“We Work With People, Not Numbers”

An Exploratory Report on Data Collection Practices in Ontario’s Consumer/Survivor Initiatives & Peer Support Organizations

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Acknowledgements

We extend our sincerest gratitude to all the leaders who participated in this study. We cannot name you because we respect your anonymity, but you know who you are, and we are grateful to you. Your lived experience, insights, and expertise have shaped the report. We are also thankful for the support of our research assistants, Tom Walpole and Tanya Quesnel, and our editor, Mina Zahine.

As one of the leaders reminded us, “We work with people, not numbers.” We hope that we were able to communicate that through this report. We are so grateful to be a part of a community that is clear-eyed and steadfast in its commitment to our core values. Ultimately, what we took away from this project is that we, as a community, refuse to contort ourselves to fit data collection requirements. Instead, we believe that the data collection process should be shaped to fit the needs of our community.

Orienting Readers to This Document

Key Terms

Consumer/Survivor: You will see the term Consumer/Survivor Initiative/Peer Support Organizations (shortened to CSIs/PSOs) to refer to the range of these kinds of organizations inclusively, despite their organizational type.

Consumer/Survivor Initiative: We use this official term as it to refer to peer-led organizations with peer-run program mandate to provide community mental health programs and funded by the Ontario Ministry of Health.

Peer Support Organizations: We use this term to refer to peer-led or peer-run organizations that are not Consumer/Survivor Initiatives or are no longer considered Consumer/Survivor Initiatives, as an official term.

Mainstream Organization: refers to any mental health association (MHA) organization that is not peer-led and usually provides some level of treatment or professionalized interventions, such as hospital in-patient or out-patient programs, case management programs, or Canadian Mental Health Associations, for example.

LHIN: An Ontario Local Health Integration Network (LHIN) was a regional agency of the provincial government responsible for planning, funding, and coordinating publicly funded health care services within a defined geographic area from 2006 until its functions were transferred to Ontario Health in 2021.

Ontario Health Teams: An Ontario Health Team (OHT) is mandated to integrate and coordinate the delivery of health and social care services for a defined population within a geographic area under the oversight of Ontario Health.

What is an exploratory research report?

This project began with a simple curiosity: how do CSIs/PSOs collect data, and what are their experiences with data collection in the mainstream community mental health legislation and policy context? We were also interested in the implications of new, system-wide data initiatives in Ontario's mental health and addictions sector.

Not knowing exactly what we would find, we used qualitative, conversation-based interviews to gather information. This approach offered rich insights into what our organizations do, the challenges they experience, and their concerns about data collection.

We chose to present the results in an exploratory format. This means focusing on the context of these practices, using verbatim quotes to ensure the voices of the participants lead our work, and generating insights grounded in their lived experience. Given that the sector is in a transition period, this report serves as a starting point and a baseline understanding of where things stand, at a time where the system's knowledge of our work is limited and still evolving.

What this report looks like:

- An in-depth analysis of contexts and themes shared by leaders
- Heavy use of direct quotes; minimal use of number or statistics
- Some visuals to support understanding
- Clear acknowledgment that this is quantitative work and is therefore reported as interpreted by the authors
- Tentative recommendations based on leaders' knowledge, supplemented by our reflections after reviewing results.

For those without time to read the full report, we have included a one-page **Summary** highlighting the most important findings that might be useful for organizational leadership to use in their advocacy efforts. We have also included a plain language summary for the broader audience who may not have knowledge of this area of community mental health and the psychiatric consumer/survivor movement.

Reading Voices of Qualitative Work

When you see lines of work indented as shown in the example, it means it is a direct quote from a participant. We do not use the names of participants, or their organization names to protect their anonymity. When you see three evenly spaced periods in a row inside a quote from a participant (referred to as an ellipsis), this is used to indicate some words have been omitted by the writer as they might not be relevant to the rest of the quote.

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About the Project

Who worked on this project?

PeerWorks partnered with former CSI-worker and Executive Director, Tanya Shute to explore the data collection practices of CSIs/PSOs across Ontario.

Tanya Shute

Tanya Shute (she/her/elle) is an Associate Professor in the School of Social Work at Laurentian University whose work sits at the intersection of scholarship, community organizing, and social justice movements. Before entering academia, Tanya spent two decades as a front-line social worker and community developer in York Region, working primarily in women's shelters and community mental health and addictions services. She was deeply involved in the psychiatric survivor movement and served for many years as Executive Director of the Krasman Centre, a leading consumer/survivor organization advancing peer support, rights, and community-led mental health alternatives.

Tanya has also worked extensively in social work education. She was faculty and program coordinator in Seneca College's Social Service Worker program and played a key role in building new pathways for community-based practice education as the lead curriculum author, program coordinator, and faculty member for Seneca's Honours Bachelor of Community Mental Health and Addictions and its post-graduate Mental Health Intervention certificate program.

Tanya's (she/her) research program is grounded in community-engaged and movement-accountable approaches to knowledge creation. She works collaboratively with community organizations and grassroots movements to generate research that supports social change, with a focus on 2SLGBTQIA+ health and wellbeing, homelessness and poverty, psychiatric survivor and consumer initiatives, and mutual aid and peer support.

Allyson Theodorou

Allyson Theodorou (she/her/elle) is the Executive Director of PeerWorks, a not-for-profit membership-based organization committed to supporting Peer Support Organizations and Consumer/Survivor Initiatives across Ontario. Allyson began working for PeerWorks back in 1993 in its earlier incarnation as the former CSDI. Originally tasked as an administrative assistant, she has taken on other responsibilities including office finances, conference organizer and, working with graduates of the PeerWorks Peer Support Core Essentials Program while they complete their internships. She is certified with Peer Support Canada, and is qualified to deliver PeerWorks Peer Support Core Essentials™ Program training. Allyson lives with her husband, two teenaged boys and their dog Scout who they adopted from a rescue organization. In her spare time, Allyson enjoys spending time with family and friends, trying new vegan recipes and exploring a healthy lifestyle.

Funding

We received a national grant through the Social Sciences and Humanities Research Council (SSHRC), which allowed us to engage two peer research assistants for this project. The Laurentian University Research Ethics Board provided approval for the project. PeerWorks provided in-kind contributions to the project. Tanya Shute, as the principal researcher, did not receive any of the funding personally, and engaged in this project as part of her service role as a professor at the Laurentian School of Social Work.

Method

The study was guided by the question: What are the current data collection practices in Ontario CSIs/PSOs?

We used a qualitative approach, conducting semi-structured conversational interviews with 11 CSIs/PSOs leaders across Ontario between 2020 and 2022. Participants were selected through purposive sampling, which means that they were not randomly selected but rather invited from PeerWorks' member organizations to reflect the diversity of organizational forms. The final sample include:

- 5 CSI leaders;
- 4 leaders of PSOs in flow-through or amalgamated arrangements with non-CSI/PSO organizations; and
- 2 leaders of alternative businesses.

Interviews were transcribed using NVivo software. Tanya carried out the content analysis, with early findings shared and validated at the annual general meeting of PeerWorks member organizations. The report was co-authored by Tany and Allyson, with input and support from many others mentioned in the Acknowledgements section.

Timing and Context

Data collection began during the later stages of the COVID-19 pandemic, a period marked by major challenges for CSIs and PSOs. Alongside navigating pandemic-related service disruptions, organizations were also adapting to new governance structures under the Ontario Health Teams (OHTs) and facing uncertainty about their place within the system.

At the same time, the Ministry of Health (MOH) launched the Digital Data Initiative (DDI) in 2021, which shaped the broader policy environment in which this project unfolded. The MOH also introduced a 5% increase for mental health and addictions organizations to help offset pandemic-related costs. However, CSIs and PSOs did not receive this increase at the same time. Some PSOs —particularly those operating within larger host organizations—did not receive the 5% boost at all, depending on how their arrangements were structured.

Findings Summary

Consumer/Survivor Initiatives (CSIs), first funded in the 1990s, were created as independent, peer-led alternatives to mainstream mental health and addiction services. Rooted in mutual aid, self-determination, and low-barrier access, they intentionally offered something different from clinical programs. Over time, many CSIs lost autonomy through amalgamations or closures, and today only about 10 remain fully independent. To reflect the diverse forms these groups now take, we use the broader term Peer Support Organizations (PSOs).

This study highlights both the value and vulnerability of these organizations. CSIs/PSOs provide safe, empowering, and non-judgemental supports that are preferring by many service users over mainstream services. However, chronic underfunding and exclusion from key Ministry of Health investments have left them operating with minimal staff and infrastructure. Workers often taken on multiple roles, such as administration, compliance, and direct peer support, while earning below a living wage. Despite these challenges, CSIs/PSOs continue to deliver high volume of support, filling critical service gaps with limited resources.

Data collection has emerged as a new central concern for CSIs/PSOs. While organizations track participation and service user to meet accountability requirements, they lack the staff and systems for more robust evaluation. The leaders interviewed as a part of this study stressed that data practices must align with peer support values rather than replicating clinical models. They must protect trust, privacy, and non-clinical approaches. Ontario's new Digital Data Initiative (DDI) and Provincial Data Set (PDS), while aiming to improve system-wide consistency, risk overwhelming small PSOs and undermining the principles that make them effective unless tailored supports are introduced.

System pressures also extend to partnerships. Under the Ontario Health Team (OH) framework, integration with larger organizations is often promoted as a solution to limited capacity. Yet leaders caution that imposed partnerships can erode autonomy shift work toward clinical roles and ultimately erase peer-led spaces. This history of nearly 30 lost CSIs through closures or amalgamations reinforces this concern.

Despite these risks, PSOs remain committed to their founding purpose: providing flexible, accessible, and empowering peer support rooted in lived experience. To strengthen the sector while preserving these values, this study recommends developing peer support-aligned data strategies, securing dedicated infrastructure and capacity funding, adopting flexible reporting practices, carefully managing partnerships to protect autonomy, and embedding evaluation into ongoing service delivery. These steps aim to enable PSOs, funders, and larger organizations to collaborate in ways that respect the unique contributions of peer support while enhancing accountability and sustainability.

Summary for Broader Engagement

Peer-Support Organizations (including Consumer/Survivor Initiatives) are peer-led mental health and addiction groups that offer safe, supportive, and non-judgmental spaces for people with lived experience. These groups were created as community alternatives to clinical services and are based on values of mutual help, choice, and respect. Over time, many have lost independence or closed, and only about ten remain fully community-run in Ontario.

This study shows that PSOs play a vital role but face serious challenges. They are underfunded, short-staffed, and often excluded from government funding programs. Many workers are paid below a living wage while doing several jobs at once. Despite this, PSOs continue to provide essential, high-quality support to many people who prefer their approach over traditional services.

Collecting data is becoming more important, but PSOs lack the staff and systems to do this easily. Leaders emphasize that data collection must protect privacy and stay true to peer support values—not copy clinical models. New government data systems may create extra pressure unless they are adapted for small organizations.

Finally, PSOs are being encouraged to join larger health teams, but this can reduce their independence and change the nature of their work. The report recommends fair funding, better infrastructure, flexible reporting, and respectful partnerships that keep PSOs peer-led and sustainable.

Background

Established in the 1990s, Consumer/Survivor Initiatives (CSIs) were originally funded by the then-Ontario Ministry of Health and Long Term Care (MOHLTC)[1]—as it was then organized—as autonomous consumer/survivor-operated community mental health support organizations and alternative businesses. Rooted in the psychiatric ex-patient/consumer/survivor social movement, CSIs were built on values of mutual aid, self-determination, and peer support.

CSIs provide a variety of support and survival services in non-judgemental, non-clinical, peer-led environments. Although the existing research is somewhat dated, the evidence demonstrates that Ontario's CSI services are effective in achieving positive mental health outcomes for consumer/survivor participants and visitors. Importantly, many users prefer CSIs to mainstream mental health services, finding them less stigmatizing and more empowering than the traditional offerings of the mental health system (Shalaby & Agyapong, 2020).

Our community has debated between remaining autonomous, grassroots organizations and joining mainstream mental health organizations, where a potentially co-opting effect can accompany sustainable government funding and integration/collaboration (from: Drift from Peer Support Values and Standards Position Statement and Call for Action, authored by de Bie & Michetti-Wilson, 2024).

Over the past two decades, many originally independent and autonomous CSIs have lost their operating independence through amalgamation or closure. Some organizations no longer hold the CSI designation but continue to provide peer support-based services. We use the term Peer Support Organizations (PSOs) be inclusive of all the different forms these organizations now take.

Consumer/survivor-led and peer-led mental health organizations often face significant challenges in securing adequate funding and resources compared to mainstream, clinical mental health services. These resource disparities can hinder the effectiveness and sustainability of peer-driven organizations, which are increasingly recognized for their value in promoting recovery and community-based support (Shalaby & Agyapong, 2020; White et al., 2020), Research on peer-led organizations, including CSIs/PSOs, consistently shows that they are underfunded and under-resourced (such as, Cyr, McKee, O'Hagan, & Priest, 2016; Fortuna et al., 2022), particularly those that do not operate from the bio-medical model of understanding mental and emotional distress (Mohomed, 2020). They receive far less than their share of operational and special-grant funding from the Ministry of Health. For example, CSIs/PSOs were excluded from the COVID-19 special grants that were provided to other mental health and addictions organizations.

The chronic underfunding forces peer-driven organizations to make difficult decisions. Many prioritize direct programs and services over infrastructure, leaving little for fair wages or

[1] Note: The MOHLTC was restructured in 2019 into the Ministry of Health and the Ministry of Long-Term Care. Funding for CSIs now falls under the Ministry of Health.

administrative support. Staff are often paid below a living wage, and many organizations rely heavily on volunteers to fill out roles that would otherwise be paid positions in mainstream mental health organizations. Without back-office or executive teams, everyone working at CSIs/PSOs must take on multiple roles. This can range from administration to compliance and direct service delivery. Meanwhile, these small organizations are still required to meet the same reporting, budgeting, and compliance demands as larger, better-funded agencies. The pressure to do more with less is constant and considerable.

Yet, CSIs/PSOs are not simply "small service providers." They have strong ties to the psychiatric consumer/survivor civil rights movement and have always held a mandate beyond that of the Ministry of Health. Designated as alternative organizations, CSIs emerged out of the direct action, resistance, and advocacy for mental health system reform. The original funding policy recognized peer-led, mutual-aid alternatives as essential to recovery, and intentionally tasked CSIs to provide low-barrier, high-access support that would not replicate mainstream mental health services (noted in the CSI Builder Report, O'Hagan, et al., 2009).

The Consumer/Survivor Development Initiative (CSDI)—PeerWorks' predecessor—established in 1991 by the then Mental Health formalized this vision. It funded both local CSIs and the Ontario Psychiatric Survivors Alliance (OPSA) as a provincial body. Proposals for CSI funding were required to:

- "Use an egalitarian approach and not mimic professional organizations.
- Establish themselves as independent organizations as soon as possible.
- Hire consumers/survivors only, with a board elected by the membership," (CSI Builder Report, 2009)

Initially, more than 40 CSIs, including alternative businesses were funded, offering peer support, advocacy, and employment opportunities during a time of recession. By the mid-1990s, however, many had been absorbed into mainstream organizations such as CMHAs and hospitals. Today, only about 10 CSIs remain fully independent and autonomous, while others exist as programs, flow-through entities, or divested organizations that regained independence after leaving a mainstream host. (see chart on page 13)

This history highlights both the value and vulnerability of the sector. In the current political and fiscal climate, which is marked by transitions to Ontario Health Teams (OHTs) and new provincial priorities such as the Digital Data Initiative (DDI) and Provincial Data Set (PDS) [2], small organizations with limited infrastructure. Protecting and strengthening CSIs/PSOs is therefore critical. Through PeerWorks, community members are working to building capacity, safeguard these organizations' unique mandates, and ensure their contributions to mental health and addictions recovery are recognized.

[2] Titles for legislative frameworks and priorities at the time of the study

The Problem of Good Data

All CSIs/PSOs collect the data they can with what they have, primarily head counts and participation metrics, to maintain accountability to funders. These numbers show the high volume of program users and visitors and are a good indicator of the value for funding dollars. However, the sector requires a feasible data collection and evaluation methods that can demonstrate the unique contributions of CSIs/PSOs to participant wellbeing, support program quality improvement, sustain funding, and grow the sector.

Data initiatives in the broader MHA sector tend to be large, expensive, and clinically focused, making them a poor fit for the values and principles of the CSI/PSOs. If imposed, these approaches risk inefficiency, ineffectiveness, and conflict with the peer support philosophy. Leaders consistently emphasized data collection practices must respect the high levels of trust CSIs/PSOs foster with their communities, including privacy, anonymity, and non-hierarchical relationships. In short, data must be meaningful, respect sector principles, and enhancing organizational sustainability without compromising core values---a balance one leader described as “dancing on the edge of a sword.”

CSIs/PSOs are pro-data as long as collecting data support quality programming, establishes evidence for the sector, and strengthens the voice of peer-led organizations in advocacy and system-level decision-making. However, the decline in the number and independence of CSIs across Ontario has diminished this voice. As one leader explained:

“Sadly, the voice of CSIs has really diminished. There are a lot less of us across the province, and some are still here but have lost their independence, and many of us are working like we are next on the chopping block, and our advocacy role has been diminished…it’s just been a wave of pressure and things getting stacked against us.” (Central Ontario CSI leader)

While DDI and related efforts like PDS are intended to standardize and strengthen data collection cross the sector, their requirements can be difficult for small peer support organizations to meet and may conflict with the ethos of CSIs/PSOs. Tailored, feasible, and values-aligned approaches are needed to allow peer support organizations to demonstrate impact while remaining true to their foundational principles.

Policy Context: the DDI/PDS

The development of a consistent and robust data collection mechanism is becoming increasingly important in Ontario’s mental health and addictions sector. Pressures in the funding environment and system-level demands have placed a new emphasis on standardized data collection.

As the political directive at the time of writing, Ministry's Digital and Data Directive (2021), notes, "Data will play a critical role in driving both service quality and accountability. The MHA Data and Digital Initiative will make it easier to deliver better care, report on performance and track the value of investments."

The DDI sets the foundation for this transformation through:

- a standard set of provincial data definitions and elements for mental health and addictions that will ensure that collection of data across the sector and lifespan is standardized;
- a mental health and addictions data repository with secure linking of data so that information can be collected and shared among service providers and between care settings;
- real-time access to a full range of digital health records for clients and providers; and
- advanced data analytics and reporting (Ontario Health, Mental Health and Addictions Centre of Excellence)

Building on this framework, Ontario introduced the Mental Health and Addictions Provincial Data Set (PDS). The PDS would implement a staged-approach to standardize client-level data to support system performance measurement and inform service planning at the local, regional, and regional levels. According to the OHT, the first release of PDS will include:

- "Client data including demographics, social determinants of health, episode of care information
- Program information including referral data, assessment dates, enrollment information, encounter data
- Health Service Provider data including information and location information"

These directives formed the context in which CSI and PSOs leaders were trying to navigate preserving their values and methods of caring and support and the expectations of the mainstream community mental health system. At the time we were speaking to leaders for this project, it was not yet known what would be required of CSIs/PSOs funded by the Ministry of Health.

While leaders and the community understand that these developments aim to strengthen system-level insight, they raise significant concerns for CSIs and PSOs. Many community-based programs deliberately limit or avoid collecting personal information in order to foster trust, anonymity, and accessibility. For individuals who have experienced harm, trauma, or stigma with the mental health system, anonymity is often the only reason they feel safe enough to seek support. Unlike mainstream MHA providers, CSI/PSOs are rooted in peer support and mutual aid, not clinical treatment, and their approach to data and how it is collected/stored/used reflects these values, which again, was not known if this would be recognized or accommodated in these provincial data initiatives.

Currently, most CSIs/PSOs collect only minimal service-use data. This includes counts of daily visits or group attendance, which are often tracked manually in simple forms or spreadsheets. The PDS, in contrast, will require organizations to purchase and operate complex, health-sector software systems designed to capture identifying demographic and clinical data.

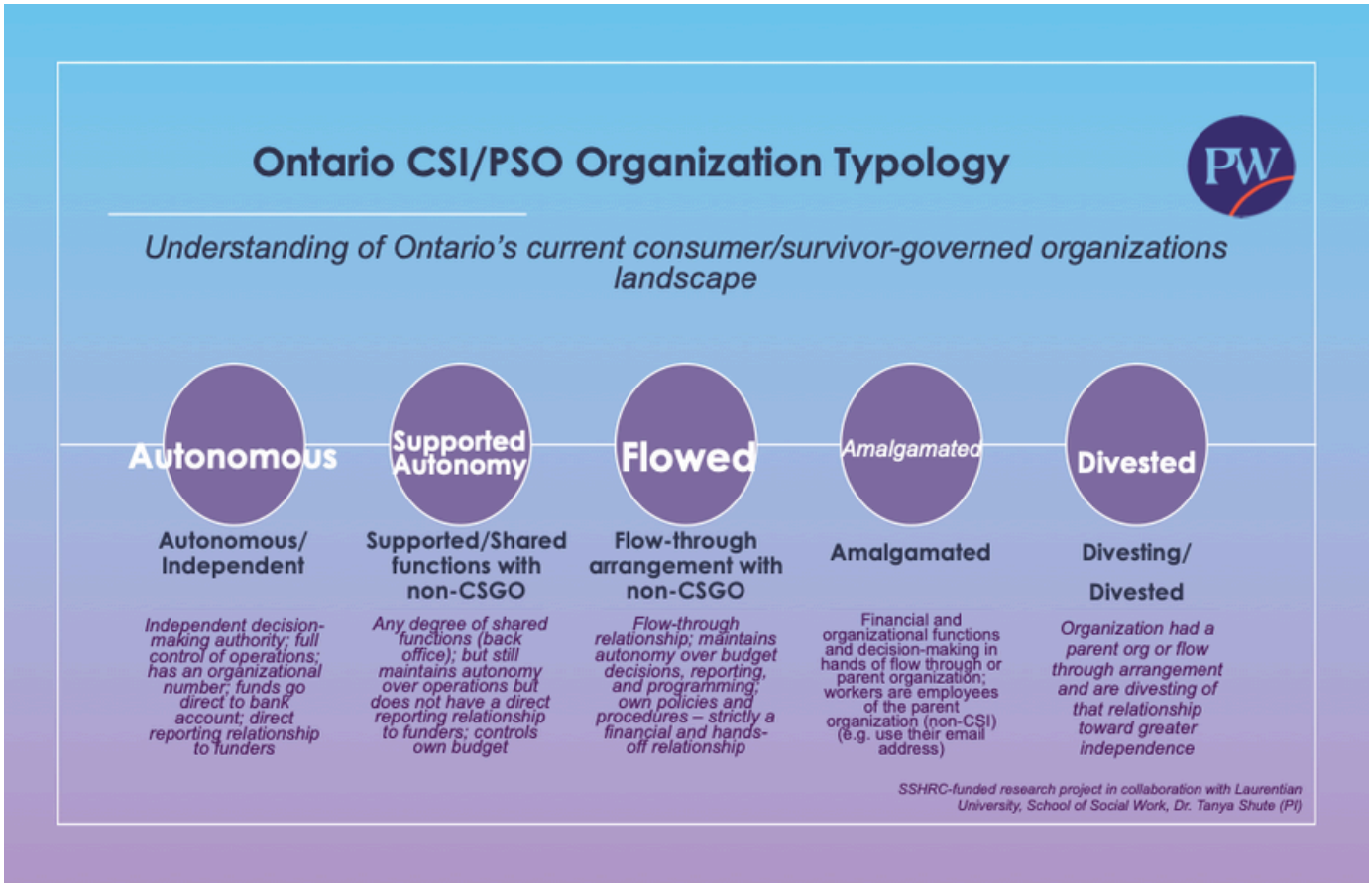
At the time of writing, no funding or implementation support has been announced to help small organizations afford licensing, training, or ongoing maintenance. Organizations are also expected to begin submitting standardized data by December 2026, placing additional strain on already limited capacity.

Peer Support Positions

Ontario's CSIs and PSOs support meaningful data collection to demonstrate the value of our work and to plan quality programs. However, data practices must reflect the unique role of peer support organizations; low-barrier, anonymous, and grounded in trust. Requiring the same standards as clinical providers risks undermining the very qualities that make peer support effective and accessible. Our sector needs a tailored approach to data collection that can sustain rather than burden our work, respect privacy and anonymity, and capture our story on our terms.

As one CSI leader in Northwestern Ontario noted: "We are a small crew, and we do everything from administration to cleaning to facilitating groups. We do it all. They really get their money's worth from us, that's for sure. Trying to get extra funding is like pulling teeth."

Today only 10 CSIs retain organizational independence, with others operating under varying degrees of integration with mainstream mental health/addictions organizations. This diversity highlights the need for flexibility. Ontario must invest in data collection approach that are feasible and respectful of community-based organizations so that we can meet the intent of standardized data initiatives from funders without erasing the distinct identity and contribution of peer support. This chart below reflects the organizational arrangements of CSIs/PSOs in the Ontario landscape.



Sector Concerns about Pressures to Partner with Mainstream Organizations:

There are some potential benefits that accompany partnering with larger organizations, such as back-office supports and other resource-intensive assets. There are also considerable risks for smaller organizations, such as being over-shadowed, over-powered, and unable to maintain their organizational approaches and spaces. Small organizations risk often face the risk of losing their egalitarian structures when entering partnerships with larger, better-resourced agencies. Hierarchical employment relationships and top-down decision-making can undermine the values at the core of CSIs/PSOs. Choosing the right partners and setting clear boundaries to protect egalitarian principles is, therefore, essential to preserving the integrity of our work.

For many organizations, past amalgamations were seen as necessary response to limited capacity and survival pressures. Today, under the OHT framework, partnerships are not only encouraged but, in some cases, required to secure future funding. At the time of our data collection, these expectations were a source of significant concern for CSI/PSO leaders, who fear that forced partnerships could threaten both their independence and their original mandate.

Protecting and Defending our CSIs/PSOs= Protecting and Defending Peer Support Offerings for Mental Health and Addictions Support

A lack of shared understanding about what peer support truly is makes it difficult to collect meaningful data. Its grassroots and non-professionalized nature contributes to this. Standardized methods that assume case notes or rigid protocols are simply not aligned with peer support practice.

As one leader explained, reflecting on a peer support training held at a community mental health organization, “This employee kept barging into the training, contradicting what we were saying, like ‘no, you can’t give out a personal phone number’ and we were like ‘yes, you can.’ This is peer support. Yes, people will take the opportunity and call you after hours when they are in trouble. You can put them in your car if they need a ride… but think about peer support in non-peer-led settings… it’s like surveillance” (Central Ontario CSI leader).

“We stick true and strong to the peer support model, and we are not funded by [MOH]… and I can honestly say, of all the individuals we have had here, I don’t think we’ve ever had anyone come through our doors that we’ve looked at and said ‘this isn’t going to work – they are never going back to work or back to school.’ Over time, we watch that growth and we’ve seen it happen. And they do their healing and it’s them that says when they are ready.”
(Northern Ontario peer support organization leader)

There are instances where peer work is being coopted by non-PSO mainstream organizations: "We found out… at the hospital, they were doing our groups, like WRAP and everything, instead of referring to us. I said, 'Can you people stop? Just stop! You can't have it all. You're a nurse – you don't identify with lived experience. I don't do your job, don't come do mine'… When they said they were doing it because there was so much demand, we couldn't cover it ourselves. But then they keep us so poorly resourced." (Southern Ontario CSI leader)

"We end up seeing a lot of the individuals who have nowhere else to land because they fall into the cracks. That's our system – it is what it is. Our approach means there are no cracks, they land with our no-barrier approach. But I wish the mainstream mental health services would recognize and appreciate the value that's there instead of dismissing it as just a service that can be amalgamated. Like with us, someone can get support right away – a coffee and a conversation, to get out of your home or be connected to others." (Central Ontario CSIS/PSOS leader)

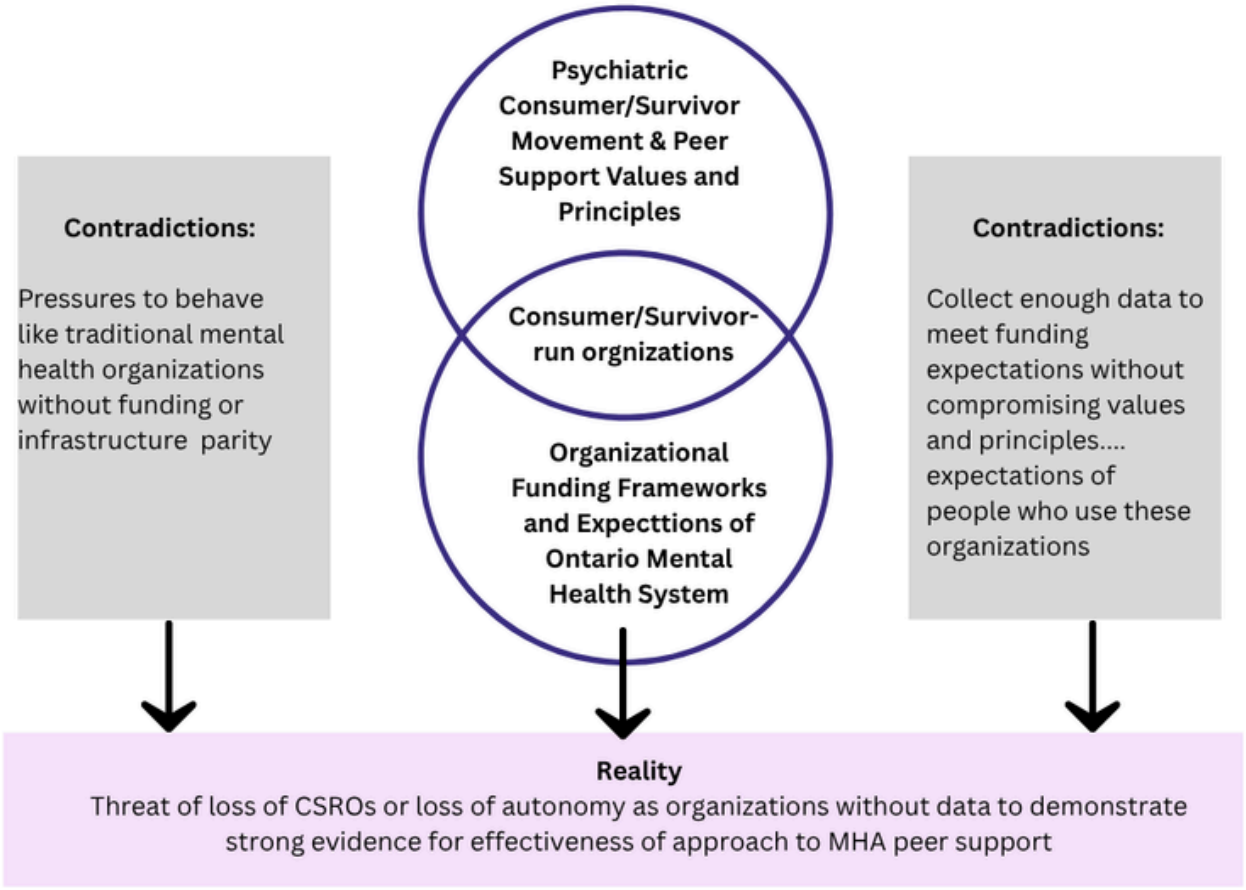
"Because we are funded by the province, we are part of that system. But we've always managed to sort of keep one foot out the door. And I think that's served us well, and most importantly, served the people we support well. To be able to still maintain some of our grassroots essence, which I think we still presently hold, but I see a lot of external threats to that." (Central Ontario CSI leader)

Findings: What We Learned From Participants

We spent considerable time discussing the broader environment in which CSIs/PSOs operate because data collection practices are shaped not only by structural challenges but also by the sector's deep commitment to peer support values.

At the time of our conversations, leaders highlighted several overlapping concerns: chronic underfunding, increasing pressures to partner or amalgamate under the OHT model, and uncertainty created by provincial data initiatives. These challenges were compounded by the reality of wearing many hats with limited staff, the strain of managing multiple reporting requirements without administrative support, and the burden of custodial relationships with larger organizations. At the same time, leaders expressed a stronger desire for better data to demonstrate impact, while cautioning that reporting tools must remain consistent with psychiatric consumer/survivor/peer movement support principles.

The following concept map illustrates the context of data collection for PSOs and CSI leaders, a multi-layered and sometimes double bind. Good data becomes good evidence for: a) the organization, but potentially the PSO/CSI sector, and b) ideally, also helps in securing sustainable funding for the organization based on evidence of effectiveness. However, collecting too much or collecting “clinical data” represents drift from consumer/survivor movement and peer support values, and can cause a loss of trust or act as an access barrier for visitors.



The following speaks to these issues and integrates the voices of the leaders of themselves.

Our Approach to Data Collection: The Minimum Necessary

This approach stems from structural limitations, such as lack of administrative infrastructure and capacity, and an ethical commitment to peer support values.

Historically, reporting requirements were minimal. Before the introduction of OHTs, organizations were generally required to only track the number of unique participants and some frequency measures. For participants who provided no identifying information, or for programs that did not track individuals, organizations reported aggregate counts of "not uniquely identified" service users.

This was, and continues to be, done with necessity-driven simplicity, using low-tech tools such as Microsoft Word or Excel spreadsheets. These numbers were then compiled into monthly or quarterly reports for funders, Boards of Directors, or internal program planning.

"We collect the basics required by the funder, so basically how many people come in. They're called attendance days in ministry-speak, so we track attendance days. But it's tough to do, if you're out there [in the drop-in programming space], out of your office talking to people, we find it more useful to keep doing that than to stop and write down who we talked to about what and for how long. But it's a start that we capture just in general, but we don't identify as specific person [in the stats]. So, we know the basic math, if we have 10 visitors, that's 10, but it might mean 50 interactions with various workers. We capture how many groups we run, and what the group attendance was. We track how many calls our warm line receives, how many one-on-ones, how many groups and group attendance… In some programs we collect a bit more, like accompaniments to appointments, but nothing that challenges our peer values."
(Northern Ontario CSI leader)

Some organizations opted to use sector-standardized tools, such as the OCAN or OPOC-MHA[3], but participation was voluntary. Many resisted and emphasized that CSIs/PSOs are not clinical services, are not part of a "circle of care," and wanted to remain independent from other providers.

"So… things like OCAN are the system's tools – you give them the statistics, but it never really comes back to you in any way." (Southern Ontario CSI leader)

[3] OCAN is the Ontario Common Assessment of Need and OPOC-MHA is the Ontario Perception of Care Tool for Mental Health and Addictions

Occasionally, CSIs/PSOs engaged in satisfaction-based evaluation, such as distributing feedback forms after groups or conducting annual member surveys. While they are valuable, leaders pointed out that this type of data does not establish a strong evidence base for effectiveness. From a CSI perspective, the real question is: What data matters to us?

"We do capture some information about the folks we serve, but it does not look like what hospitals look like, it doesn't look like what the mainstream organizations who have all these databases collect. We have always, for many years, documented our interaction with every person, but the problem is just around using this data to demonstrate and share information about outcomes. I've got some questions around that sort of definition, of what an outcome looks like from the system level where we have a very different lens." (Central Ontario CSI leader)

One PSO with a strong in-house research team created its own validated tool to measure outcomes that mattered to them, such as levels of belonging.

"We use [the validated tool we developed] annually to evaluate ourselves. If we needed to for other purposes, we could add measures in terms of symptom reduction or whatever clinical measure the province would find interesting, but none of that shows up in our measure now. It is about: did you feel like you could be yourself? Do you feel like you belong somewhere and contribute to community? And do you feel like you had a space to become better? This an oversimplification of the questions for now, but that's what the measure does, because we care about our origins: belonging, being, and community." (Northern Ontario CSI leader)

At the same time, leaders highlighted the strain of managing multiple funder reporting requirements without dedicated administrative resources. Short-term and project-specific grants often assumes the existence of stable core funding, which many CSIs lack.

"They have all these different reports, and they all want something different. I'm sorry, that's part of the reason I had to keep bailing on you [to do this interview] because I keep ending up in emergency meetings with different Ministry reps because all of them, for some reason or another, have decided to need something different at the last minute that we didn't plan for in the beginning, so weren't tracking…. It's not something we do-- "track" people—and we do most of our stuff with Excel, so we don't have any databases set up for these, because the costs are ridiculous. To have somebody come and customize a database for you, that's just not something in our budget to do." (Northern Ontario peer support organization leader)

"We only keep enough notes so staff can step in for one another; we keep very vague notes, just because if one steps away and another has to pick up, we don't want individuals to have to keep re-telling their story." (Northern Ontario peer support organization leader)

Some funders have shown willingness to adapt reporting requirements, but the lack of infrastructure remains a critical barrier.

"I'm going to make a note of that on file, He said, maybe going forward, he said, maybe we can work together. Because I said even some of the questions you ask don't make sense for us, some of the questions on the template, like didn't even make sense for us. So, they are actually going to work with us to design the reporting so that it's similar to what they are looking for but lines up with what we can do. But then other funders… how do I build a database that we can pull all of these different things from and not lose us?" (Northern Ontario peer support organization leader) …. Like, people who get this funding, have people in departments that just do this job. They when you're talking about peer support services, you're trying to run the place, run the program, get someone into housing tonight, check in with the staff that they are ok, oh, and collect and report this as data – we provide the service AND collect the data AND report it – and clean the toilets".

Finally, the role of volunteers complicates the data collection further. Many CSIs rely on volunteer peer supporter to run programs like warm lines, where reporting is intentionally kept minimal to avoid burdening volunteers.

"Right now, it's just number of calls we report. There's no reporting like the nature of the call, or if it was a crisis call or not, or where callers were referred to etc. It's strictly number of calls because it's a volunteer-run service, so not to burden them." (Central Ontario CSI leader)

It should be noted, though, that there are strict and rigorous protocols for crisis calls and serious incidents, with the same reporting accountability required in other organizations.

Capacity: Operating with Disproportionately Lower Funding

In an era marked by austerity in government spending, most CMHA organizations are reporting that they are expected to do far more with far less funding. Service, operational, and governance demands outpace capacity. All 11 leaders noted have to accomplish the impossible with their budgets.

"Our budget shortfalls make it very very hard for us to do that… and mental health organizations have not seen an increase to their budgets in well over a decade. So, what that actually boils down to, what it actually means is that over 12 years we've been receiving systemic cuts, right? Because not increasing our funding with costs being so high as they are the same thing. That squeeze just gets tighter and tighter and tighter." (Metropolitan Alt Business leader)

Even if the data collection, somehow, aligned with peer support values, there remains a very practical problem. Our approach to data collection is often a function of capacity, not skills. Without dedicated staff that can work to enhance reporting, data collection, or evaluation research, we collect the data we need to continue our work. That is not to say there is no research being done in our sector, but they are usually ad hoc projects. They take place sporadically, on top of other duties, or initiated externally by interested scholars. Some were able to build in costs for small-scale evaluation projects with non-MOH project funders. However, these are one-off projects that are limited in scope.

"You know there is a lot of talk about standardized methods of capturing information for the system and feeding into that system is going to be a real challenge for us for many reasons, including staffing but also this is not what our participants come to engage with us for. And just the administrative side of things. The amount of administration required, expertise, and technology is another thing. We probably have to really; we really need a lot of extra funding in order to be able to do it properly. We just don't have the structures in place." (Central Ontario CSI leader)

"We have to do fundraising on the side to cover the shortfall, because there is always a shortfall from the government funding. There hasn't been a base increase [4]in quite a few years. Community mental health is underfunded, so fundraising has to go to keeping the lights on and making payroll." (Northern Ontario CSI leader).

The trend in new funding assumes a level of organizational infrastructure capacity that is more easily met by large, mainstream organizations, but poses a double-edged sword for small ones. IF they decline the funding, they cannot serve their communities. IF they accept it, they risk being seen as lacking the capacity to manage growth, which fuels pressure towards amalgamations. What is missing is recognition of the chronic underfunding and unsustainable funding patterns facing CSIs/PSOs, where short0term, contract-based funding has not translated into stable increases to core operations. This strain has only deepened through the transition from LHINs to OHTs. Referring to this context, a central Ontario CSI leader noted,

"So, just to start there [with the transition to OHTs], that in and of itself becomes a big strain on the agency. As, smaller organizations, we are already strained. We've been all about the growth, but that growth has been distinctly about, as funders would say, 'boots on the ground'. They only want to see people delivering more services. But what hasn't come with that is the additional admin support that service requires, the infrastructure, the space--the office space, the programming space and al the infrastructure that is needed to support the services that's needed, and we are really seeing that pressure now because our direct service has just continued to expand. But that puts a lot of strain on the admin side, on the leadership team, on management and supervisors.

[4] Until the time of writing (late-2023), no base funding had been received

So that's been a bit of a battle because we haven't had a good, substantial, if at all, base funding injection that would allow us to grow as an organization to meet, be on par with our programming growth… Also, it's been tough because we don't have the staff to say, sit on this committee or that one, but the number of working groups that go along with the different funding pockets… we have to be mindful of the workload of our colleagues. I have to do most of them myself, but that's put a real strain on us" (Central Ontario CSI leader).

Capacity: Wearing Too Many Hats

In CSIs/PSOs, staff and leaders juggle multiple responsibilities, often balancing direct service with administrative, managerial, and reporting tasks. This reality means that while the skills and knowledge to collect meaningful data exist, limited time, funding, and capacity make it difficult to prioritize.

"Because I'm a stats person, I want to do more, but there's just no time or energy or hours in the day. We have the knowledge here, which I know not a lot of other places have, but those people are busy doing other necessary things…. Not enough time, not enough money, and we could actually generate some actionable data. And they would like to see this kind of data; they just don't attach it to base funding. It would be nice to have a full time data person, but we don't even have full time admin or reception, so there are needs that outweigh data collection, unfortunately." (Northern Ontario CSI leader)

"I am a consumer/survivor; I've also worked in the sector for a long time. I've been a client and then actually turned from being a client to working in the same program. That's kind of how I started out. I've worked in other mental health programs, a lot of employment counselling, financial literacy, things like that… but always supporting people with their mental health. My role [at alt business] right now is programs manager, which is interesting: it's partly management and partly front-line… and that's why data is such a small part of my job because I also run programs and facilitate a program. A critical part of any consumer/survivor organizations is job maintenance with employees – job maintenance and peer support." (Alt Business leader #2).

"You're looking at the finance department, the reporting department, the HR department, the stats department, the IT department…." (Central Ontario CSI leader)

We Want to Establish our Current Evidence Base through Data Collection

Leaders consistently expressed a desire for stronger data collection and evaluation, not just to satisfy funders. They want to better understand and demonstrate the impact of their work. However, chronic underfunding, staffing shortages, and reliance on custodial relationships with mainstream organizations leave CSIs/PSOs without the time, resources or autonomy to collect the kind of meaningful data they want.

"We have the good intentions to track better, but we don't always succeed because we are so under-resourced and so short-staffed that just in order to generate enough money from government… the cost of tracking is too much. The scarce budget we have means poverty wages for our staff, so the cycle of poverty perpetuates itself and some organizations exploit that. It actually creates an enormous amount of dissonance in the institution: fatigue, burnout, disillusionment among staff because they don't see themselves as being able to have a secure retirement or any of those protections…we have a lot of good intentions and we're are having a hard time fulfilling them because we're spread like too little butter over too much bread. You know that scraping? That's us." (Metropolitan CSI/Alt Business leader)

"I would say data collection is not something we do enough of. it's definitely not. It is in our priorities for this year, but right now we are mostly collecting just what the funders need, which is just the numbers [of people we serve] … what we're really lacking is evaluation data… That's our goal. To finish out the year and then begin to find a way to ask about and measure think like, 'rate your food security' or 'rate your wellbeing'... like my boss really wants to pay someone to do this, and we've submitted some grant applications and we put in money for evaluation, but it hasn't happened yet… and things always come up that become a lot more pressing that have to be dealt with…Even if we have the expertise in-house, there's no time." (Alt Business leader #2)

Mutuality and burden:

"I have an interest in research if it can help us, just check ourselves, right? Are we doing what we said we would do? Are we happy with where we're at? But research on its own would not be as valuable to me as somebody occupying dual roles where the research is collected based on the ongoing contact with the participants. That happens in a supportive role. Also, there tends to be a fair bit of overmining for information in anti-poverty spaces, without the benefits of that coming back to us and to the people we serve. But there's a way in which that information can be gathered as part of the exchange that sees that you've supported someone over time.... people are really struggling with deep trauma and other things, you know, medication challenges and like ending up in the psych ward, regular life…. So, someone in that research role would serve a dual function, support and research… we're in this sort of system where we are doing all this great work but can't prove it the way that people in the system want it proven." (Metropolitan Ontario CSI/Alt business leader)

"It's tough. Because everyone wants to work with you because we are grassroots, and do things according to our community's expectations, and you want to say yes to do all these things [partnerships, collaborations], like we are the in the best position to offer harm reduction and needle exchange programs, and if not us, then who? But then you have all this messy operational stuff [referring to being a flow through of a larger mainstream organization] about their insurance and their liability. We would take on the risk, but we don't have the financial means or the infrastructure to support additional programs, and that's when it gets really tough. If we were on our own, we'd find a way." (Central Ontario Consumer/Survivor Organization)

Shifting Terrain: The Challenge of "Partnerships"

For many CSIs/PSOs, "partnerships: with larger organizations are framed by government and funders as the solution to chronic underfunding. But leaders stressed that integration cannot be the only answer. Partnerships that are imposed or that require merging back-office support risk undermining peer support principles, eroding autonomy, and erasing the grassroots character of CSIs. One leader explained,

"***Sometimes we find ourselves a bit of deer in the headlights. It's sort of full steam ahead with this [service integration under the OHTs] and I guess if push comes to shove and we have to, I think we have to partner with an organization of our choosing, rather than being told…So we'd much rather build those relationships and make those choices for ourselves. However, that's always very difficult too…Our fear is that we get into that sort of a marriage and then those advocates and supporters and allies leave, and we find ourselves in a sudden death sort of situation." (Central Ontario, Consumer/Survivor Initiative leader)***

Concerns about custodial relationships were especially strong. Leaders described how reporting requirements and flow-through arrangements often shifted their work away from authentic peer support toward clinical models:

"…often, I've seen many times in these partnerships, how often they [the custodial organization] tied their hands in the things they do and what they are supposed to do and how, and also how it was supposed to be because of the reporting they had to do for them…. I know for some it works well, they actually get to see their budgets and stuff, but I know others that don't get to see any of that. I know ones that have been just so twisted. I'm like, isn't this supposed to be peer support? It sounds to me like you are doing clinical work. That's not peer support... we aren't case managers… But because of their flow-through, they are getting pushed into these models…. The body at the top has the voice." (Northern Ontario Peer Support Organization leader)

The looming threat of amalgamations was a recurring concern. Leaders reflected on the loss of approximately 30 CSIs in Ontario through closures and amalgamations that absorbed peer-led programs into larger organizations, often stripping them of their identity.

"Back in the early days, when it was CSDI [Consumer/Survivor Development Initiative] … they went all over Ontario and they [CSIs] gave us the opportunity to apply for jobs, good jobs. Of course, most people like me said, "oh, sure, I'll fill this out. I'll never get this job. I don't have any qualifications other than that I have mental health problems. Then they gave us the organizations… but I wish they were as kind to us when we make mistakes; it shouldn't be the end of the world." (Southern Ontario CSI leader)

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At the time of the interviews, some CSIs were also under direct pressure to take on more responsibility without adequate support:

"I'll help them out to save them from closing their doors, but it's like starting over" … but I kept saying to [the funder], this is a set up…Like you're asking me to triple my workload. My board is taking on all this responsibility, but you're not making any changes to your investment or our funding. And it's a set up."

Leaders worried that further amalgamation could erase the unique contributions of CSIs:

"We worry so much that if we do get amalgamated, it's going to stifle a lot of what we do…We won't have any wiggle room to do what we do. Like, there's no wait time for us – people can drop in the same day they need something and get right into daily groups and things. Someone can come in off the street. There's no six-month wait time… And those other services have their place, and we have our place in the system. I think it's important that we all stay part of it. I would hate to see us have to move to that kind of functioning." (Northwestern Ontario CSI leader)

"I've been around awhile, and what typically happens, small programs such as peer support, as soon as they become a part of a larger organization in any way, like a hospital, before they know it, they slowly disappear. They just no longer exist. That's another reason why we have to be careful that we don't get lumped in…We have to try and keep our unique identity and stay out of those organizations, or we'll get lost. There's no doubt we'll get lost." (Southern Ontario CSI leader)

Data Collection and Consumer/Survivor/Peer Support Movement Values

All aspects of CSI/PSO work, including data collection, must align with the peer support sector's values and principles. Leaders emphasized that genuine recording of impact is inherently complex, given the non-linear nature of recovery journeys. Being forced to capture data in ways designed for clinical or mainstream systems risks distorted services and undermining peer support approaches.

One leader explained the mismatch between mainstream systems and CSI approaches:

"Most data systems assume a one-time service or an on-going relationship, and that the nature of the relationship is one-way and linear…we might see someone today and not see them again for two years, or we might see them every day for the next five months. We never know, and that's okay by us. It works. We're flexible in that way, without appointments and expectations… Oversight and monitoring sort of model of working with people—that's doesn't work for drop-in style approaches or low threshold services, where we're not going to number a client and follow their journey, or take credit for their progress, and we're not going to assign staff to participants… people become units and workers become reporters." (Central Ontario CSI leader)

Another described the pressure to adopt standardized tools:

"I attended a meeting about data initiatives being standardized [in the MOH sector] and I was just zoning out because it was so detailed. The level of training just to be able to train our staff to be able to do it. It would completely change us. That would be the focus of our work…It gets farther and farther away from the person and connections with people. It's a real push-pull because we are under huge pressure to go in that direction… it's not even just pressure…The system assumes we have been doing something similar all along, and this isn't much of a change…But at the same time, their backlogs and long waitlists... huge, long wait lists… are the reason people are turning to us and why workers are referring to us so much….We don't work this way and therefore we don't have waitlists. If we were to jump on that train, all the barriers it would introduce, it would create more gaps in the system …you can't have it both ways…if you're recognizing the value of services like ours that are quick access, we're there when people need us… no waitlist, no intake, non-traditional hours…we can't just do what everyone else is doing." (Central Ontario CSI leader)

Others noted how funder requirements often reduce work to number that miss the essence of peer support:

"I think one of the difficult pieces is that it's kind of ever-changing, but that's all they ask for is the number of unique individuals and non-identified individuals, and that really doesn't capture what we do. So, we asked the Ministry if we could report on repeat visits/use, because we think that gives a better idea of what we are actually about…but some funders allow for narrative reporting, and although that's a bit stressful for the staff at times, at least it gives us the opportunity to try to capture and really share what some of what we do looks like." (Central Ontario CSI leader)

For some, opting out of clinical-style data systems is a deliberate act of principle:

"This is part of the ethos of psychiatric survivor work and peer support, to not engage in that sort of—what could be perceived as—interrogation, or documentation of pain or pathology… but our peer navigators who work in the hospitals, they report, or document, in the hospital client system, but they do it in a very principled peer support way, so it won't be about observing or monitoring or pathologizing…other than that it's just high level notes, very factual, very short—nothing intrusive." (Central Ontario CSI leader)

This resistance extends to tools like OCAN:

"They're coming in for peer support… something different than what they get elsewhere, not for 'let's sit down first and do this assessment' that's part of what makes us different…I think that's why a lot of agencies make it mandatory for clients. We won't make anything mandatory to get support." (Central Ontario CSI leader)

Leaders also highlighted the burden of custodial relationships with mainstream organizations, which often push intake processes and data requirements:

"… one of the things [they required] was we have to do intakes, because previously this was not done – it was more of a drop-in style. So, it was tough, because we want to be as low barrier as possible and quick access, with no waiting for long. But that was something that was really pushed on the agency to do. That's why we have some intake information as part of our records… [Staff] were really pushing back on it…And so, we held off until our hands were forced. There was no choice." (Central Ontario CSIs/PSOs)

At the heart of it is a fidelity to consumer/survivor social movement:

"Our membership are huge advocates for us and the work we do. The amount of people we've heard say that the program itself has saved their life. But we don't take credit for that, we are just here. We do the programs but it's their work. We don't take credit for their success because that's them." (Northwestern Ontario CSI leader)

Conclusion & Recommendations

Our Approach to Data Collection: The Minimum Necessary

Conclusion

This exploratory report highlights the ongoing tension in CSIs/PSOs between meeting funder requirements for data and maintaining the core values of peer support. CSIs/PSOs operate with chronic underfunding, limited administrative capacity, and pressures from partnerships or system integration. Despite these challenges, CSIs/PSOs demonstrate innovation, resilience, and a commitment to core peer support values.

Key Considerations

- Consumer/Survivor Movement and Peer support values: The data collection approach must respect anonymity, non-intrusiveness, and the non-linear nature of recovery. Standardized clinical tools conflict with these values.
- Capacity constraints: CSIs/PSOs juggle multiples roles and small organizations often lack dedicated team members to manage data.
- Funders and partnerships: Reporting requirements are diverse and sometimes imposed through custodial relationships with larger organizations.
- Outcome definitions: Traditional metrics (attendance counts, referrals) do not capture meaningful outcomes for CSIs/PSOs. Outcomes should reflect peer support values, such as belonging, empowerment, safety, and access to low-barrier services.

Recommended actions

1. **Develop peer support sector-aligned data strategy**
    a. Collaborate across CSIs/PSO to define meaningful outcomes beyond attendance metrics (e.g., belonging, empowerment, serving those others cannot).
    b. Align data collection with peer support principles
    c. Consider piloting innovative approaches before full-scale adoption

2. **Centre for Excellence (or sector lead) support**
    a. Provide guidance on data collection strategies
    b. Ensure alignment with sector needs, respecting anonymity and ethical principles.
    c. Support experimentation and pilot studies to evaluate impact without disruption of services.

3. **Capacity funding and infrastructure**
    a. Allocate funding for dedicated administrative/data roles, IT systems, and training.
    b. Provide resources for sustainable core operations, avoiding short-term project-only funding.
    c. As always, establish parity funding with other community mental health and addictions organizations; amalgamating for infrastructure should not be on the only practice offered.

4. **Flexible, collaborative reporting**
    a. Negotiate with funders for reporting templates that capture narrative and contextual information.
    b. Reduce duplication or externally imposed data requirements.
    c. Encourage funders to support narrative-based evidence to reflect peer support impact.

5. **Preserving autonomy and identity**
    a. Approach partnerships carefully to avoid amalgamation pressures or custodial control.
    b. Ensure CSIs/PSOs retain decision-making authority over program design, service delivery, and data collection.

6. I**ntegrated evaluation**
    a. Build evaluation into ongoing service delivery rather than as a separate, burdensome activity.
    b. Use findings to advocate for sector-specific funding, policy recognition, and program support.

Message from PeerWorks Director, Allyson Theodorou

Peer support is built on trust, privacy, and confidentiality. Peer access peer support services because they are non-clinical, low-barrier, and stigma free environments. The data collection practices that are being demanded of us are at complete odds with our ethos at PSOs/CSIs. We anticipate a significant drop-off in participation, especially among people experiencing homelessness or housing insecurity, survivors of trauma, or individuals with past negative clinical experiences, if we are expected to provide identifying information.

Instead, we propose aligning data collection with CSI and peer support values. By allowing for non-identifying or coded data, Ontario Health will be able to understand the impact of the program without infringing upon people's privacy. This data could include:

- Counts of unique participants per program
- Demographic ranges (not tied to an individual profile)
- Frequency of engagement
- Anonymized outcome indicators
- Program type and intensity

This would meet Ontario Health's data and accountability objectives without compromising the safety and confidentiality that peer support requires.

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