the technical requirements related to Community Information Exchange. If a structure similar to POs existed for CBOs, or if POs expanded scope to include CBOs, this would give considerable help to CBO staff and allow them to benefit from the existing infrastructure

Appendix F: Stewardship, Meetings, and Documentation

Stewardship of the Task Force

- The co-chairs of the task force are Janée Tyus and Ed Worthington, as representatives of Community Health Innovation Regions (CHIR).
- The task force is supported by the Michigan Public Health Institute (MPHI) and Greg Bloom of the Open Referral Initiative.
- task force has been convened and staffed by MDHHS.

Meetings

Task force meetings are held once a month through at least June 2023. Members are expected to attend all task force meetings.

- Members shall engage with materials and complete necessary preparation in advance of meeting
- Members are expected to engage in discussion during meetings
- Members are invited to facilitate progress by self-organizing additional ad hoc meetings as necessary and appropriate; outputs from these meetings should be documented in SharePoint and shared with the Executive Committee.
- Members are expected to respect others, recognizing when to lean in and lean out

Documentation

- All documents are stored in a shared space accessible to all on SharePoint and on Miro board[13]
- When editing documents during discussions, MPHI will document comments, concerns, revisions and provide a revised document for consideration at the following meetings
- Members may provide feedback and revisions by email to MPHI and MDHHS between meetings
- Members may also suggest edits in shared documents on the SharePoint site
- Revisions will be made by committee and brought back to the group for final approval

[13] https://miro.com/app/board/o9J_krJX4QU=/

Appendix G: Knowledge Base Index

Topic	Title	Summary
Coordinating Entities	Community Care Hubs: Making Social Care Happen	Background on the role of Community Care Hubs to serve as a hub for coordinating a local community-based organization network.
Definition of CIE	Collaboration and Cross-Sector Data Sharing to Create Healthier Communities	CIE toolkit highlighting insights and strategies on how San Diego approached development of a local CIE.
Definition of CIE	Michigan CIE Task Force- Glossary of Terms	Key terms with definitions
Definition of CIE	Who Has the Power? An Analysis of Where Power Lies Within SDOH Interventions	An analysis of where power lies within SDOH interventions.
Definition of CIE; Standards; Resource Directory Data; Identity; Consent; Vocabulary	Tackling Data Dilemmas in Social Care Coordination	Summary of common challenges that hinder SDOH efforts, focusing on how data are shared among organizations across institutional contexts.
Governance	Leveraging Community Information Exchanges for Equitable and Inclusive Data: CIE Data Equity Framework	CIE systems-change work requires a community to adopt an anti-racist framework. The CIE Data Equity Framework will help institutions, organizations, and communities to understand, acknowledge, and reconcile systems change work in their communities.
Governance	IDS Governance: Setting up for Ethical and Effective UseActionable Intelligence for Social Policy, Expert Panel Report	In 2016, AISP convened four panels of industry experts and documented best practices in the IDS field related to governance, legal issues, technology and security, and data standards.
Identity	A Framework for Cross-Organizational Patient Identity Management	Recommendations to improve patient matching nationally across different organizations, disparate technologies, and networks.

Topic	Title	Summary
Legal	Is that even legal? A guide for builders experimenting with data governance in the United States	Drafted by Mozilla Insights, this research provides builders with an overview of the current legal landscape governing the collection, management, sharing, and use of data; and to identify opportunities for alternative data governance models in existing legal landscapes.
Legal	Data Sharing to Build Effective and Efficient Benefits Systems: A Playbook for State and Local Agencies	Benefits Data Trust has designed this Playbook as a "how-to" guide for using data sharing to make benefit systems more effective and efficient.
Legal	Finding a Way Forward: How to Create a Strong Legal Framework for Data Integration	Finding a Way Forward: How to Create a Strong Legal Framework for Data Integration was created by Actionable Intelligence for Social Policy (AISP) to support the essential and challenging work of exchanging, linking, and using data across government agencies.
Longitudinal Data Aggregation / Consent	MI Community Care Washtenaw Health Initiative	Overview of CIE in other states and local efforts in Michigan
Michigan CIE Landscape	MI Community Care Washtenaw Health Initiative	Overview of MI Community Care (Livingston/Washtenaw region)
Michigan CIE Landscape	Impact and Vision in the Livingston/Washtenaw Region	Impact and vision report in the Livingston/Washtenaw region
Michigan CIE Landscape	Michigan Health IT Roadmap: "Bridge to Better Health" Report	Overview of CIE in other states and local efforts in Michigan
Michigan CIE Landscape	Michigan's Roadmap to Healthy Communities	MDHHS social determinants of health strategy.
Michigan CIE Landscape	Overview of Health and Social Care Coordination Efforts in Michigan	Overview of Michigan CIEs in Michigan

Legal	Data Sharing to Build Effective and Efficient Benefits Systems: A Playbook for State and Local Agencies	Benefits Data Trust has designed this Playbook as a "how-to" guide for using data sharing to make benefit systems more effective and efficient.
Michigan CIE Landscape	Environmental Scan of Social Determinants of Health & Community Information Exchange Efforts Across Michigan	Draft findings from MPHI landscape analysis of Michigan health plans, PIHPs, and social service organizations
Topic	**Title**	**Summary**
Michigan CIE Landscape	Active CIE use cases/scenarios in Michigan	Detailed write up of CIE scenarios that are in production in SE Michigan and Kalamazoo.
Natural Landscape	Assessment of Community Information Exchange Landscape in US	Environmental scan of existing CIEs across the country.
National landscape	Findings From Year 1 of Highlighting and Assessing Referral Platform Participation (HARP)	Project highlights from community resource referral platform among Trenton community-based organizations.
National landscape	Connect2 Community Network Unified Network Infrastructure Request for Proposals	Request for Proposal for Connect2 Community Network CIE.
National landscape	Rising Equitable Community Data Ecosystems (RECoDE)- The Voices We Trust: Building Equity-Centered Community Data Ecosystems that Work for Everyone	Findings from the Rising Equitable Community Data Ecosystems project, seeking to better understand how we can undo antiquated and dangerous data systems that limit the power over where when and how data is used to improve individual and community outcomes.
National landscape	Social Determinants of Health Information Exchange Toolkit	This Toolkit, created by the ONC, is intended to support conveners, facilitators, implementers, and the health IT community.
National landscape	HHS Approves Groundbreaking Medicaid Initiatives in Massachusetts and Oregon	Initiatives will ensure children in Oregon have continuous Medicaid coverage until the age of six and expand access to coverage and address nutrition and housing needs in Massachusetts and Oregon.

Resource Directory Information Capacities	Averting Tragedy of the Resource Directory Anti-Commons: A Practical Approach to Open Data Infrastructure for Health, Human, and Social Services	This article analyzes the service directory problem and describes a set of strategic frameworks for the sustainable provision of service directory data as an infrastructural public good.
Standards	MiHIN Interoperability Pledge	Michigan Health Information Network Interoperability Pledge
Sustainability	Social Care/SDoH Michigan Payer Incentives Comparative Table	A listing of practices regarding the general framework of social care payer policies.
Topic	**Title**	**Summary**
Sustainability	In Pursuit of Whole Person Health: Leveraging Medicaid Managed Care & 1115 Waivers to Address SDOH	Manatt explores how states are using two key tools-Medicaid managed care contracts and 1115 waivers- to address unmet social needs of people with Medicaid coverage.
Sustainability	Financing Strategies to Address the Social Determinants of Health in Medicaid	Overview of Medicaid financing strategies in use to address unmet social needs of consumers.
Sustainability	SHO# 21-001 RE: Opportunities in Medicaid and CHIP to address Social Determinants of Health (SDOH)	Medicaid guidance issued by the Center for Medicare and Medicaid Services (CMS) for states to address the social determinants of health
Sustainability	How North Carolina is Using Medicaid to Address Social Determinants of Health	Report from the Center for American Progress regarding their use of a Section 1115 Medicaid waiver to address unmet social needs.
Sustainability	Incorporating Community-Based Organizations in Medicaid Efforts to Address Health-Related Social Needs: Key State Considerations	Report from the Center for Health Care Strategies exploring insights from early state innovators to help guide states, HCOs, and CBOs in shaping and navigating successful CBO-HCO relationships.
Sustainability	BCBSM Physician Group Incentive Program	Interpretive guidelines developed by Blue Cross Blue Shield of Michigan for their Physician Group Incentive Program regarding patient-centered medical home and patient-centered medical home-neighbors.

Values, Principles, Rights	Michigan Multipayer Initiatives: Guiding Principles for Data Sharing in Performance-Based Payment (PBP) Models	An overview of data sharing principles in performance-based payment models.
Values, Principles, Rights	The Community Bill of Rights	The Community Bill of Rights was created by community leaders with support from the Full Frame Initiative. The Community Bill of Rights is a guiding tool to bridge the gaps between what truly matters to the community and the systemic injustices they endure while navigating institutions and services.
Values, Principles, Rights	Blueprint for an AI Bill of Rights	A guide for the use of automated systems that may impact the public's rights, opportunities, and/or access to critical needs.
Topic	**Title**	**Summary**
Values, Principles, Rights	CMS Manual System Pub. 100-07 State Operations Provider Certification Interpretive Guidelines for Hospitals and Critical Access Hospitals	Clarification and summary for existing hospital regulations in 42 CFR 482.13(a) and (b) and 42 CFR 482.14(h), concerning hospital patients' rights, including advance directive and visitation rights. Clarification for critical access hospitals regarding 42 CFR 485.608(a) concerning compliance with federal laws and regulations including regulations governing advance directives and required patient disclosures. Guidance for new 42 CFR 485.635(f) concerning CAH patient's visitations rights.