

# Recommendations: Support for Community-based Organizations to Participate in CIE



## Introduction and Purpose

The [Community Information Exchange \(CIE\) Workgroup](#) has been tasked by the [Health Information Technology Oversight Council](#) (HITOC) under [House Bill 4150](#) (2022) with providing recommendations on strategies to accelerate, support, and improve statewide CIE in Oregon.

The CIE Workgroup met in April and May 2022 to discuss strategies on how to best support community-based organizations (CBOs) to participate in CIE. This concept paper is a result of the discussions and was given to HITOC in August to inform their draft report to the legislature in September and final report in January 2023 as required under HB 4150.

To supplement this information, a health equity consultant conducted CBO interviews and a survey on CIE in May and June 2022 to further inform the recommendations. The report on the [findings of the CBO interviews and survey](#) was given to HITOC in August as well to inform their draft report to the legislature in September. In August the CIE Workgroup reviewed the CBO interviews and survey report and updated this concept paper as a result.

## Problem

CBOs are *the* key partners in successful CIE. As the entities providing services and supports to address people's needs, which research shows largely drives health outcomes, it is imperative that CBO resources are part of any CIE network. Only with broad CBO participation in communities can CIE help improve health and well-being through completed closed loop referrals and service provision; without CBO participation this cannot be accomplished. CIE participation takes significant time, money, and human resources for CBOs. They must manage the adoption of technology, new workflows, and the increase in service demand due to receiving more referrals. Many CBOs that provide vital services operate under limited budgets and staffing structures that are already stretched to capacity. In addition, while healthcare organizations have received more funding and face more requirements around advancing technology, improvements and funding for CBOs have not moved as quickly,

### What are CBOs?

For the context of this paper community-based organizations (CBOs) are generally non-profit organizations working to support social needs and advance health equity across Oregon particularly in communities of color, Tribal communities, disability communities, immigrant and refugee communities, undocumented communities, migrant and seasonal farmworkers, LGBTQIA2S+ communities, faith communities, older adults, houseless communities, and others. This definition is not meant to be limiting.

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leaving a disparity in technological capabilities and financial resources between CIE partners. Sustained support for CBO participation in CIE is critical for the success of statewide CIE in addressing health inequities.

## Summary of Recommendations

When widely adopted in communities, CIE helps eliminate many of the barriers between people and the services designed to support them. CIE enables a broad variety of service providers to connect easily and quickly, which is essential to supporting Oregon in addressing health inequities and the overall well-being of individuals.

**The CIE Workgroup recommends that legislation support CBO participation in CIE.** Support should include ongoing sustainable funding and grants, technical assistance, coordination and convening, and education. The Workgroup's top priorities within these areas are:

1. **Ongoing sustainable funding and grants:** Priority recommended areas for funding and grants are staff capacity, incentivizing CIE use, supporting organizational infrastructure, and increasing overall services.
2. **Technical assistance:** Priority recommended technical assistance (TA) areas are privacy and data integration, workflow, data support for funding, and user training.
3. **Coordination and convening:** Priorities for coordination and convening are alignment of efforts, governance, a referral coordination center, best practice sharing, and research and evaluation.
4. **Education:** The Workgroup identified five priority education topics for CBO CIE use: billing/budgets, use of CIE data, consent processes, privacy compliance, and trauma informed practices. Three additional audiences for which education may be beneficial and support CBOs' participation in CIE were also identified.

*Community-based organizations, peer-run organizations like ours, we are, you know, feet on the ground organizations, we're grassroots, and I think this tool to be able to reach out, because we're always underfunded, we're always understaffed, you know, and this cuts down on hours and hours and hours of time that we would be on the phone, we have to do one referral, we can send it out, we can make notes, we can talk back and forth with other people, we only have one consent form, you know, all these things have made it a lot easier for us to operate, made it to where we can spend more time with our feet on the ground. – Interviewee*

## Overarching Principles

The overarching principles to be considered in implementing these recommended solutions are:

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- The needs of communities and CBOs should drive discussions and decisions around CIE; listening to CBOs and communities is crucial to the success of CIE and to advancing health equity.
- Recognize the capacity of CBOs; any increase in expectations or burden should be offset by increased funding and other supports.

## Recommendations

The following recommendations and details are written in ranked order according to the priorities set by the CIE Workgroup.

### 1. Ongoing sustainable funding and grants

**Principles:** The Workgroup recommends that several key principles guide funding/grants to CBOs to support their participation in CIE.

- Support for CBO participation in CIE must include ongoing sustainable funding and grants as the success of CIE is inextricably linked to CBO sustainability.
- Minimize associated reporting to focus funding on dedicated CBO resources to address referrals. Any anticipated increases in reporting and referrals should be offset by accompanying increased funding support.
- Recognize CBOs may not be able to respond to all referrals; research reasons behind this and investigate how to further support them.

Adopting CIE is an investment in a changing health and social support ecosystem that runs the risk of not achieving the benefits if it is not sustainable. To reach the anticipated value of CIE (i.e., meeting social needs and moving toward health equity), investments in overall CBO capacity must be sustainable. CIE network participation and technology use will impact CBOs at multiple levels. A core aim of the technology is to facilitate easier referrals, which may increase the number of requests a CBO receives. This will result in greater stress on the system, and document and reveal unmet needs, necessitating the presence of additional funding and grants for CBOs, both around CIE and around service provision and operations.

*If you wanted to really open the doors, and really have it be a successful system, we would need a much more increased capacity, which would just be staff costs, and all the other things associated with that, including infrastructure money.  
– Interviewee*

To support CBO participation in CIE, the Workgroup recommends that sustainable funding and grants focus on the following areas.

1. **Support staff capacity:** A critical priority will be CBOs' need for increased staff capacity to engage in a CIE network, including both use of a CIE platform as an

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alternate method for working with partners, and to address the likelihood of increased referrals for services (see 4 below). They may also need additional staff support due to training time dedicated to CIE.

## 2. **Incentivize use:** A second priority for support is to incentivize adopting and using CIE.

For example:

- Tie utilization of CIE to dedicated funding and to meeting certain criteria (e.g., # of referrals or value-based payment model social care contracts)
- Pay for engagement
- Pay to pilot a CIE and provide onboarding support

*CIE is an important tool, but it is also important to consider how that tool is adopted, used and shared within the community. We risk alienating smaller clinics or CBOs if we force them to onboard to a system that we cannot incentivize them to use either with staff time or supports. – Survey respondent*

## 3. **Support organizational infrastructure:**

Sustainable funding or grants could support organizational infrastructure and data capture/use. As part of CIE implementation, CBOs may need:

- To update information technology (IT) equipment
- To integrate with existing IT systems CBOs already use (e.g., APIs or application programming interfaces, enabling automated connections between existing systems to reduce data entry burdens)
- Assistance utilizing and analyzing CIE data
- Operations support

## 4. **Increase overall services and resources:** While the technological infrastructure to support ease of referrals is critical, so are the underlying resources to address the need. For CIE to be successful, it is also a priority that CBOs are appropriately resourced to increase services. CIE can demonstrate resource availability in regions or which types of resources may be lacking, however, for CBOs to join, it is important to anticipate there will be an overall increase in demand for services.

*There's still a lot of reservation among CBOs...with the CIE when there isn't funding that comes with it. But because it's, we see it as increasing demand without increasing supply. – Interviewee*

**Prioritize certain types of CBOs:** As CBO funding support is designed, it must be available to a broad range of organizations that provide vital support to communities throughout the state. Within the breadth of organizations, key types must be prioritized including CBOs that support culturally and linguistically specific populations. Over time social needs may change, and CIE data can track and reveal these gaps. Initially the Workgroup believes CBOs that focus on

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housing and food accessibility and availability should be prioritized. Ultimately, the focus of prioritization should be to reduce inequities.

## 2. Technical assistance

**Principles:** The Workgroup recommends that several principles guide technical assistance (TA) to CBOs to support their participation in CIE.

- Ensure that key people from impacted communities receive training in how CIE works.
- A commitment to continual TA and training rather than a one-time opportunity.
- Tailoring training for each CBO, if desired, to explore how they want to engage in or use the network.

TA and training can cover a wide variety of areas and can support CBOs in managing complex change while also helping them leverage CIE to support existing strategic initiatives. While all areas are important in providing support for CBOs, some TA options are a higher priority.

- 1. Privacy and data integration:** TA support and training in rules and regulation compliance, especially around HIPAA, FERPA, and 42 CFR Part 2<sup>1</sup>, and information as to how different systems can achieve interoperability or integration around data is also needed. This will support CBO work overall, and connections between social service providers and other types of partners, while increasing knowledge around key information sharing rules and regulations.
- 2. Workflow:** CBOs need TA to support changes and adjustments to existing organizational processes and workflows as CIE is adopted and utilized within the organization. This ensures that users understand what the technology does and does not do, how it fits with current processes, and how processes may be improved.
- 3. Data support for funding:** This TA will support and train CBOs to build reports and analyze data within CIE to show service delivery, gaps in needed services, and other items that support continued and enhanced funding for staff and services, particularly for reporting to grantors.
- 4. Training:** Many CBOs are in the nascent stage of CIE implementation so support for trainings should include new and advanced use, software, super users, and training of

*In our nonprofit, we'd say like, there's no such thing as like, too much communication. And in that same regard, I would say that there's no such thing as like too much support. I would say, you can't go wrong with having multiple different ways to provide support.*  
– Interviewee

<sup>1</sup> HIPAA-Health Insurance Portability and Accountability Act; FERPA-Family Educational Rights and Privacy Act; 42 CFR Part 2-Confidentiality of Substance use Disorder Patient Records

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trainers to help ensure that CIE is used to its greatest capacity to support the aims of CBOs. Helping CBOs have full awareness of CIE capabilities will enhance the user experience while maintaining appropriate expectations.

## 3. Coordination and convening

**Principles:** The Workgroup recommends that the following principles be kept in mind when considering coordination and convening to support CBOs.

- A key principle is that CBOs must be substantively included in governance at all levels.
- Also, coordination needs to happen across social service, health, and government systems including with policymakers. This will help streamline social service information gathering and referrals as well as promote rules, policy, and legislation that facilitates the provision of sufficient and appropriate services to those that need them.

Coordination is necessary to ensure that CIE is usable across social service and healthcare organizations, useful across sectors, and leveraged by policymakers. Various efforts, investments, and organizations will need to align for successful statewide CIE. Also, the different players need to convene to best coordinate. Convening would consist of two separate but aligned efforts: best practice sharing and governance.

**1. Governance:** For successful governance, it is critical to establish trusted partnerships where all sectors are represented and there is equal distribution of power.<sup>2</sup> CIE necessitates CBOs be equal partners in statewide and local decisions, and that community drives governance needs. Governance must enable CBOs to engage locally as well as participate at the broader statewide level. Governing of CIE needs to include equal CBO to non-CBO representation for uptake and buy-in. CBOs should drive expectations, network standards, and membership in their area.

*My understanding is that CIE...has been driven by major stakeholders in the health sector...and not been fully informed by the other half of the users, which is community-based organizations or people or organizations that are being referred those clients.*  
– Interviewee

- 2. Referral coordination center:** In addition, a referral coordination center that accepts calls and referrals and helps traffic them to the appropriate CBO, or other network partner, would help alleviate some burden from CBOs.
- 3. Best practice sharing:** Best practice sharing on CIE use would support CBOs to learn from each other, and other types of organizations across sectors. This would take place through local, regional, and state level convenings.

<sup>2</sup> From Office of National Coordinator for Health IT (ONC) [SDOH Learning Forum](#)



- Peer-to-peer meetings and discussions would allow CBOs within the same service area or serving similar populations to support each other, building each other's knowledge and skills with an understanding of the specific needs of their organizations and communities.
- Cross-sector convenings and meetings would expand conversations and highlight different use cases that may spark innovation and new ways of thinking about using CIE to facilitate coordination across the different sectors or services.
- Statewide convenings and meetings would enhance new and existing networks and connections across Oregon, allowing organizations serving similar populations in different areas of the state to discuss needs and best practices.

**4. Research and evaluation:** Coordination is needed for research and evaluation of CIE to demonstrate the value, determine what gaps remain, support policy advocacy, and examine what additional investments are necessary for the continuation and sustainability of successful CIE. Evaluation is also needed to make improvements to technical systems, workflows, training, education, and governance. The resources for adequate evaluation need to be included in any developed support.

## 4. Education

**Principles:** In considering CIE education that supports CBO participation in CIE, a key principle is to listen to CBO staff and the community regarding how education should look for them. Also, support for training and education should be available in various forms (e.g., virtual, in-person, pre-recorded).

**1. Various topics for CBOs:** Education in the following areas is necessary to support the implementation of CIE technology and processes. Priority areas are:

- Billing/budgets
- Use of CIE data
- Consent processes
- Privacy compliance
- Trauma informed practices

*CBOs across the state, we're just yeah, we're all worn really thin. And so asking us to do anything else is like, Oh, no. So whatever support y'all can provide, would be a leading selling point.*  
– Interviewee

The following types of educational support would be beneficial to CBOs as well as additional partners in participating in CIE across Oregon. Education to others in the landscape beyond CBOs will support their own participation in CIE and thus support statewide CIE.

**2. Promotion and public awareness:** Education needs to move forward with promotion and public awareness as well. It is important to publicize participation in CIE and inform the community about CIE through methods such as highlighting stories of success,

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benefits to communities, new functionality, grants, and opportunities to support utilization.

- 3. Community leaders:** Education and awareness would also help build CIE advocacy by community leaders. This advocacy is necessary for continued engagement with and enhancement of CIE as it matures and develops within the state. This could be supported by education and training for community leaders.
- 4. Consumer/client:** Consumer/client education is needed around CIE as well. This could take the form of handouts, talking points for staff at CBOs, and/or community videos to support education on the tool itself and how and why information is shared. Familiarizing people with CIE could increase the likelihood of engagement in services when they receive outreach from a CBO as the result of a referral.

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