

CONSUMER/SURVIVOR INITIATIVES: IMPACT, OUTCOMES & EFFECTIVENESS



power

CONSUMER

value

SURVIVOR

HEALTH

SUCCESS



initiative

support

recovery

STRATEGY

funding



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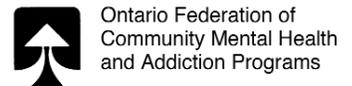
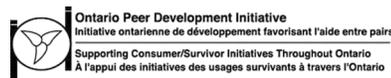
This publication has been written and produced through the joint efforts of the Canadian Mental Health Association, Ontario; Centre for Addiction and Mental Health; Ontario Federation of Community Mental Health and Addiction Programs; and the Ontario Peer Development Initiative.

Canadian Mental Health Association, Ontario is a volunteer led, professionally managed charitable organization with a community focus dealing with all aspects of mental health and mental illness. Its mission is achieved through public education, social action and advocacy, research and policy development as well as programs and services delivered through 33 branch offices across Ontario. Heather McKee, Community Mental Health Analyst, was the lead researcher/writer for this document.

Centre for Addiction and Mental Health (CAMH) is Canada's leading addiction and mental health teaching hospital. CAMH works to transform the lives of people affected by addiction and mental illness, by applying the latest in scientific advances, through integrated and compassionate clinical practice, health promotion, education and research. CAMH has central facilities located in Toronto, Ontario and 26 community locations throughout the province. CAMH has contributed the design and printing of this document.

Ontario Federation of Community Mental Health and Addiction Programs represents more than 200 front-line, community-based providers who recognize people and their families as the core of their organizations and ensure their basic human rights and dignity. Since 1988, the Federation has envisioned a community mental health and addiction system that is accessible, flexible, comprehensive and responsive to the needs of individuals, families and communities, shaped by many partnerships, dignity and accountability to those it serves. The Mental Health Council, including Brian McKinnon and Barbara Frampton, led the development of this document.

Ontario Peer Development Initiative (OPDI) supports Consumer/Survivor Initiative organizations and affiliates, building on skills and capacities to maximize individual opportunities and be full citizens in their communities. Peer Advisors provide tailored workshops in cooperation with CSIs self-identified needs in their organizational development and capacity building. OPDI furthers networking opportunities to promote a strengthened consumer/survivor provincial voice, while working within the context of the Ministry's mental health reform process. Raymond Cheng, Peer Advisor, was an instrumental contributor to the research and writing of this document.



INTRODUCTION

Consumer/Survivor Initiatives (CSIs) play a critical, yet undervalued, role in Ontario's mental health system. Studies have proven that CSIs support people in recovery and reduce their use of hospital, crisis, and other expensive services. CSIs represent a way to both ease and enable people's transition from formal mental health services back into the community.

While successive governments have recognized the need for a client-centred health care system and have acknowledged the innovative role that CSIs play in providing services, CSIs have not received any substantial new investments since they were first funded more than 15 years ago. Many CSIs have lost their funding altogether, while others have lost their organizational autonomy.

Consumer/Survivor Initiatives are run for and by people with mental health problems and/or those who have received mental health services. CSIs embody the principles of inclusiveness and recovery that underlie the current government's transformation agenda for the Ontario health care system. CSIs contribute to desired outcomes by supporting people in their recovery so that they have less need for formal mental health services. But without appropriate levels of funding, recognition, and respect for CSIs, the health care system is at risk of losing a valuable partner.

The current government has an immediate opportunity to act on more than 20 years of recommendations, supported by evidence-based research. They have an opportunity to demonstrate leadership by committing to make Ontario a leader in consumer/survivor empowerment, by allocating a significant percentage of mental health funding to CSIs, and by mandating the inclusion of consumer/survivors in the planning, running, and evaluation of all mental health services through government policy and accountability measures.

Consumer/Survivor Initiatives bring a valued and distinctive mix of peer support, alternative businesses, and other empowerment models to the health care system in Ontario. CSIs require acknowledgement for their valued role and increased funding to continue to fulfill this role.

Our purpose in preparing this paper is to show that Consumer/Survivor Initiatives are active in communities across Ontario, to illustrate how evidence-based research has proven their value and effectiveness, to demonstrate that CSIs face significant challenges related to insufficient recognition and inadequate funding, and to make recommendations that will address these challenges and will ensure a continuing role for CSIs within a transformed health care system in Ontario.



UNDERSTANDING THE VALUE OF CONSUMER/SURVIVOR INITIATIVES

Consumer/Survivor Initiatives contribute to reductions in the use and cost of services — including community mental health programs, hospitals, psychiatrists and general practitioners, income support programs and other services — funded by the Ministry of Health and Long-Term Care and the Ministry of Community and Social Services.

- CSIs provide a **natural network of peers and friendships**, reducing the social isolation that is often a significant factor in relapse.
- Participants in CSIs spend **less time in hospital**, use fewer crisis services, and can often reduce their use of psychiatric medication, all of which reduce government costs.
- CSIs offer **employment and training** to consumer/survivors. Many people earn additional income to supplement or replace their benefits from the Ontario Disability Support Program, enabling them to contribute back by paying income tax.
- CSI staff and volunteers offer friendly visits to hospital inpatients. After discharge, consumer/survivors can **benefit in their daily living activities** through CSI program participation or through telephone support. CSI staff and volunteers serve as models. They demonstrate the unique value of having “been there” and thriving since.
- Many CSIs run “connection” programs that connect long-term clients in the hospital with peers who live independently. People leaving hospital learn by example from their peers, thereby **easing the transition to community living**.
- Patient Councils provide a voice for consumer/survivors in the institutional environment where people are typically at their most powerless. The involvement of Patient Councils can lead to **improvements in quality of care, patient safety and respect for patients’ rights under the law**.
- CSIs have been shown to **reduce participants’ use of outpatient services and physician visits**, thus reducing the workload of these professionals.

initiative
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recovery
STRATEGY
funding

CONSUMER/SURVIVOR INITIATIVES ARE AN INNOVATIVE AND PROGRESSIVE FEATURE OF ONTARIO'S HEALTH CARE SYSTEM

Consumer/Survivor Initiatives are an essential part of the continuum of health care. CSIs have many unique and innovative features:

- All or a significant majority of the staff, board of directors or advisory committee, and the membership of CSIs are individuals with **direct experience** of mental health problems and/or the mental health system.
- CSIs are based on **empowerment, peer advocacy and peer support**. They are “a system of giving and receiving help founded on key principles of respect, shared responsibility, and mutual agreement of what is helpful” [Mead, Hilton, & Curtis, 2001].
- Consumer/survivors “own” their organization – they are responsible for the decision-making process within the group, as well as its outcomes and successes. For many mental health consumer/survivors, a CSI is often the first place in their lives where they feel they are **in control** of what happens to them.
- CSIs provide people with the **opportunity to give** back to the community. For example, many former “patients” now own and operate alternative businesses and are once again contributing members of the workforce, supporting the local economy, and are no longer dependent on government income support.
- Peers in a CSI see each other as **real people with stories to be shared and listened to**, rather than as “cases” defined by impersonal diagnostic labels.
- Peers in a CSI can challenge one another to reject the limitations of being a “mental patient” and take **personal responsibility for their recovery** with group support.
- Peers in a CSI act as **role models** for the ongoing experience of recovery.

Consumer/Survivor Initiatives in Ontario include a range of organizations:

- Self-help groups and alternative businesses that were originally funded through the Consumer/Survivor Development Initiative (CSDI) of the Ministry of Health and Long-Term Care. CSDI began in 1991 by providing \$3.1 million dollars in funding to non-service or alternative models that drew upon the skills and expertise of consumer/survivors to develop unique ways to deal with shared mental health care and other issues [Health Systems Research Unit, 1997].
- Self-help groups and alternative businesses who were funded prior to CSDI, or who received core or project funding from other sources
- Independent initiatives with their own board of directors
- Initiatives that are sponsored by another organization (often a mainstream mental health agency or another CSI)
- Patient Councils funded by hospitals
- Regional networks of CSIs, both funded and unfunded
- Unfunded groups and alliances
- Organizations with provincial mandates, both funded and unfunded

We recognize and respect that people use different terms and criteria to describe people who receive mental health services and consumer/survivor programs. For the purposes of this paper, Consumer/Survivor Initiatives includes those groups who define themselves as consumer/survivor-controlled and driven. This means that self-identified consumer/survivors make up the majority of the membership,

staff, and board of directors or other governing body. Many of these groups use peer advocacy, peer support and self-help models as alternatives or complements to medical and psychosocial models.

Several CSIs include both consumer/survivors and family members in their membership and leadership. A few groups include both people with personal experience of mental illness and the mental health system and those with addictions.

CONSUMER/SURVIVOR INITIATIVES PROVIDE SUPPORT WHERE PEOPLE NEED IT

Through the support that people give and receive via Consumer/Survivor Initiatives, people learn that recovery is real. Following is a sample of the wide spectrum of valuable work being done by CSIs across Ontario:

- **People Supporting People**, a group sponsored by the CMHA Barrie Branch, offers 16 different “wellness” workshops on issues of interest to consumer/survivors, such as self-esteem and managing conflict. After attending the workshops, people have the opportunity to become trained facilitators who are paid to conduct further groups.
- **A-Way Express**, in business since 1987, employs close to 50 consumer/survivors as couriers, including people who have been out of the workforce for decades.
- Through **Brantford Vocational Training Association’s** “We Care” program, a CSI staff person and member visits the psychiatric inpatient unit of the local hospital to provide people with a bag of donated personal care items and information about peer supports in the community.
- **Sunset Country Psychiatric Survivors**, with offices in Kenora, Dryden, Red Lake and Fort Frances, offers its members opportunities at least once a year to get together and attend a board training or public education event.
- **Patient Councils** in both general and psychiatric hospitals work in partnership with staff to provide education to consumer/survivors and others (families and staff) on the choices and resources available to them.
- **Mental Health Support Project** of Lanark, Leeds and Grenville, with offices in Smith Falls and Brockville,

is in the process of developing a program where members can create their own “recovery plans,” including monitoring their mood levels and quality of life and setting goals for change, with help from a peer support practitioner.

- **Northeast Regional Consumer/Survivor Outreach Program** is sponsored by another CSI, People for Equal Partnership in Mental Health in North Bay, to support developing self-help consumer/survivor groups in the region in the areas of non-profit management, organizational, board and leadership development. This group is one of several regional networks. The others include the South Western Alliance Network and Eastern Regional Network.
- **Northern Initiative for Social Action (NISA)** in Sudbury is a consumer-run, occupation-based group which runs a variety of programs including the Open Minds quarterly journal of creative works by consumer/survivors.

**CONSUMER/SURVIVOR
INITIATIVES EMBODY THE
PRINCIPLES OF INCLUSIVENESS
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FOR THE ONTARIO HEALTH
CARE SYSTEM.**

CONSUMER/SURVIVOR INITIATIVES DEMONSTRATE VALUE AND EFFECTIVENESS

CSIs have demonstrated that they contribute to reductions in the use of hospital services and improve the quality of life of consumer/survivors. Researchers have used recognized methodologies, such as participatory action research, to measure the value of peer support while remaining true to self-help principles.

A Longitudinal Study of Consumer/Survivor Initiatives in Community Mental Health in Ontario was funded by the Ministry of Health and Long-Term Care from 1998 to 2004. Dr. Geoff Nelson, the principal investigator, states that prior to the study the general impression was that CSIs were valuable, but they lacked evidence to back up their claims [Nelson, 2005]. With the most recent studies, CSIs can now demonstrate through evidence-based research that they embody current best practices in community mental health.

PARTICIPATION IN CONSUMER/SURVIVOR INITIATIVES REDUCES HOSPITAL USE

Research consistently demonstrates that people who participate in Consumer/Survivor Initiatives experience significant reductions in their use of hospital services.

Findings from the Longitudinal Study show that

- at the beginning of the study, participants had an average number of 8 days of psychiatric hospitalization in the previous 9 months
- after participating as active members of CSIs for 18 months, the number of days in hospital dropped significantly, to below 2 days

In contrast to the control group in the Longitudinal Study, members who actively participated in their local CSI experienced significantly greater

- **reductions** in hospitalizations
- **reductions** in symptom distress
- **improvements** in social support
- **improvements** in quality of life (daily activities) [Longitudinal Study – Summary Bulletin, 2004].

These findings support an earlier study of CSIs conducted in 1996-97. In “Beyond the Service Paradigm: The Impact and Implications of Consumer/Survivor Initiatives,” the researchers report that members of CSIs need to use fewer mental health services, especially the most expensive services – inpatient hospital treatment and crisis services.

- Before joining a CSI, study participants had a mean number of 48.36 hospital inpatient days.
- After joining, the **days dropped** to 4.29.
- Before joining a CSI, participants had a mean number of 3.54 contacts with crisis services.
- After joining, the figure **dropped** to 0.81 contacts [Trainor, J., Shepherd, M., Boydell, K.M., Leff, A., & Crawford, E., 1997].

The Therapeutic Relations/Connections program study, which took place in 1998-2002, measured the role of CSIs in helping people make the transition from hospitalization to living in the community. Funding for the programs and related study came from a variety of sources, including the Canadian Health Services Research Foundation and the Trillium Foundation. The study showed that **the service produces significant benefits:**

- “This new way of helping people with mental illness [to] make the difficult transition from hospital to community **saved more than \$12 million** through shorter hospital stays” [Forchuk, 2002].
- People who were connected with peer mentors from a CSI were discharged from hospital an average of 116 days sooner [Forchuk, 2002].

- Consumer/survivors who described themselves as “lonely” and were partnered with a peer mentor “used an average of **\$20,300 less per person** in hospital and emergency room services during the year after discharge.” They also reported improved quality of life and level of functioning which lead to reduced costs in services [Forchuk, 2002].

Alternative businesses are a type of CSI that are “operated entirely by Consumer/Survivor employees and [have] been created through a Community Economic Development (CED) approach” [Ontario Council of Alternative Business, 2002].

According to a study published in the Canadian Journal of Community Mental Health, people who were employed by an alternative business reported

- **significant reductions** in the number of days of inpatient hospital treatment – down to 2.5 days per year from 51.5
- **significant reductions** in crisis contacts
- **significant reductions** in the number of times in hospital [Trainor and Tremblay, 1992].

A two-year study involving participants in Northern Initiative for Social Action (NISA), a consumer-run group in Sudbury that runs a variety of occupation-based programs, also showed a significant reduction in hospitalizations. As reported in the American Journal of Occupational Therapy, only one participant was hospitalized during the study.

- “Of the other 37 NISA members at the time of the study, **none were hospitalized or used crisis services** during the 2-year study period. Many members had previously had at least one hospitalization per year, with an average length of stay of 6 weeks” [Rebeiro, Day, Semeniuk, O’Brien and Wilson, 2001].

CONSUMER/SURVIVOR INITIATIVES ARE INCLUSIVE

Consumer/Survivor Initiatives are inclusive of people who are among the most marginalized in society – those individuals who are considered to be suffering from severe, long-term mental disorders. This is the priority population for services funded by the Ministry of Health and Long-Term Care [Ontario Ministry of Health, 1999].

According to the Longitudinal Study,

- “While people who use Consumer/Survivor Initiatives are somewhat different than people who use Assertive Community Treatment (ACT), it is important to note that Consumer/Survivor Initiative members experience a number of **significant social and health challenges**, some more serious than those who use ACT” [Longitudinal Study – Summary Bulletin, 2004].

Among members of the four CSIs who participated in the Longitudinal Study,

- 64 percent have a diagnosis of a mood disorder
- 33 percent have a schizophrenia diagnosis
- 90 percent were taking a psychotropic medication
- 75 percent had a primary therapist or caseworker
- 49 percent were also involved with some other community mental health agency [Longitudinal Study – Summary Bulletin, 2004].

The 1996-97 evaluation study also found that CSIs members had had **significant involvement in the mental health system**:

- “92 percent of respondents reported on their experience in provincial psychiatric hospitals,” and
- “74 percent reported on inpatient experience with general hospital psychiatric units” [Trainor, et. al., 1997].

CONSUMER/SURVIVOR INITIATIVES LEAD TO IMPROVEMENTS IN THE HEALTH SYSTEM AND CHALLENGE STIGMA AND DISCRIMINATION

CSIs are active in making change at the system level, “including public education, political advocacy, community planning and action research” [Longitudinal Study – Summary Bulletin, 2004].

The impact of these activities includes

- “**changes in perceptions** about mental health issues by service-providers, policy makers and the general public,” and
- “**concrete, tangible changes** in service delivery practice, service planning, public policy or funding allocations” [Longitudinal Study – Summary Bulletin, 2004].

As an example, “CSI members lobbied a local municipality to reinstate bus pass subsidies for people living in residential care facilities, many of whom were consumers. Their efforts were so successful that the subsidy was not only brought back, but increased to a full 100 per cent” [Making a Difference, 2004].

In addition to giving people a chance to show that they can work and earn an income, alternative businesses

- “**raise survivor expectations** of the nature and quality of their lives,”
- “**question the determinations** other people (professionals, family members, the public) make about survivors and their abilities to provide for themselves,” and
- “assist survivors to ‘**unlearn**’ the dependencies of ‘**patienthood**’” [Church, 1997].

CONSUMER/SURVIVOR INITIATIVES PROVIDE EMPLOYMENT

People with serious mental illness experience an unemployment rate of up to 90 percent [Standing Senate Committee on Social Affairs, Science and Technology, 2004].

CSIs offer **supportive workplaces** for many people who have been told that they were permanently unemployable:

- At the end of their first year of existence, CSIs funded by the CSDI funding envelope had created 81 full-time equivalent positions, employing over 300 consumer/survivors.
- 75 percent of these new employees had been on social assistance prior to their job with a CSI [Ontario Peer Development Initiative, 1997].
- Alternative businesses across Ontario currently **employ approximately 800 people** [Ontario Council of Alternative Business, 2002].
- The BUILT Network is an employment training program with two locations in Ontario sponsored by the National Network for Mental Health. They train people in customer service and, in the 2004-2005 fiscal year, supported 43 people into employment [McKnight, 2005].

- According to Mary Lucas, executive director of A-Way Express, many employees of this alternative business courier company had been out of the workforce for many years – including one individual who was unemployed for 23 years – prior to working at A-Way [Lucas, 2005].

The Connections program, which matched peer mentors with an individual being discharged from hospital, was challenged by its own success at training and empowering consumer/survivors because peer mentors developed such valuable skills and expertise through the program that many of them returned to paid work, which restricted their availability to volunteer. At the end of the project, both volunteers and former patients alike were left with untapped skills due to lack of resources [Connectionsprogram.org].

CONSUMER/SURVIVOR INITIATIVES HAVE EARNED THE RESPECT OF GOVERNMENT AND THE HEALTH CARE SYSTEM

At least 20 provincial government-sponsored reports since 1983 have called for increased investment in and reform of the mental health system [CMHA Ontario, 2003]. These reports specifically recognized the value and effectiveness of CSIs and the importance of involving consumer/survivors in all aspects of the mental health system. The South Western Alliance Network of CSIs has published relevant excerpts highlighting the importance of CSIs [South Western Alliance Network, no date].

According to the most recent report, “The Time Is Now: Themes and Recommendations for Mental Health Reform in Ontario” [Provincial Forum of the Mental Health Implementation Task Forces, 2002].

Peer services must be equitably funded as clinical services and be identified as relevant and mainstream partners in local systems of care.

Community mental health agencies and hospitals have also long recognized and championed the value and effectiveness of Consumer/Survivor Initiatives. The Canadian Mental Health Association, Ontario, the Centre for Addiction and Mental Health, and the Ontario Federation of Community Mental Health and Addiction Programs made the following statement in a recent joint submission to Ontario’s minister of finance:

Investment into consumer and family initiatives is a key component of putting the consumer at the centre of the system and providing a much needed continuum of care for people with mental illness... None of the investments the Government has made thus far, while they have been greatly appreciated, are supporting consumer and family initiatives. We encourage the Government to develop a clear strategy to build consumer and family initiatives, beginning with increased funding for these vital services [CMHA Ontario, CAMH, OFCMHAP, 2005].

CONSUMER/SURVIVOR INITIATIVES MEASURE THEIR SUCCESSES IN MANY WAYS

In addition to evidence from formal research studies, Consumer/Survivor Initiatives are ultimately successful on their own terms.

- CSIs “**lead by example**,” according to Jennifer Chambers, coordinator of the Empowerment Council, a member-run advocacy organization of people who have been in the mental health and addiction systems. All consumer/survivors, not just those who are directly involved in CSIs, benefit from seeing that consumer/survivors can run their own organizations, from “having our own voice” and from seeing that “we are perfectly capable” [Chambers, 2005].
- The **open-door policy** of many CSIs means that they play an essential role by “filling the gaps” created by the systemic underfunding of the mental health system. CSIs are open to anyone who defines themselves as a consumer/survivor and, in some cases, to family or friends looking for support for a loved one. Without waiting lists, clinical intake processes or exclusionary criteria, CSIs are where people turn when they are unable to access services at overburdened hospital or community mental health agencies. CSIs are also open to people who are unwilling or unable to access traditional mental health services.

- CSIs create **safe spaces** for consumer/survivors to share experiences and work together for change in the mental health system. This safe space leads to positive outcomes both for individuals and the system as a whole.
- Consumer/survivors, who use traditional mental health services, as well as those who have found traditional services to be coercive and traumatizing, both describe CSIs as a “respite” from professional involvement in their lives, a place where they are **people first** and not merely the recipients of help.
- The system benefits from supporting consumer/survivor-only spaces. The Empowerment Council led the development of a Bill of Client Rights at the Centre for Addiction and Mental Health. During the development process, they found that consumer/survivors only felt safe to discuss traumatic or disrespectful experiences when they were in a group without professionals present.
- Mental health professionals have found that employing consumer/survivor researchers, such as the Can-Help Quality Assurance Program in Fort Frances and Kenora, to conduct satisfaction interviews with clients leads to better results as consumer/survivors feel safer speaking with a peer. This parallels the findings of the Connections and the Longitudinal Study.
- According to Mary Lucas, executive director of A-Way Express, many of the employees have serious physical health problems, including diabetes and heart disease [Lucas, 2005]. A-Way’s couriers use public transportation for their work, rather than a car, and many have commented on the improvement in their physical health as a result of the physical demands of walking throughout the day.

CONSUMER/SURVIVORS OFTEN LIVE IN INADEQUATE AND UNSAFE HOUSING, GO HUNGRY, AND CANNOT AFFORD MEDICAL SERVICES THAT ARE CONSIDERED “EXTRAS.”

DESPITE THE EVIDENCE OF THEIR VALUE AND EFFECTIVENESS, CONSUMER/SURVIVOR INITIATIVES FACE A GROWING NUMBER OF CHALLENGES

After many years, Consumer/Survivor Initiatives are starting to break down from the strain of coping with extremely limited resources while the number of people who need their help continues to grow. While membership has increased, the number of staff has not, and unpaid volunteers can only do so much. Furthermore, CSIs must deal with the increasing complexity of reporting to funders and the pressure of accountability.

Another key challenge facing CSIs is the lack of respect and recognition for their valuable role in the continuum of health care. While report after report praises the role and value of CSIs, they are still too often marginalized within the mental health system. CSIs seek to be recognized as representatives of the voices and experiences of consumer/survivors.

Following are some of the specific challenges that CSIs are currently facing. Many of these challenges are shared by the entire community mental health sector, while others are unique to CSIs.

CHALLENGES FACING CONSUMER/SURVIVOR INITIATIVES

Consumer/Survivor Initiatives have effectively faced a financial freeze for over a decade. Patient Councils are typically operating with fewer dollars per institution served than when they were originally developed and funded over a decade ago. Underfunding is one of the most significant systemic challenges that CSIs face.

Many CSIs began as time-limited projects in a Ministry of Health and Long-Term Care anti-recession strategy. Their base budgets have therefore never been comparable with existing community mental health partners. CSIs funded by community mental health dollars recently received their first increase in base funding – of 2%. Under the current government, there have been new investments for the community mental health and hospital sectors.

To date, CSIs have been shut out of this new funding, except for a single initiative¹.

The impact of underfunding is experienced in a number of ways by CSIs and the people who participate in them:

- **CSIs support and train many consumer/survivor employees** who have often been out of the workforce for years. As they evolve from members requiring support to peers helping others and they take on volunteer roles, their self-esteem and their expectations about the future improve dramatically. Yet CSIs are only able to offer **limited employment options**. These trained people move on, often recruited by mainstream mental health agencies. Consumer/Survivor Initiatives are ambivalent about this process – while they celebrate the success of their “graduates,” they have lost their investment in grooming these valued individuals.
- **Agencies without core funding have to rely on time-limited project or contract funding**. They experience the same cycle of building people’s skills and confidence, but when the funding runs out, everyone is laid off. This has negative personal consequences, and the momentum of community capacity-building is lost.
- CSIs often **cannot afford to hire replacements for staff on leave**, which puts additional stress on the remainder of the working team.

¹Sound Times Support Services received \$252,000 out of \$27.5 million invested in community mental health services [Ontario Ministry of Health and Long-Term Care, 2005].

- The vast majority of CSIs are **not able to offer competitive wages** to any employee, even compared with their counterparts in the already underpaid community mental health sector.
- CSIs continue to **struggle to find extended health care benefits from insurance providers** due to the unavoidable fact that all their employees having pre-existing health conditions.
- CSIs often have **barely adequate facilities**, a chronic problem that has worsened over time as membership continues to grow. Some CSIs lack proper kitchen and washroom facilities. Meeting critical needs, such as providing showers for members who are homeless, is beyond their financial reach. Systemic barriers mean that CSIs face the dilemma of finding decent yet affordable housing, just as their members do.
 - A newspaper profile of Phoenix Survivors in Stratford described the leaking roof, rotting doors and cramped conditions of their office. As the landlord is selling the building, Phoenix is struggling to find a suitable new space, comparable in price to the \$720 a month they currently pay, but in decent condition and accessible for their members [Sutton, 2005].
 - ABEL Enterprises in Simcoe reports that the room they use for board meetings is inadequately heated. Recently, board members had to keep their winter coats on during the board meeting [Lea, 2005].
- **Physical accessibility is a key challenge** for CSIs, whose members are often unable to afford private cars or even public transportation (if it is available in their area). CSIs need space that is located in a central neighbourhood or easily accessible by public transportation.
- CSIs **lack the information technology (IT)** capacity and necessary human resources, including time for training and data collection, to respond to funder reporting requirements.
- CSIs in rural, northern and remote communities face the challenge of **lack of extensive public transportation** or are otherwise dependent on the goodwill of others.
- CSI members face **barriers in obtaining a travel subsidy allowance through the Ontario Disability Support Program (ODSP)** in order to be able to travel to the CSI. Regional ODSP offices interpret regulations differently, and many do not consider CSIs to be “medically necessary” services (such as appointments with psychiatrists) and therefore do not provide ODSP coverage for transportation.
- Alternative businesses have waiting lists of people who want to work, but they **need additional funding for infrastructure** in order to expand their contracts or services and hire more employees. Employees enjoy their work and the environment of the alternative businesses, so they don’t leave. Some businesses can only offer a specific number of shifts to employees, who often request more. Others have to constantly maintain a balance between the number of hours that employees can work and the fluctuations of business orders.
- CSIs have indicated a need to form networks of the CSIs in a region but **need funding to create networks** in all regions where people have expressed an interest, as well as enhanced financial support for the networks that currently exist. Staffing resources for the existing networks are limited to one or two days’ worth of support.
- The **limited staffing resources** of CSIs also make it difficult for people to take time out to dedicate to networks. ABEL Enterprises in Simcoe is a long-time member of the Ontario Council of Alternative Businesses (OCAB), but they will have to stop sending staff to attend board meetings one day a month as they cannot afford to lose even a day of staff time [Lea, 2005].
- Many members of CSIs **rely upon the Ontario Disability Support Program (ODSP)** as their primary source of income. ODSP benefits are well below the poverty line and, as a result, consumer/survivors often live in inadequate and unsafe housing, go hungry, and cannot afford medical services that are considered “extras.” If they work in an alternative business or other CSIs, any additional income earned over \$160 a month is clawed back at a rate of 75 percent. This level of poverty impacts upon the CSIs, who need funding to offer transportation, meals, clothing, social events, and other basic necessities of life. In some cases, CSI employees pay for these essentials out of their own pockets, rather than see their members go hungry.

CONSUMER/SURVIVOR INITIATIVES SEEK TRUE RESPECT

Although reports and policy statements regularly highlight their value, many CSIs feel that they are paid “lip service” rather than true respect by both funders and other mental health stakeholders. Many CSIs feel that the marginalization of their groups is a result of the stigma and discrimination faced by consumer/survivors in general. As CSIs represent a small fraction of the mental health sector, itself described as the “orphan” of the health system as a whole, they are too often ignored by government and other decision makers.

Consumer/survivors also experience the challenge of having others claim the right to speak on their behalf, which serves to further marginalize CSIs. The Empowerment Council, a member-run advocacy organization of people who have experienced the mental health or addiction systems, described this in their submission to Senator Michael Kirby’s Standing Senate Committee, which is currently studying mental health and addiction in Canada:

Unlike any other group enumerated under the Charter, it is considered acceptable to hold consultations, make decisions, draft policy, run organizations, with little to no involvement of the community on whose behalf all of these activities ostensibly exist to serve [Chambers, 2003].

This sense of systemic discrimination that exists against consumer/survivors and their representative organizations is felt in many ways:

- Over the years, several of the CSIs originally funded under the 1991 CSDI Anti-Recession Strategy have **lost their independent board of directors and right to receive transfer funding directly from the Ministry of Health and Long-Term Care**. Some of these groups have remained as consumer/survivor-run programs within a larger mental health agency. Of particular concern are those cases where the consumer/survivor funding envelope has been given directly to service providers with the result that consumer/survivor-run peer support has been lost in those communities.
- **Relationships between CSIs and sponsoring agencies can be challenging**. Many CSIs have developed

relationships with sponsoring agencies where each partner is treated as an equal. However, some still find that unequal power relations between mental health professionals and consumer/survivors mean that the sponsored CSI is treated more as a program of the agency, rather than an autonomous group. In such situations, CSIs may not be provided with necessary information about budgets, or be involved in decision-making processes.

- **CSIs exist in a unique position** as both part of the mental health system and also fundamentally different from traditional providers, in that they directly represent consumer/survivors. CSI relationships with the Ministry of Health and other funders are often caught in this tension. Most ministry documentation for mental health agencies, including the Operating Manual (December 2003) and reporting documents, is not compatible with the mandate and values of CSIs. Recognition of the unique role and value of CSIs would require that the ministry requirements be flexible enough to encompass CSIs or, alternatively, work in partnership with CSIs to develop a separate set of policy directions, reporting requirements and other documentation.
- **Patient Councils are undergoing a period of transition with the divestment of psychiatric hospitals**. While many hospitals have stated that they recognize the value and unique role played by the councils, some have already seen their budgets reduced, and others are concerned about the future of their financial support and organizational independence once these institutions are returned to the community.

**CSI RELATIONSHIPS WITH THE
MINISTRY OF HEALTH AND OTHER
FUNDERS ARE OFTEN CAUGHT IN
THIS TENSION.**

SEIZING THE OPPORTUNITY TO “DO THE RIGHT THING”: RECOMMENDATIONS TO GOVERNMENT

The current government has an opportunity to act on more than 20 years of recommendations. They have an opportunity to recommit to making Ontario a leader in consumer/survivor empowerment. The clearest demonstration of government leadership would be to implement the following recommendations, based on a review of the research literature and input from Consumer/Survivor Initiatives.

OUR RECOMMENDATIONS

- ⇒ To alleviate the intense pressures facing Consumer/Survivor Initiatives, the government should immediately double CSI funding, from the approximately \$4.5 million currently received to \$9 million.
- ⇒ Develop a strategy to allocate a dedicated percentage of health care core funding directly to Consumer/Survivor Initiatives. Ensure the active involvement of CSIs in the process of establishing the amount of funding required and distributing the funds. Some related recommendations to consider:
 - ⇒ Set a minimum percentage of base funding for CSIs within the mental health system. According to Canadian, Ontario and international researchers, allocating 5 percent of the current annualized community mental health budget to CSIs would signal government support for the essential role they can play in any transformed health care system [Longitudinal Study, 2004; Campbell and Leaver, 2003; McEwan and Goldner, 2001].
 - ⇒ Provide access to funding for CSIs who are currently unfunded or who have sustained themselves with short-term project funding, many of whom have demonstrated their effectiveness.
- ⇒ Allocate a minimum percentage of protected funding for Patient Councils within hospitals, including those undergoing the process of divestment.
- ⇒ Provide sufficient funding to cover the specific costs of running a CSI, such as health benefits, training, and accessible physical space.
- ⇒ Provide sufficient funding to ensure that CSI staff salaries are competitive within the health care sector, taking into account that consumer/survivor employees have experiential knowledge and skills related to their personal involvement with the mental health system, and that these qualifications are equal in value to traditionally recognized qualifications (which many consumer/survivors may also have). CSIs also need support to develop training and recognition for these skills through a formal peer support certification or recognition program.
- ⇒ Provide funding for regional and provincial organizations of CSIs in order

OUR RECOMMENDATIONS continued

- to strengthen and expand these networks, while allowing for a plurality of voices and experiences among consumer/survivors.
- ⇒ Provide funding to expand the types and numbers of programs and supports offered by CSIs, based on locally determined values and needs. Programs may include peer volunteer coordinators to connect people leaving hospital with peers in the community; education and employment; housing and crisis supports; and evaluation and research studies.
 - ⇒ Provide resources for CSIs to demonstrate their effectiveness using methods and measurements that are consistent with peer-support values.
- ⇒ Ensure that Consumer/Survivor Initiatives and consumer/survivors play specific roles within the transformation agenda and process, including Local Health Integration Networks.
- ⇒ Make resources available to CSIs and consumer/survivors to allow them to participate fully and on an equal basis.
- ⇒ Support and encourage organizational autonomy and the independent voice of Consumer/Survivor Initiatives.
- ⇒ Provide sufficient funding to support CSIs in developing the organizational capacity (skills development, board and leadership training) to run independent initiatives.
 - ⇒ Require community mental health agencies and hospitals to dedicate a minimum percentage of their funding to the creation and support of sustainable independent consumer/survivor-run programs.
 - ⇒ Encourage the inclusion of CSIs in partnerships among mental health agencies and hospitals for the purpose of policy development or government advocacy.
- ⇒ Mandate the inclusion of consumer/survivors in the planning, running, and evaluation of all mental health services through government policies or accountability measures.

power
CONSUMER *value*
SURVIVOR
HEALTH **SUCCESS**
initiative
support
STRATEGY *recovery*
funding

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ACKNOWLEDGMENTS

We would like to acknowledge the contributions of the following people and organizations for their participation in the preparation of this document.

Key Informants from Consumer/Survivor Initiatives and others:

Jennifer Chambers, Empowerment Council
Theresa Claxton, Ontario Association of Patient Councils

Ellen Cohen, Northeast Regional Consumer/Survivor Outreach Program

Mary Deciantis, Sunset Country Psychiatric Survivors

Barbara Frampton, South Western Alliance Network

Sheila Gamblen, Mental Health Support Project Lanark, Leeds, Grenville

Ron Lea, ABEL Enterprises

Mary Lucas, A-Way Express Courier

Carolyn Menzies, People Supporting People
Dr. Geoff Nelson, Wilfrid Laurier University

Consumer/Survivor Initiatives and others who attended planning and reviewing meetings and who provided feedback throughout the research and writing process:

Laurie Albertini, People Advocating for Change through Empowerment

Rod Albrecht, Fresh Start

Heather Arnold, Sunset Country Psychiatric Survivors

Peggy Birnberg, Houselink

John Bowcott, People for Equal Partnership in Mental Health

Jennifer Chambers, Empowerment Council
Dennis Cheng, Mood Disorders Association of Ontario

Raymond Cheng, Ontario Peer Development Initiative

Theresa Claxton, Ontario Association of Patient Councils

Ellen Cohen, Northeast Regional Consumer/Survivor Outreach Program

Alfred Cormier, Centre for Addiction and Mental Health

Sonja Cronkhite, Eastern Regional Network

Mary Deciantis, Sunset Country Psychiatric Survivors

Peter DeWagner, Chatham Kent Consumer/Survivors

Glen Dewar, Community Resource Connections of Toronto

Doug Dixon, Ministry of Health and Long-Term Care

Jack Edwards, Oxford Self-Help Network

Erick Fabris, Sound Times Support Services
Nick Falvo, Street Health

Julie Flatt, Canadian Mental Health Association, National

Lana Frado, Sound Times Support Services
Barbara Frampton, South Western Alliance Network

Dave Gallson, National Network for Mental Health – BUILT Network

Sheila Gamblen, Mental Health Support Project, Lanark, Leeds and Grenville

Lisa Gammage, Self Help Alliance (Waterloo Region Self Help, Cambridge Active Self Help, Wellington Dufferin Self Help and Mood Disorders Association of Waterloo Region)

Carla Harmer, Council of Initiatives of Muskoka-Parry Sound

Helen Hook, Consumer/Survivor Information Resource Centre

Mary Hopkins, Consumer/Survivor Association of Lambton

John Jones, Canadian Mental Health Association, Waterloo Region Branch/Wellington Dufferin Branch

Christine Krawczyk, Teach! Empower! Advocate! for Community Health (T.E.A.C.H.)

Marie Kwok, Hong Fook Mental Health Association

Shawn Lauzon, Ontario Peer Development Initiative

Ron Lea, ABEL Enterprises

Karen Liberman, Mood Disorders Association of Ontario

Mary Lucas, A-Way Express Courier

Arif Majeed, People for Equal Partnership in Mental Health

Susan Marshall, Can-Help

Brian McKinnon, Alternatives

Connie McKnight, National Network for Mental Health

Carolyn Menzies, People Supporting People
Jai Mills, Mental Health Support Network of Hastings and Prince Edward Corp.

Kathy Mitchell, Consumer Initiative of Huron

Doris Moneweg, Krasman Centre

Patrick Murdy

Carole Nelson, Peer Support of Kingston

Dr. Geoff Nelson, Wilfrid Laurier University

Lynn O'Farrell

Mary Claire O'Brien, Northern Initiative for Social Action

Bonnie Pape, Canadian Mental Health Association, National

Liz Powell, Ontario Federation of Community Mental Health and Addiction Programs

Peg Purvis, Canadian Mental Health Association, Brant County Branch

Diane Raynard, Consumer Initiative of Huron

Patti Rosehart

Martha Rybiak, Brantford Vocational Training Association

Deborah Sherman, Mental Health Rights Coalition of Hamilton

Tanya Shute, Krasman Centre

Karen Simpson, Phoenix Survivors Perth County

Yvonne and Alan Smith, Dryden Mood Disorders Support Group

Maryanne Stevenson

Allan Strong, Self Help Alliance (Waterloo Region Self Help, Cambridge Active Self Help, Wellington Dufferin Self Help and Mood Disorders Association of Waterloo Region)

Susan Toderian, Sunset Country Psychiatric Survivors

Janice Towndrow, Ontario Peer Development Initiative

Tania VanNorman, Protect Our Children, Stop Sexual Abuse

Mary E. Wiktorowicz, York University

Len Wood, Ontario Peer Development Initiative