Consumer Survivor Initiatives in Ontario:

Building for an Equitable Future

CONSUMER SURVIVOR INITIATIVES
IN ONTARIO:

BUILDING FOR AN EQUITABLE FUTURE

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Dear Mr. Brown,

On behalf of the CSI Builder Project Steering Committee, I am delighted to enthusiastically endorse the following document that has been developed in consultation with the CSI organizations/agencies across the province of Ontario and over 191 informants. A report was commissioned to address the issues of Consumer Survivor Initiatives (CSIs), as raised in Recommendation 9 of the report by David Reville & Associates, On becoming new best friends: Integrating front and back offices in community mental health and addictions (the Reville Report).

In agreeing to provide recommendations to the Ministry of Health and Long-Term Care about how best to support and enhance the role of CSIs in Ontario, the committee with the help of the consulting team has explored various issues of Consumer Survivor Initiatives by:

- reviewing international studies and literature that identified evidence-based practices, indicators of success and capacity issues for CSIs, and how other jurisdictions address these issues,
- reviewing Ontario studies and literature that identified Ontario specific solutions to support CSIs,
- studying the capacity of CSIs in Ontario by consulting with CSIs and key informants.

The CSI Builder Project Steering Committee strongly believes that this document is of paramount importance given the increased concerns around mental health and illness. We hope that meetings will be held throughout Ontario including with the Ministry of Health and Long-Term Care, to discuss what we can do collectively to ensure that the role of CSIs in the province are fully supported and equitably placed alongside healthcare services.

Respectfully submitted,

Mr. Allan Strong
Chair CSI Builder Project Steering Committee

ENDORSEMENT

Members of the CSI Builder Project Steering Committee have endorsed this report with their support and approval.

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CONSUMER SURVIVOR INITIATIVES
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REPORT

FOR CSI BUILDER PROJECT

Mary O'Hagan, Heather McKee & Robyn Priest

Ontario Federation of Community
Mental Health and Addiction Programs
Sharing Resources, Exploring Common Issues

June 2009

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EXECUTIVE SUMMARY

Consumer/Survivor Initiatives (CSIs) are self-help groups, alternative businesses or support services run by people diagnosed with mental illness, for people diagnosed with mental illness. There are a large number of funded and unfunded consumer/survivor groups in Ontario, including Patient Councils and around 50 to 60 CSIs funded with provincial health dollars through the LHINs, that provide a wide variety of supports in non-hierarchical, reciprocal settings.

In 1991 Ontario led the world in its formal recognition of CSIs as part of the core services offered within the mental health sector when it began to formally fund over 40 CSIs across the province. Since then CSIs have been elevated as a core service in Ontario's mental health policy. The growing international evidence-base on peer run initiatives like CSIs, demonstrates that they reduce hospitalization and 'symptom' distress as well as increase quality of life and social networks. There are now many new methodologies and examples of good practice to draw upon from Ontario and different parts of the world. Peer run initiatives are also a popular option for the people who use them, some of whom feel alienated from the less personal, more controlling nature of some mainstream mental health services. (In this report we use the more universal term 'peer run initiatives' in reference to other countries or when speaking generally, and consumer survivor initiatives in reference to Ontario. They mean the same thing.)

Despite the policy, evidence and popularity of CSIs, only 0.2% of the total community mental health budget for Ontario is invested in them, the same as in 1991. Though this compares well with many other jurisdictions, Ontario is starting to lose its leading edge internationally in the development of peer run initiatives. Coordinated support for the development of CSIs has been patchy in Ontario over the last eighteen years and they now face a number of challenges, in addition to inequitable funding.

Unlike most other mental health services, funded CSIs are very new, though consumers/survivors have organized to fight for their rights and support each other since the asylum era. CSIs lack standards, performance measures and credentialing; they cannot easily borrow these from other parts of the mental health sector because of their unique values and style. CSI staff do not have reliable access to training either, and they often work in isolation from each other. This has led to problems and failures in governance and management in some CSIs. In many of these cases the funder has insisted that the CSIs be absorbed into mainstream agencies, where they have lost their autonomy.

In this climate some CSIs have barely moved on from where they were 20 years ago. They have not necessarily been exposed to or taken up new methodologies, best practice or the new approaches to recovery and social justice. They have often failed to attract marginalized groups such as ethno-cultural minorities, young people and older people. The CSI leadership is largely white and ageing.

Because of their own marginalized status as people with a diagnosis of major mental illness, the people who lead and participate in CSIs tend to have more difficulty than their professional colleagues in non-CSI community mental health settings, in locating and pushing the levers of power. Some have felt deeply harmed by their own experience of using mental health services and feel ambivalent about engaging with the other parts of the system. Mental health professionals on the other hand can still harbour stigmatizing attitudes towards consumer/survivor colleagues and may not understand the experience and impact of marginalization.

CSIs in Ontario and elsewhere are proving their worth and could well be the fastest growing type of service in mental health systems throughout the world over the next 20 years. They are a very new type of service and the people who participate in them are disadvantaged by their experience of marginalization and stigma. For all these reasons policymakers, funders, planners, researchers and development agencies in Ontario must give urgent and ongoing attention and resources to CSIs and their workforce.

The team who prepared this report looked at international research literature as well as legislation, policy and funding for peer run initiatives in different parts of the world. We held focus groups and interviews with 173 people from CSIs, other mental health service providers, researchers, staff from Local Health Integration Networks (LHINs) and the Ministry of Health and Long Term Care (MOHLTC), ethno-cultural minority groups, aboriginal Canadians, and consumers/survivors not associated with CSIs. Their messages to us were surprisingly consistent and we have reflected them in our recommendations which we summarize here:

1. The provincial consumer/survivor leaders and MOHLTC, with involvement from LHINs, and the backing of the Minister's Advisory Group and the Select Advisory Committee, create new policy and funding frameworks for CSIs, using recovery and social justice principles.

2. The provincial consumer/survivor leaders and MOHLTC, with involvement from LHINs, create guidelines for the LHINS and others, to assist them develop a strong and equitable CSI presence in Ontario.

3. The provincial consumer/survivor leaders, with the involvement of MOHLTC and the LHINs, strengthen the provincial consumer/survivor development and advocacy role for CSIs.

4. The strengthened provincial development and advocacy structure/s offer opportunities and resources to CSIs to develop and evaluate their services.

5. The strengthened provincial development and advocacy structure/s offer opportunities and resources for the CSI workforce to be recruited, trained and educated.

6. Five other reports over the last 13 years have made recommendations on the development

of CSIs. Little action followed these reports. Our overriding recommendation is that action must follow this report.

The implementation of these recommendations needs to be led by consumers/survivors. Once implemented, Ontario will again lead the world in the development of an exciting new evidence-based service that needs to be available to all consumers/survivors.

1. INTRODUCTION

The Consumer/Survivor Initiative (CSI) Builder Project was launched by the Ontario consumer/survivor community with financial support from the Ministry of Health and Long Term Care (MOHLTC) and administrative support from the Ontario Federation of Community Mental Health and Addiction Programs (OFCMHAP). This project arose in response to the MOHLTC commissioned report 'On Becoming New Best Friends' (Reville & Associates 2007). It recommended 'that the MOHLTC should issue an RFP for a review of CSIs with a view to understanding more about how to support a strong CSI presence in Ontario'.

The goal of this CSI Builder Project is to 'create a policy framework that supports a strong and equitable CSI presence in the mental health system' (Consumer/Survivor Initiatives Builder Project Steering Committee, 2008). This report provides information and recommendations for the CSI Builder project to achieve this goal, through advising the MOHLTC on how it can enhance its support for CSIs.

The team that led this included survivor/user consultants, who have direct experience with consumer/survivor-run organizations. In the preparation of this report we examined the opportunities and barriers faced by CSIs in Ontario and elsewhere. We focused on systemic issues (such as legislation, policy and funding), internal issues (such as governance, management and human resources), and external relationships (for instance with the mental health system, other providers and other consumers/survivors).

We gathered the information through:

- A review of CSI literature from Ontario, Canada and other countries (see Appendix 1).
- A review and analysis of relevant legislation, policy and funding frameworks in Ontario and other jurisdictions in similar countries.
- An examination and analysis of examples of CSI programs in Ontario and other jurisdictions that demonstrate creativity and innovation in the delivery of service.
- Conducting 15 focus groups in Ontario and 36 individual interviews with key informants from Ontario and other countries, as well as receiving 15 written submissions (see Appendix 2).
- Creating a database for information on individual CSIs in Ontario (see Appendix 3).

We then collated and analyzed the information and have made recommendations that flow logically from the information and the analysis. We have attempted to ensure the recommendations push the right levers, reflect CSI aspirations and are achievable for the MOHLTC and the Local Health Integration Networks (LHINs) over the next several years, so that Ontario can move towards a strong and equitable CSI presence in the mental health sector.

2. CSIs IN ONTARIO

CSIs, and their equivalents in other provinces and countries, emerged out of the international consumer/survivor movement which began in the early 1970s, around the same time as the civil rights movement, gay rights, the women's movement and indigenous movements. All these movements have in common the experience of oppression and the quest for self-determination.

The consumer/survivor movement exists mainly in democratic countries. It has changed in the past 40 years from a small, unfunded, radical movement to a larger, more diverse and diffuse collection of people. The movement originally worked independently of the mental health system on two main fronts – peer support and political action. In peer support we aim to change ourselves and recover from our experiences. In political action we aim to change the people and systems that affect our well-being. In the last decade or two many consumers/survivors have also taken up new opportunities to work within the mental health and addiction service system.

In 1991 3.2 million was given to CSIs with no clear direction and within 2 years things had blown apart.

CSIs have been around in Ontario for many years, but they did not receive substantial funding until 1991 when the Consumer/Survivor Development Initiative (CSDI) was established by the then Ministry of Health. Funding was made available to develop a provincial organization, the Ontario Psychiatric Survivors Alliance (OPSA) as well as local CSIs. To qualify for funding, CSI proposals had to show their intention 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 (Everett, 2000, pp 152-153).

Much of the impetus behind CSDI was to provide consumers/survivors with employment opportunities in a time of recession. The Ministry originally funded over 40 CSIs to provide a broad range of peer support, advocacy and alternative businesses. Some of these CSIs remain today, but since the mid 1990s a number of them have been absorbed into mainstream organizations. (In this report we define mainstream organizations as mental health organizations that are not run by consumers/survivors). However, not all CSIs are funded through this initiative.

Another type of CSI in Ontario is Patient Councils, funded by the Ministry of Health through the hospitals they operate in. These are consumer/survivor led organizations within hospitals that have psychiatric beds; they aim to give people a voice in situations where they may feel disempowered and isolated. They provide individual and systemic advocacy for consumer/survivor inpatients as well as peer support, system navigation and recovery education. Patient Councils have a broad membership of people who are current or former inpatients. The Ontario Association of Patient Councils represents the different Patient Councils at the provincial level.

CSI development support was originally provided by a team of consumers/survivors led by a mental health professional seconded to the Ministry of Health. OPSA also received CSDI funding to play a development role until it ceased operating. In 2001 CDSI became incorporated and changed its name to the Ontario Peer Development Initiative (OPDI). After a review in 2005 OPDI lost half of its funding and the mandate to provide developmental support. There is now no comprehensive provincial development support for CSIs in Ontario.

There is an emerging evidence base for the effectiveness of peer run initiatives, particularly peer support, which includes:

- Reduction in hospitalization.
- Reduction in ‘symptom’ distress.
- Improvements in social support.
- Improvements in quality of life.

(Canadian Mental Health Association, Ontario Division, Centre for Addiction and Mental Health, Ontario Federation of Community Mental Health and Addiction Programs, & Ontario Peer Development Initiative 2005).

Currently CSIs in Ontario face a number of challenges:

- The absorption of CSIs into mainstream organizations.
- Lack of specific CSI standards, performance measures and credentialing.
- Inequitable funding.
- Lack of coordination as well as planning and development for the growth of CSIs.
- Absence from the power circles that determine the shape of mental health services.
- Problems and failures in some CSIs due to weak governance and/or management.
- Lack of a young or ethnically diverse leadership.

Patient Councils that represent the interests of people staying in general hospitals with psychiatric beds; specialty hospitals or former provincial psychiatric hospitals told us they experience similar challenges to CSIs, including reductions in funding from their hospitals.

3. DEFINITIONS AND VALUES

3.1 Definitions

Broadly speaking, a consumer survivor initiative (CSI) is an entity run by consumers/survivors for consumers/survivors. Their activities may include various forms of peer support, systemic and individual advocacy, economic development, education, research, evaluation, information provision and recreation as well as cultural and artistic activities.

They range from small, local volunteer based self-help networks to fully staffed million dollar agencies that provide a range of programs. CSIs in Ontario appear to divide roughly into three categories – local self-help volunteer networks, fully staffed programs that may also use volunteers, and alternative businesses.

The current system pulls people out of the river but it doesn't look at why they fall in, in the first place.

Consumer/survivor initiative is an Ontarian term. Other provinces and countries may use:

- peers, service users or clients instead of consumers or survivors
- services, programs, organizations or supports instead of initiatives.

This diversity in language sometimes just reflects simple word differences between countries, but it may also reflect differences in ideology. For instance, in some other parts of the world survivors are associated with the radical end of the movement whereas consumers are moderates, though it has been suggested that the distinction between the two is more complex in Ontario.

There are also ongoing definitional debates over questions such as:

- Are people who have not been hospitalized or who have just used primary services, eligible to be a consumer/survivor?
- Should we even name ourselves in a way that defines us in relation to the mental health system, with terms such as consumer or survivor?
- Does a CSI continue to be one when it's absorbed into a mainstream organization?
- What is the difference in role between friendship and the peer support relationship?
- What is the difference in role between paid staff and members in a CSI or between

volunteers and members?

- If services are defined by the traditional professional-client inequality, then should we even define CSIs as services?

3.2 Values

The vast majority of the people we consulted believed CSIs apply values that differ from those applied in mainstream services, and this is backed up in the literature[1]. These values revolve around four themes:

Power relationships (described by respondents as egalitarian, reciprocal, autonomy, self-determination, empowerment, choice, voice, social justice).
- Consumer/survivor members control the organization (Mowbray, Holter, Stark, Pfeffer, & Bybee 2005).
- Consumer/survivor members are free to choose their supports (MacNeil & Mead, 2005).
- There is a ‘spirit of advocacy’ in the group (Zinman in Le Blanc, & St-Amand, 2008, p 187).

Identification with each other (described by respondents as camaraderie, empathy, acceptance, no discrimination, community).
- Peer support involves reciprocal roles of helping, learning and responsibility (MacNeil & Mead 2005).
- There is less role distinction between peer staff and members than there is between professionals and clients (O’Hagan, 1994).

Understanding of mental health issues (described by respondents as holistic, recovery, hope, different language).
- The value of personal narrative is elevated, particularly one that moves people away from an illness and victim identity (MacNeil & Mead 2005).
- There is an implicit or explicit critique of the mental health system (O’Hagan, 1994).

Relationship to mainstream mental health organizations
- CSI organizations should not be governed by mainstream organizations if at all possible.
- CSIs should have the same status and resources as other provider groups.
- CSIs increasingly see the benefits of influencing and partnering with the mainstream system.

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[1] For further information on these values see Appendix “Literature Review”, under “Definitions and Values”

4. SUCCESSES AND STRUGGLES

4.1 Examples of success

Despite the difficulties outlined in this report there are thriving CSIs in Ontario and elsewhere. Below are just a few of them, selected to show the diversity of peer run initiatives.

CAN Help – Kenora and Rainy River Districts, Ontario

CAN Help is a service that is continually evolving. It currently provides:

- Education in schools
- Training for disability workers about mental illness
- Systemic advocacy
- Assistance in the establishment of volunteer self help groups
- Information and resources
- Support for people using forensic services

> *When I go to the CSI I'm not a patient anymore. I'm a human being with strengths and abilities.*

CAN Help also runs consumer/survivor conferences and conducted a regional evaluation of mental health services a few years ago. It was also involved in a job sizing and wage comparison process with all mental health services in the region that resulted in fair wages for CSI staff relative to other services.

www.cmhaff.ca/can-help

A Way, Toronto

A Way is a social purpose enterprise courier service which was established over 20 years ago. It employs 70 part time and full time people. Some of these staff are homeless but still maintain their employment. The service is like any other courier company providing a same day service guarantee. Couriers use public transport rather than vehicles or bicycles and are paid a commission per delivery. They have a strong business ethic.

www.awaycourier.ca

Sound Times, Toronto

Ten years ago Sound Times had a budget of around $200,000; it now has funding of over one million dollars. Sound Times has been supported by government via capital funding to buy a building. It provides:

- The opportunity to learn from peers to give and get support.
- Support to find food & clothing etc.
- Advocacy.
- Service co-ordination and referral.
- Education for members.
- Social and recreational opportunities.
- Support for consumers and survivors in contact with criminal justice.
- Harm reduction for drugs and alcohol.
- Community support.

Sound Times has been heavily involved in providing a consumer/survivor voice in the current health changes. Staff are expected to work from consumer/survivor informed practice.

www.soundtimes.com

The Culture of Recovery project

This project advances a recovery perspective to consumers/survivors and professionals using participatory and experiential education. It provides:

- A recovery clearing house
- A leadership network of consumers/survivors
- Self-help recovery education
- Recovery education for mainstream allies
- Like Minds: Peer support education
- Showings and discussions on ‘Extra Ordinary People’ – an anti-discrimination documentary

www.cultureofrecovery.org

CHANNAL, Dear Lake, Newfoundland & Labrador

CHANNAL aims to strengthen self-help initiatives among individuals, combat isolation and educate the public on issues relevant to consumers. They are seen as an innovative service due to the fact that they have limited funding and yet retain a strong membership base.

www.channal.ca

Mind Your Mind, London, Ontario
An award winning website developed by youth for youth. The website contains information, resources and tools to help youth manage stress, crises and mental health problems.

www.mindyourmind.ca

National Empowerment Center, Massachusetts, USA
A national consumer/survivor initiative in the USA that champions recovery and provides:

- Resources
- Networking
- National representation of consumers/survivors
- Event planning
- Consultation

www.power2u.org

Peer Support and Wellness Center, Georgia, USA
This service has been operating for one year and provides alternative wellness supports. They aim to keep people from going to the hospital and have three beds where people can stay up to seven nights. The program also allows people to come during the day and access varied programs. These include:

- Talking the taboo
- Aroma therapy
- Computer training
- WRAP
- Negotiating peer relationships
- Food
- Double trouble in recovery (for people with ‘dual diagnosis’)
- Trauma informed peer support
- Sport and recreation
- Music and wellness
- Sacred space
- Creative writing
- Arts
- A ‘give back’ group

People can self-refer. Evaluation results already show the program has cut hospitalization significantly. (Darnell, A. 2008, July)

www.gmhcn.org/wellnesscenter

Learning and Recovery Center, Maine, USA

This sits under the umbrella of a mainstream mental health service. The recovery center respite service allows people to stay between three and seven days and the service provides peer support in emergency rooms. It also provides weekly peer meetings and ongoing education to mainstream staff.

The service has worked through many issues in its partnership with the mainstream services including HR policies that excluded people with a criminal history working for the Center which they successfully challenged. There has also been mistrust and lack of referrals between the Center and mainstream services which is now largely resolved.

The Center has been engaged in narrative evaluation of the service since it opened.

www.sweetser.worldpath.net/peers.aspx

Craigmillar Peer Support Service, Scotland

This is a recovery orientated service staffed by peer specialists who build a relationship with people to assist them in finding a way forward in life, as well as involving them in social activities. The staff have worked hard at gaining the trust of professionals, but this is still a challenge. An evaluation of the pilot showed that people who use the service were very satisfied with it and had been able to exceed their own expectations.

www.penumbra.org.uk/craigmillarpeersupport.htm

CAN Mental Health, New South Wales, Australia

CAN Mental Health was awarded money from the Commonwealth government to deliver innovative new service types:

- A hospital-to-home transition team.
- A national warm line.

The hospital to home team receives referrals from the hospital and works with people on whatever is needed for the first 28 days after their discharge. A peer led external evaluation tool has been developed by Victorian Mental Illness Awareness Council, a state wide consumer network. Staff are required to complete peer support training and undergo supervision, developed by Australian and US consumers. All staff are paid.

The service also runs a recovery centre.

www.canmentalhealth.org.au

Leeds Survivor Led Crisis Service, England
This service is part of mental health network in Leeds but maintains its own identity. The service operates:

- A help line in the evenings
- A house that is open in the evenings at the weekends, which can arrange transport for people who come, and includes a family room where people can come with their children

The service is staffed by paid employees and volunteers who have regular supervision and a monthly reflective practice group. Staff are trained in working with self harm, suicide, hearing voices, loss and bereavement. There is also a small emotional support budget for staff which includes counselling, gym membership and so on.

www.lslcs.org.uk

Mind and Body Ltd., Auckland, New Zealand
Mind and Body is a limited company. It provides:

- One-to-one peer support work.
- Anti-discrimination work.
- Consumer advisors to mainstream statutory services.
- Certified training for peer support workers.
- Consumer led research.

Mind and Body has a strong philosophy that underpins everything it does. It invests in a lot of training and supervision for staff.

www.mindandbody.co.nz

COMPASS, (Community Mental Health Peer Advocacy and Support Service)**, Nelson, New Zealand**
COMPASS provides individual and systemic advocacy in relation to local services. Prior to starting all staff complete a comprehensive training course and are then mentored by another staff member. The service allows staff to work flexible work hours and it recruits diverse staff that reflects the population make up of local consumers/survivors.

www.healthaction.org.nz/COMPASS_Community_Mental_Health_Peer_Advocacy_and_Support_Service.htm

4.2 Elements of success

We searched the literature, asked the people we consulted, and asked people involved with the innovative initiatives above – what makes a successful peer run initiative? There was a lot of congruence in the literature and in people's responses:

Translation of peer run initiative values into action

The values are what sets peer run initiatives apart from traditional mental health services. Conscious and ongoing translation of these values into practice is crucial, particularly as some peer run initiatives have drifted from their values base and defaulted to being like traditional services.

An independent, workable organizational structure

Independence from mainstream services helps peer run initiatives stick to their values. If complete organizational independence is not possible and they are absorbed into mainstream agencies, then there needs to be a clear agreement on their respective powers and responsibilities and a willingness to allow a high degree of autonomy for the peer run initiative.

Peer run organizational structures also need to be simple and workable, with good oversight from a board or a director. One person we talked to in New Zealand said he developed his initiative as a company to avoid governance and management conflicts. This option however, would not be acceptable to many peer run initiatives that want to be membership run.

An efficient, viable business

Peer run initiatives have sometimes been slow to adopt sound business practice, which for some have created tensions with their values (O'Hagan, 1994). Most recognize that successful peer run initiatives have to develop the discipline and controls to be efficient and viable, as well as stay true to their egalitarian and empowerment values.

Access to information, development support, and advocacy for peer initiatives

Many people said that peer run initiatives need a structure that looks after their interests as a collective – to advocate for peer run initiatives to funders, policy agencies and government, to establish opportunities and resources for organizational and workforce development, to provide information and advice, and to connect peer run initiatives to each other.

Strong inclusive leadership

Successful peer run initiatives have leaders, who are trusted, know how to translate their values into actions that permeate the essence and operation of the organization and have the business skills to run an organization. They are transparent and include staff and members in decision making.

Sound, supportive and accountable HR practices

Successful peer run initiatives combine their values and sound HR practice with their staff. Managers mentioned careful recruitment and competitive pay. They talked about the importance of ongoing training, specific to the role of the staff member. Staff had routine one-to-one supervision as well group supervision, where the team had an opportunity to reflect on their practice. Staff needs support and workplace accommodations but they also need to be accountable.

Empowerment of members

Empowerment of members is a core value of peer run initiatives and this can be achieved in many ways, such as easy access or self-referral to the initiative, the freedom to choose the supports they want, the ability to give as well as receive support, involvement in decisions about the initiative, an atmosphere that offers validation and hope and programs that offer genuine opportunities for recovery, personal development and social inclusion.

Consumer/survivor led evaluation

As a relatively new type of response, resources need to go into the evaluation of peer run initiatives to assist them to keep improving, to refine our understanding of what peer-run initiatives are or need to become, and to build up the evidence base on their effectiveness. These evaluations must be designed and undertaken by consumers/survivors using deliverables and measures that matter to them.

Equitable partnerships with mainstream services and community organizations

Successful peer run initiatives create equitable partnerships with mainstream services and agencies. They do not exist in silos. They know the rules of engagement and how to promote peer run initiatives to the system. If they meet resistance, then they deal with it assertively rather than with ongoing anger or withdrawal. Successful CSIs network within their communities and agencies around them, opening up opportunities for contact between the local communities and CSI members.

4.3 Struggles

The CSI sector is at a developmental stage, but CSIs usually lack the organizational development resources and capacity found in large mainstream organizations. Most CSIs are not in a financial position to purchase their own organizational development expertise, and the generic or mental health expertise they access may not always fit their needs. Currently, there is no comprehensive or coordinated development support for CSIs.

The rest of this report deals mainly with the structural and resource barriers to the success of CSIs in Ontario. These include inequitable funding, the absorption of many CSIs into mainstream agencies and the lack of capacity within some CSIs. But first, some of the attitudes that create barriers for CSIs need to be pointed out.

Some people we talked to believed bureaucrats, planners and funders may have lower expectations of CSIs than they do of mainstream agencies. If this is the case, the impact of this attitude cannot be overstated. Lower expectations, at whatever level of consciousness, can lead to an oscillation between neglect of CSIs, and too much interference when things go wrong. This oscillation appears to have been a feature in Ontario at times.

Others said that people in the mainstream mental health system do not understand CSI history, values and difficulties. This means they are likely to regard CSIs as either second-rate or just like mainstream services that happen to be run by consumers/survivors. They asserted that CSIs really need to be regarded as 'equal but different'.

Like any funded helping support or service, CSIs need to change with the times. We saw and heard about drop-ins that people didn't seem to develop in, or move on from. There was little evidence of a social justice or a recovery approach in these CSIs. Some seem to have lapsed into a traditional mental health service style of delivery or hadn't changed the way they operate for over 20 years.

We were also intrigued that while respondents were much focused on the welfare of CSI staff very few mentioned how the situation in CSIs was affecting the members. We noticed that some CSIs believed they were accessible to marginalized and minority consumers/survivors just by having the door open. There was also little discussion on CSI responsiveness to consumers/survivors with addictions.

> *Independent boards are responsible to their membership; advisory boards are responsible to the "normies". It's a mouse and elephant partnership. At best advisories can do great things to support the CSI, and to challenge the medical model and services of the mainstream organization. At worst advisories are like a consumer/survivor Uncle Tom.*

5. POLITICAL CONTEXT

5.1 National Canadian context

Canada has a solid human rights record when it comes to protecting the rights of disabled people. It took a leading role in the formulation of the Convention on the Rights of Persons with Disabilities (United Nations, 2006).

The federal government has little direct authority over provincial health systems in Canada but it can influence through policy, funding and research. It also has direct jurisdiction over health services for Canada's indigenous peoples, federal offenders and the Canadian Armed Forces.

The Mental Health Commission of Canada (MHCC) is two years old. It was created to focus national attention on mental health issues and to work to improve the health and social outcomes of people living with mental illness. The MHCC's draft framework for a mental health strategy for Canada acknowledges the importance and effectiveness of peer run initiatives in a reformed mental health sector (Mental Health Commission of Canada, 2009).

5.2 Ontario

In 2006 the Ontario government passed legislation to devolve health planning, funding and monitoring to 14 Local Health Integration Networks (LHINs), with an emphasis on standardization, community engagement and integration. The LHINs are still in the development phase and the impact they will have on CSIs is unclear, but a number of opportunities and threats were discussed by the people with whom we consulted.

Many people agreed that the LHINs have the potential to strengthen communication and collaboration, though people hadn't seen much evidence of this at the time of consultation.

One opportunity has been the $30,000 allocated by the MOHLTC to each LHIN to fund a CSI or local consumer/survivor network, to take a lead in coordinating consumers/survivor initiatives to engage with the LHIN and each other. The LHIN network leads have formed a provincial council called the Provincial Consumer/Survivor LHIN Leads (PCSLL). The LHIN network leads role is to advocate for CSIs across all LHINs, though the LHIN leads are not funded to work at the provincial level.

Various threats were also raised by respondents:

- The LHIN structure is potentially fragmented, with fourteen planners and funders instead of one, making it more difficult to influence change across the whole province.

- The medical, deficits-based culture of the LHINs may lead to an under appreciation of the value of CSIs.

- Consumers and survivors do not consistently or equitably participate in LHIN mental health committees and projects, and may have difficulty in knowing how to influence change.

Recent government health priorities haven't had a big impact on mental health services. The Minister of Health, David Caplan however, announced in late 2008 that 'in the months and years ahead, I will focus on three important areas...chronic diseases...eHealth strategy...improving mental health issues and addictions services'.
(Health Achieve Conference, November 5, 2008
http://health.gov.on.ca/english/media/speeches/archives/sp_08/sp_20081105.html)

5.3 Consumer/survivor politics

The consumer/survivor movement in Ontario has strong roots going back morer than 35 years. It has an international reputation for its CSIs, particularly the alternative businesses or social purpose enterprises. The movement has however lacked a common agenda according to one author (Everett 2000). Many of the people consulted said the movement, including CSIs, was uncoordinated and poorly resourced. This has led to conflict within the movement and may have politically weakened it. This phenomenon however, is not unique; ideological conflicts are common within and between many stakeholder groups in mental health systems worldwide. We were also told that some mental health sector leaders use a lot of rhetoric but have not actively supported CSIs.

There are several provincial consumer/survivor networks and agencies in Ontario. They include:
- Ontario Peer Development Initiative (OPDI)
- Ontario Council for Alternative Businesses (OCAB)
- Provincial Consumer/Survivor LHIN Leads Network (PCSLL)
- Ontario Association of Patient Councils (OAPC)

Respondents indicated that there is some consumer/survivor mistrust of provincial CSI agencies and networks. Concerns were raised that some of the networks and agencies are duplicating aspects of each others' roles and appear to exist in silos. Respondents also felt that the provincial bodies represented the interests of their members and there was no provincial CSI that had the role of advocating primarily for the interests of consumers/survivors in Ontario as a whole.

6. LEGISLATIVE AND POLICY CONTEXT

6.1 Ontario

There is no Federal or Ontarian legislation that has a direct impact on the development of CSIs.

Ontario's mental health policy over the last 15 years has signalled the need for CSI development. In the Ontario government's framework for the reform of mental health services (Ontario Ministry of Health, 1993, p 13) CSIs are pictured as one of four hubs of the new consumer focused framework for community support (along with families, generic agencies and the formal mental health system). CSIs, however, were barely mentioned in the provincial implementation plan following from the framework for reform (Ontario Ministry of Health 1999). But they did feature more strongly in the companion operational framework (Ontario Ministry of Health, 2001), where the Ministry supported their status as best practice, called for evaluation of their effectiveness, for public and professional education on the value of self-help, and for the recruitment and training of strong leaders for self-help groups.

Despite the policy, little positive progress has been made in the development of CSIs since they were funded in 1991:

- Many CSIs have been absorbed into mainstream agencies.
- CSIs have not increased their share of the mental health budget.
- Individual CSIs tend to be very underfunded.

There's a total lack of policy direction for CSIs.

In addition to this, the new LHIN structure and the provincial eHealth strategy, with their focus on standardization and integration, pose a potential threat to the unique cultures and roles of CSIs in Ontario:

- LHINs could use the newly legislated integration orders to force more CSIs to be absorbed into mainstream agencies. The legislation defines integration broadly from coordination, to joint provision to organizational mergers (Maureen Quigley & Associates, 2007).

- At the same time, the devolvement of funding and planning from MOHLTC to fourteen LHINs, carries the risk of increased fragmentation.

- LHINs are standardizing the planning template, through the Community Annual Planning Submission (CAPS) and the subsequent Multi-Sector Accountability Agreements (M-SAA), with common performance indicators across the huge diversity of health services that are not all suitable for CSIs.

- The provincial eHealth strategy also includes plans to implement electronically-based processes such as eReferrals. Some LHINs are planning Community Care Access Centres (CCACs), which are responsible for assessments, resource matching and referrals. There is a risk that CCACs will not consider CSIs to be viable services, or that some CSIs will not have the information technology capacity to handle eReferrals.

- The long-term goal of the provincial eHealth initiative will be to enable all health service providers across Ontario to access individuals' electronic health data. This will place CSI staff in some ethical dilemmas as they will have access to confidential information about their members that is not relevant to the CSI. Furthermore, CSI staff will have a mandate to pass on information about individual members to mainstream services, and mainstream service providers will have access to CSI data entries about individual members. Many CSIs currently do not keep files on their members.

6.2 Other countries

We looked at legislation and policy in New Zealand, Australia, the USA, England and Scotland. We could find no legislation that had a direct impact on peer run initiatives.

The overarching mental health policy documents in England and Australia do not mention peer run initiatives. There are very few peer run initiatives in these countries. Queensland is the only state in Australia that mentions peer run initiatives in its state wide mental health plan.

New Zealand's current mental health strategy (Ministry of Health, 2005) mentions peer support services as part of a broader range of services. New Zealand also has a service user workforce development strategy (Mental Health Commission, 2005). There is not much evidence that the peer related actions in these two strategies are being implemented. There is slow growth of peer run initiatives in New Zealand, but district level funders rather than policy seem to be driving this.

In the USA, the President's New Freedom Commission on Mental Health, (New Freedom Commission on Mental Health, 2003) stated in its second goal that 'consumers will play a significant role in shifting the current system to a recovery-oriented one by participating in planning, evaluation, research, training, and service delivery'. Peer run initiatives were already established in many states before the Commission, and they have continued to grow since then.

In 2007, the US Centers for Medicare and Medicaid Services (CMS) declared peer support an 'evidence-based' model of mental health service delivery, and they specified requirements for Medicaid funded peer support (Eiken & Campbell, 2008).

National level agencies such as the National Association of State Mental Health Program Directors (NASMHPD)[2] and the Office of Technical Assistance (formally National Technical Assistance Center - NTAC)[3], as well as the state level Offices of Consumer Affairs have been active in promoting peer run initiatives.

Scotland's latest mental health policy document (Scottish Executive, 2006) states that a training program for peer support workers will be in place by 2008 and peer workers will be employed by three boards by the end of that year. Five boards are implementing this; four have employed peer support workers and one is contracting them through a peer run organization. The Scottish Recovery Network[4] has been instrumental in promoting peer run initiatives, as well as recovery.

These countries and states show that the existence of policy is important for the development of peer run initiatives. But policy is never enough, particularly in decentralized health systems such as New Zealand and Ontario. Policy needs to be championed by individuals and agencies that are close to the decision makers at the levels of planning and funding, and in the large provider organizations.

7. FUNDING

7.1 Ontario

CSIs (both self-governing and absorbed into mainstream agencies) that receive provincial government funding have not seen an increase in their share of the provincial mental health budget since they were first funded in 1991. Their share is tiny – estimated to be 0.2% of the total mental health budget and around 3% of the community mental health budget (Centre for Addiction and Mental Health, Canadian Mental Health Association, Ontario, Ontario Mental Health Foundation, & Government of Ontario, 2004).

More specifically, we were told that some CSIs get funded at a lower full time equivalent (FTE) rate than other community mental health providers. For example, we were told that one funder

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[2] www.nasmhpd.org

[3] www.nasmphd.org/ntac.cfm

[4] www.scottishrecovery.net

offered local CSIs lower FTE salary rates than other community providers. One CSI objected and achieved an equal rate, but others accepted it and were funded at the lower rate.

One or two people also informed us that some of the CSI funding ‘got lost’ in the transfer from MOHLTC to the LHINs.

People told us that many CSIs are unsustainable. Apart from cost of living increases, funding levels have stayed static since 1991. CSIs that have been absorbed into larger agencies have not always had cost of living increases passed onto them, though one or two said they had been subsidized by their agency.

> *Our CSI is afraid of asking for help because we might get integrated.*

The inequitable funding of CSIs does not tally with:

- Mental health policy statements over the last 15 years (Ontario Ministry of Health 1993, Ontario Ministry of Health, 1999).
- Promotion of peer support as a best practice and a core service (Health Systems Research Unit, Clarke Institute of Psychiatry, 1997, Mental Health Advocacy Coalition, 2008).
- Evidence on the effectiveness of CSIs (CMHA Ontario, et al., 2005).
- Knowledge of their popularity with people who use them.

The people we consulted suggested various reasons why CSIs as a whole get such a tiny slice of the pie, and also, why individual CSIs are poorly funded in comparison to other community mental health providers:

- There is still no comprehensive transparent funding formula in Ontario. The overall funding for services does not appear to be based on, for example, the number of full time equivalent staff needed, or the number of consumers/survivors that need a particular intervention or service. Funding decisions appear to be ad hoc to a degree, based on what is available rather than a consensus on what and how much is needed. This may have led to favouring the types of services that are already well established.

- Funding in Ontario flows through different functional centres, which are descriptions of the different types of interventions to be funded. CSIs are primarily funded through the alternative business or peer support/self-help functional centres. We were told some CSIs want to name everything they do as peer support and have difficulty identifying with the roles and accountabilities of other functional centres, such as social recreation or crisis services. Yet, they often provide these kinds of responses. One respondent told us funding through other functional centres could offer CSIs an opportunity to increase their individual budgets as well as their overall share of mental health funding.

- Funders and mental health leaders in Ontario are sometimes ambivalent about CSIs because they may not understand them or because CSIs lack definition and standards. In addition to this they have seen a proportion of CSIs that have had significant difficulties, are not innovative, or have not kept up with the times.

- CSIs have a limited evidence base compared to some other funded responses, which may discourage funders from investing in them. As one person put it, ‘you have no evidence, you get no funding: you have no funding, so you can’t produce the evidence’ (Curtis et al., in MacNeil & Mead, 2005, p 243).

- CSIs are easily viewed as a cheap option and add-on to ‘real’ services rather than as core services or supports in their own right.

- CSIs across Ontario are not coordinated, and some lack the political contacts and know-how to get their voice heard by planners and funders, who themselves sometimes neglect to involve them in planning and funding discussions. For instance, some CSIs we talked to didn’t know they could have the opportunities to apply for funding outside the usual CSI functional centres.

Respondents said poor funding results in recruitment and retention problems, sub-standard locations, high stress, and reduced ability to meet all contract requirements.

Some people asked if it would be better to lose the CSI funding ringfence[5] and to break away from the CSI funding ghetto, making them more likely to compete for a bigger pool of funds. Most believed the ringfence should remain.

It’s clear that CSIs in Ontario are not equitably funded. This may be in part due to the perception within CSIs and outside them, that CSI funding is necessarily restricted to two functional centres.

We asked people what percentage of the mental health budget should be allocated to CSIs. The most common response was a modest five percent.

7.2 Other countries

All countries and jurisdictions have unique mental health funding structures in terms of central control, devolvement, taxpayer funding or private funding, and the diversity of funding agencies or sources. These all have a unique influence on the way peer run initiatives develop in each jurisdiction. Despite this, there are many common themes between jurisdictions on the

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[5] “Ringfence” in this context is used to refer to the dollars that are protected in each LHIN for CSI funding through the agreements with the MOHLTC.

funding of peer initiatives, suggesting that more basic forces than specific structural ones are at work; these could include stigma and discrimination within the system, the relative lack of influence of CSI providers compared to clinical providers, and a continuing over-reliance on expensive clinical services ‘at the bottom of the cliff’.

Peer run initiatives in other jurisdictions are in a similar or less advantageous position to Ontario. These jurisdictions include other parts of Canada, the USA, Scotland, Australia and New Zealand.

Many peer run initiatives in these other jurisdictions receive government funding, though initially in the movement there was resistance to this due to mistrust, and to fears of loss of independence (Van Tosh, & del Vecchio, 2000).

Peer run initiatives are always very poorly funded as a percentage of overall mental health funding. For instance, in New Zealand peer run initiatives make up 0.5% to 1.0% of the total mental health budget (Mental Health Commission, 2005). They are also poorly funded individually. For instance, they rely a lot on volunteers (Brown, Shepherd, Wituk, & Meissen, 2007, Scottish Executive 2007).

Funders in these other countries generally do not have guidelines on the quantity of peer run initiatives needed. However, New Zealand’s Blueprint for Mental Health Services quantified the services needed to implement the mental health strategy (Mental Health Commission, 1998). The Blueprint states that consumer advisory services and consumer run initiatives are to be funded at four full time equivalents per 100,000 population. Queensland in Australia has recently set a funding benchmark for peer run initiatives at three places for consumers per 100,000 population (Queensland Government, 2008).

Most countries do not have a definition or description of the types of responses provided by peer-run initiatives, so contracts are often ill-defined or inappropriately modelled on traditional mental health services. However peer run initiatives will soon be added to New Zealand’s National Service Specifications; these are the Ministry of Health’s descriptions of services that are eligible for funding.

The New Hampshire Department of Health and Human Services has two ‘rules’ relating to peer support[6]. One rule covers the major features of peer support services such as purpose, supports and services, responsibilities, fiscal management, Board issues, staff development, and quality improvement. The other rule covers the rights of people receiving peer support services, such as notice of rights, fundamental rights, personal rights, suspension of membership, member and participant rules and grievance procedures.

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[6] Available from www.dhhs.state.nh.us

Peer run initiatives are often praised for being cost-effective and peer support in all walks of life has its origins in unfunded community volunteering. However, respondents felt a number of CSIs are being exploited and marginalized and that equitable funding is needed if they are to be an integral part of reformed mental health systems.

Experience suggests that a sudden, significant boost in funding can destabilize organizations, including peer run initiatives, by disrupting power relationships and accelerating organizational growth beyond the capacity of that organization to meet increased demands (Shimrat, 1997). This highlights the need for staged, long-term funding increases in Ontario.

In recent years more mainstream agencies in New Zealand and the USA as well as Canada have funded peer initiatives through employing peer support workers or establishing peer initiatives within the mainstream service. This has been controversial in all countries, including Ontario.

In some countries and jurisdictions there have been calls for peer run initiatives to be allocated a percentage of the total mental health budget, usually in the region of five to ten percent. (Campbell & Leaver, 2003; Centre for Research and Education in Human Services, 2004; Lurie, 2008)

8. GOVERNANCE & MANAGEMENT

8.1 Governance

Two major models of governance operate in CSIs in Ontario:

- Independent legal entities governed by consumers/survivors, usually members.
- CSIs absorbed into larger organizations, advised by a committee of consumers/survivors, but governed by the board of the larger organization.

People agreed that while some CSI governance boards have been very effective others have struggled to attract skilled people, or to provide them with the skills required. CSIs in Ontario have been more insistent than some of their equivalents in other jurisdictions that they are member led, but there is often low interest among the members, and skilled consumers/survivors who are not members do not always want the automatic public disclosure of their mental health problems that comes with being on a CSI board. Many respondents told us that CSI board members need training to perform their roles successfully.

In the case of the social purpose enterprises or alternative businesses, the employees of the business are defined as the members. The Ontario Council for Alternative Businesses (OCAB) has promoted a governance structure, developed by some of the early social purpose enterprises, where the employees can serve on the board – combining elements from both a board of directors and a workers' owned co-operative structure (Canadian CED Network, 2006).

Originally, in order to get funding, CSIs had to be independent agencies or moving in that direction. Now many CSIs have been absorbed into larger mainstream organizations, often against their wishes, at the behest of the funder. People told us this sometimes happened when CSIs were having funding, governance and management problems. At the same time, some mainstream agencies have had a growing interest in including peer support as part of their service.

We came across a minority of CSIs that were satisfied with the arrangement they had with the mainstream organization they had been absorbed into. These CSIs had a clear agreement with the agency about who was responsible for what, they were free to set their own agenda, and they retained a lot of autonomy. However, virtually everyone was uncomfortable with the trend to place CSIs within mainstream organizations:

> *No longer do we lock someone away forever if they're having problems, but it's happening to CSIs. They're moved to mainstream services but aren't let out when they're well. again.*

- They defined CSIs as having 51% to 100% of consumers/survivors on the governance board.

- Some believed CSIs placed in other organizations did not qualify as CSIs because consumers/survivors did not have ultimate governance powers.

- Most CSIs that had been absorbed by larger organizations believed they had too little autonomy.

- Some stated that members who are mistrustful of mainstream services would be reluctant to use CSIs inside a mainstream setting.

- Many viewed the absorption of CSIs as a knee-jerk and over controlling response to resolvable difficulties, especially when the usual response for mainstream organizations in trouble has been to invest in their development rather than to absorb them into another agency.

Some CSIs said they believed that absorbing their organization into a mainstream agency would help them gain access to better infrastructure support, administrative and training resources, and opportunities for full time work with additional health benefits. However, the reality has not always lived up the promise:

- Staff have not always been better off financially.
- Consumer/survivor advisory boards have been ineffective, and in some cases haven't existed at all, despite MOHLTC funding requirements to have an advisory (Ministry of Health and Long Term Care, 2003), which became defunct when the LHINs came into being.
- Advisories have also complained of being ignored or tokenized by their governance board (Auditor General of Ontario 2008; CMHA Ontario et al., 2005; Reville & Associates, 2007).
- Loss of autonomy has led to the erosion of some CSIs' values and identity as they have become submerged in the culture of the mainstream organization.

8.2 Management

The people we spoke to expected 100% of executive directors (EDs) of CSIs to have lived experience of mental illness. Surveyed respondents believe that there is a large variation in skill levels of EDs in different CSIs. They acknowledged that CSI EDs have a complex job, managing the expectations of an 'empowered' membership, organizing workplace accommodations for staff who may become unwell, managing volunteers, and developing the service with little in the way of templates and resources, as well as managing their own mental health problems at times. For all these reasons they can overwork and get burnt out.

Sometimes EDs have very weak governance boards to work with, which may add to their workloads but also place too much power in one person's hands.

EDs in CSIs are frequently paid less than equivalent managers in the mainstream services – sometimes as little as half the salary. CSIs lack career pathways, making it difficult for boards to recruit and retain them (National Empowerment Center, 2007). EDs told us they need more peer support with other CSI EDs. Some told us they want further training in areas such as working with boards, strategic management, administration systems, financial management and human resources. CSI managers need to be as skilled as any other managers, and may even need additional skills in the relatively uncharted terrain they are in, compared to mainstream services.

9. DELIVERY & PRACTICE

9.1 What is provided

Peer run initiatives can deliver a wide range of activities, which include:
- Self-help groups
- One-to-one support, which could include: counselling, harm reduction
- Case management
- Crisis services
- Supported housing
- Supported education and employment
- Economic development (small businesses)
- Systemic and individual advocacy
- Education and training (public, mental health professionals, consumers/survivors)
- Paper and online information development and distribution
- Research and evaluation
- Social and recreation
- Material support which could include: food, clothing, internet, post office box numbers
- Artistic and cultural activities
- System navigation

These activities can take place in:
- Face-to-face, on the telephone or online
- Home or community settings
- Peer settings
- Mainstream services, such as emergency rooms, inpatient settings, Assertive Community Treatment (ACT) teams, crisis teams, other community services, forensic services, social

services and the criminal justice system

There are signs of growing specialization in terms of the consumer/survivor populations that peer run initiatives support. For instance, people who have in common ethnicity, age, gender, or types of labels or diagnoses, have set up peer run initiatives for their particular group in many parts of the world. For instance, in Ontario, Patient Councils provide advocacy just for hospital based consumers/survivors, and the Mind Your Mind website targets youth.

Social purpose enterprises (consumer/survivor run businesses) are more developed in Ontario than just about any other part of the world. In the context of providing employment, they have emphasized building community, as well as respecting and accommodating people's fears of working and empowering people to overcome their disbelief in their ability to succeed. (Canadian CED Network, 2006).

We came across some debate about whether peers should offer clinical services or not, and whether they should offer 'services' at all because they create the unequal roles of staff and clients. Most respondents believed they should differ from 'services' but that this could be hard to achieve in a society where the service approach is such a dominant paradigm. One respondent told us that staffed CSIs should think of themselves as services because they are paid to provide for others.

When CSIs use service approaches they do not give the people the chance to use their own skills and capacities. Instead they become clients again.

Finally, lack of standardization helps to keep CSIs marginalized in a system that relies on definitions, an evidence base, and measures to fully develop new models of services or supports.

9.2 How it is provided

The defining delivery issue is not so much what CSIs deliver but how they deliver it. It appears that CSIs evolved in Ontario with more clarity about their values and principles than in some other parts of the world.

Most respondents suggested that definitions and standards need to be developed for peer run initiatives, particularly peer support. This has been backed up by the literature (Mowbray et al., 2005, MacNeil and Mead, 2005). Standards, competencies and performance or outcome measures should be based on CSI values.

Some 'practice methodologies' are also emerging. Perhaps the best known ones are Wellness

Recovery Action Plan[7], known as WRAP, (Copeland, 1997) and Intentional Peer Support, (Mead 2005).

WRAP is a self-administered template that provides a structure for people to monitor their distress and wellness, and to plan ways of reducing or eliminating distress. Many peer support initiatives and some mainstream mental health services train people to do their own WRAP.

Intentional peer support is a philosophy and a methodology that encourages participants to step outside their illness and victim story through genuine connection, mutual understanding of how we know what we know, redefining help as a co-learning and a growing process, and helping each other move towards what we want. Training in intentional peer support is available in a number of countries.

Other practice methodologies have been developed, such as:

- PACE (Personal Assistance in Community Existence)/Recovery Program[8] – workshops designed to shift the culture of services from maintenance to recovery and hope.
- Peer-to-peer recovery education curricula developed in Vermont[9], and in Ontario[10].
- Self-stigma workshops for consumers/survivors in development in New Zealand[11].
- User-led research project in England - Strategies for Living[12].

The field is wide open for the development and adoption of definitions, standards, competencies, measures and new practice models. Peer run supported education; supported employment and supported housing have been suggested as areas that CSIs in Ontario should expand into. (Centre for Research and Education in Human Services, 2004).

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[7] www.mentalhealthrecovery.com

[8] www.power2u.org

[9] www.sover.net/~vpsinc/recovery.html

[10] www.cultureofrecovery.org

[11] Information available from kerri-june@caseconsulting.co.nz

[12] www.mentalhealth.org.uk/publications/?EntryId5=43591

10.HUMAN RESOURCES

10.1 Recruitment and retention

Everyone we talked to agreed that lived experience with mental illness is not the only requirement for peer workers; they also need work related skills and attributes. One author has suggested that in addition to lived experience, peer workers must be stable in their recovery and refrain from substance abuse (Solomon, 2004). However, this view has been criticized with the claim that peer run initiatives have both thrived and failed because of the unique personalities and qualities of consumers/survivors (Schnell, 2005; Shimrat, 1997). The demand that people are stable is also impossible to measure and contrary to human rights.

CSIs have difficulty recruiting and retaining skilled workers because their pay is not competitive with peer workers in mainstream agencies, and some consumers/survivors are afraid of the stigma of openly identifying as such. Positions are often part-time due to lack of funding, and to allow people to keep receiving a welfare benefit. CSIs often cannot afford to pay additional health benefits, such as payment for medication and doctor's visits, which are usually available to mainstream workers and to beneficiaries. Thus, some part time CSI staff can get stuck in the perverse incentives created by the benefit system. There is also a high turnover in CSIs, as people often leave due to burnout and overwork or to work in a higher paid job. There are few career pathways for peer staff in both CSIs and mainstream services.

10.2 Work conditions

CSIs try particularly hard to create a supportive work environment. They need to negotiate workplace accommodations for staff, such as flexible work hours and sick leave entitlements, quiet work areas, acceptance of unusual behaviour, the need to take time off for appointments and so on. Some respondents suggested that not all CSIs do well at supporting their staff, due to lack of funding for supervision and training, as well as lack of management skills at times. For instance one person told us that accommodations for one staff member had overburdened other staff members with extra work.

It can be more difficult to create a supportive work environment for peers working in mainstream services, as these services may operate in ways that peers are uncomfortable with, and they may have a less supportive workplace culture. Peers may be isolated from each other, and mainstream colleagues may harbour prejudices, or are not used to working with consumers/survivors. Some people believed that these situations could be avoided if these peer workers were employed by CSIs that contracted them out to work in mainstream services.

10.3 Staff development

CSIs do not view peer work as vocational rehabilitation but as real work. However, training, supervision, performance appraisal and other processes to improve work performance are not reliably available to staff and EDs in CSIs. Barriers to education and training include lack of funding and/or failure to create a budget for staff development. Some peer workers have felt uncomfortable and excluded when they have attended mainstream training. There is also little or no training specifically for peers whose first language is not English.

> *Money aside, CSI workers get a lot of satisfaction out of seeing people grow and recover, and sensing that we contributed to it.*

Most respondents agreed that some form of credentialing is inevitable if CSIs are going to grow and become an integral part of the mental health system. But people also expressed concerns about these developments. 'Professionalizing' peer workers could erode the reciprocal relationships in CSIs, and standard workforce training could steer peer workers into taking on the language and culture of mainstream mental health services (The Herrington Group, 2005, p 6). Some aspects of peer support training will not be covered in mainstream curricula, so new curricula need to be developed. This has happened in Georgia[13], Arizona[14], New Zealand[15], and elsewhere.

Training needs to be tailored to the different roles in CSIs, such as members, staff, the ED and the board. Some training topics that would be unique to CSIs, or need to be interpreted differently for them are:

- History and principles of the consumer/survivor movement
- Values and culture of CSIs
- Peer boundaries and ethics
- Peer practices, which could include: WRAP, intentional peer support and alternative businesses
- Gaining autonomy over medication
- Working with self harm
- Working with voices
- Shared risk taking
- Working with mainstream services

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[13] www.gacps.org

[14] www.recoveryinnovations.org

[15] http://mindandbody.ac.nz/

In 2008, OPDI received a substantial Trillium Foundation grant to develop a toolkit for peer support training with the aim of training 200 consumers/survivors in the province. This is a positive development and needs to be followed up by further funding to implement the training on an ongoing basis.

10.4 Volunteers

CSIs often rely heavily on volunteers. While volunteering can be a good option for a time, for the individual and the CSI, there are some risks associated with a heavy reliance on them. Individuals can get stuck in voluntary positions and never get a paid job. Volunteer supports and accountabilities can easily become unclear. It may also be difficult to convince funders of the need to convert voluntary positions to paid ones.

We got a very different view about volunteering from an Asian CSI. In order to save face, people often approached the CSI to volunteer rather than simply use the service, to get their needs met. They considered it an honour to be a volunteer.

10.5 Members

CSIs refer to members rather than clients because they create more potential for members to become involved in the running of the CSI. Members are often more than just recipients. They also need to be considered as human resource, with training and development needs.

11.MARGINALIZED & MINORITY CONSUMERS/SURVIVORS

Ontario has a very diverse population. Nearly 30% identify themselves as immigrants and around two percent identify as Aboriginal. Nearly two percent of Canadians between 18 and 59 years identify as gay, lesbian or bisexual. (Ontario Federation of Community Mental Health and Addiction Programs, 2009, pp 5-6). Around five percent of the Ontario population is Francophone. Ontario covers a large area; most of its population lives in a small area of the south east of the province, while some rural populations live hundreds of kilometres away from their nearest mental health service.

CSDI in 1991 initially acknowledged this diversity by funding ethno-cultural CSIs and a Francophone CSI. Today there is one funded ethno-cultural CSI, absorbed into a mainstream agency, and two funded Francophone CSIs.

There is growing recognition that many CSIs do not cater to Ontario's population diversity. They tend not to attract young people, ethno-cultural minorities or Francophone people.

CSIs in rural areas struggle with few resources to reach out to a far flung population. The costs of transportation are prohibitive and the office may need to close while staff are on the road. Consumers/survivors often cannot afford the transport costs to get to the nearest CSI. Although the health system claims that transport is not a health responsibility, lack of transport in these cases could have a negative impact on people's recovery.

Many people acknowledged that CSIs often do not attract young people because they are not funded to provide for people under 16 years old, and the staff and members are usually older. Not all CSIs are accessible for people with physical or sensory disabilities. One or two people believed that gay, lesbian, bisexual and transgender people were more easily absorbed into CSIs than other marginalized groups.

The project team talked to several Aboriginal people. They stressed that Aboriginals need to develop their own networks and services, by their own people, for their own people. This was also necessary because they often live in very remote communities.

A small handful of respondents were critical of the dominance of white, middle aged people in CSIs. They suggested that some CSIs are racist, more by omission than commission; they don't see their own cultural biases or have much insight into the barriers as marginalized people perceive them. A few people said that there was low participation from marginalized groups because CSIs didn't have enough positions to hire ethnically diverse staff or the funds to translate literature into other languages. We found that a significant number of the CSI people we consulted had little or nothing to say about the inclusion of marginalized groups. They tended to believe there were no barriers to participation of marginalized groups and felt they just needed to be welcoming to them, in order for them to want to keep coming to their CSI.

> *City people don't understand that to get our outreach workers to a meeting or training, it costs at least $1,500 in mileage and food.*

One respondent pointed out that the philosophy of the consumer/survivor movement in North America is very individualistic and not family focused, which doesn't always resonate with consumers/survivors from marginalized cultures. Identity can become complex for people who belong to two or more marginalized groups. For instance consumers/survivors in ethno-cultural minorities can be devalued by their consumer/survivor peers as well as by their own ethnic community.

Different cultural groups also vary enormously in their understanding of madness; the groups that stigmatize madness the most or view it as a spiritual matter are more likely to stay away from services and CSI supports.

People recognized that consumers/survivors in custody or involved in forensic mental health services need better access to peer support but understand the difficulty in these kinds of settings. It was suggested that CSIs could have a greater role in providing services or supports to people after custodial release.

12. STAKEHOLDER RELATIONSHIPS

Peer run initiatives around the world, especially the ones established in the earlier days of the consumer/survivor movement, were often somewhat separatist and didn't want much to do with mainstream services. (Nelson, G., Janzen, R., Trainor, J., Ochocka, J., 2008; Shimrat, 1997; Van Tosh & del Vecchio, 2000) Over the decades this has changed and respondents generally agreed that building relationships with the mental health system and other stakeholders was vital to the success of CSIs. A number of CSIs however, carry ambivalence about their relationships within the mainstream mental health system which they experience as daunting, frustrating or unequal.

People mentioned that there is stigma and discrimination against consumers/survivors in the system, which can subvert good relationships. One respondent said she was told she was too slow to be on a committee of professionals. It may also be true, that people in CSIs who perceive they have some power within the mental health system are more successful handling their relationships within it.

Respondents who work inside the system told us that CSIs sometimes operate in silos and do not always take advantage of opportunities to promote CSIs and contribute to discussions about policy, planning, funding and provision of services and supports.

The move towards more integration was seen as an opportunity to improve stakeholder relationships.

12.1 Minister's Advisory Panel

There are three consumers/survivors on this panel, set up to advise the Ontario Minister of Health on mental health issues. There is potential for more consumers/survivors to be involved in the panel's sub-groups. Very few consumers/survivors we talked to knew about this panel or the consumers/survivors who were on it, raising their concerns about who the consumers/survivors on the panel are really accountable to.

We also heard that a new Ontario mental health legislative committee has been established. Very few consumers/survivors knew about it at the time of consultation.

12.2 Mental Health Commission of Canada

There are three consumers/survivors on the MHCC Board, and consumers/survivors are on the various advisory groups, but there is no consumer/survivor advisory group at MHCC, which has a family and an indigenous advisory group. We were told MHCC did not establish a consumer/survivor group because they did not want to ghettoize them, an explanation that is unlikely to satisfy many consumers/survivors. Recently the consumer/survivor advisory group members formed themselves into an informal consumer council. The MHCC's youth advisory group has established a youth consumer/survivor sub-group to advise it. People expressed dissatisfaction with MHCC's early performance in relation to consumers/survivors but were taking a 'wait and see' approach. They were pleased that MHCC is starting to take an active role in promoting peer support across Canada.

12.3 MOHLTC and LHINs

CSI respondents told us they felt MOHLTC understood CSIs better than the LHINs, where people sometimes didn't even know what a CSI is. They wanted MOHLTC to take a more active role in educating the LHINs about CSIs. Some respondents however, acknowledged that LHINs are not yet set in their ways and may be easier to influence than MOHLTC.

There are no protocols, standards or performance measures in Ontario for the participation of consumers/survivors in the shaping of mental health services. As a result of this, LHINs have either neglected to involve consumers/survivors, or they have tried with processes that don't work. For instance LHINs have sometimes handpicked consumers/survivors for committees who have little expertise, and no networks or mandate from other consumers/survivors. We were also told the LHINs had great difficulty attracting marginalized and minority consumers/survivors to committees.

12.4 Providers

CSIs had mixed experiences in their relationship with mainstream providers. They told us they often feel excluded from participation in the decisions made by large providers. They also told us some providers didn't understand CSIs or how effective they could be, so they don't refer their clients to them. CSIs do not necessarily refer members onto mainstream services either. Other CSIs had good relationships with local providers. For instance, in one LHIN a CSI had twice been chair of the local directors' network, which also supported the CSI to access additional funding.

We make fun at PSR for being irrelevant yet some CSIs are entrenched in a model that's over 20 years old, and that needs to be revised.

12.5 Ontario consumers/survivors

There is a large population of consumers/survivors in Ontario that CSIs don't reach. This may reflect a silo mentality but it is more likely that CSIs are struggling to be there for the current membership, and don't have the spare resources to reach out to other consumers/survivors.

12.6 The elephant in the room

Perhaps the biggest barrier to the development of peer run initiatives around the world has been the longstanding inequality and marginalization of people who have received a mental illness diagnosis and its impact on consumers/survivors as well as the people who work in and run the mental health system.

Many of the people involved with peer run initiatives have not felt helped by the mental health system, to put it euphemistically; some have felt deeply harmed by it. They are now taking an active role alongside or within the same system. Because of their experiences, they are sensitive to acts and/or attitudes of exclusion and control. They often feel some degree of ambivalence about engaging with the system that they see as tainted or even unsafe for them. In addition to this they may not understand the rules of power and influence that the people who run the system are familiar with, or have the networks to tap into the most powerful people.

The people who have always been relatively privileged in the mental health system may still harbour stigmatizing beliefs about consumers/survivors. If they have not had analogous life experience of being marginalized, then they may be unable to understand the situation and experiences of their consumer/survivor colleagues. Because of this, they are likely to respond defensively to consumer/survivor scrutiny. Some may feel a discomforting guilt about the harm the mental health system has done in the past, as well as today.

These dynamics are not helpful for the growth and development of CSIs. Although we have not included anything that deals directly with this in the recommendations, we believe public dialogue on these issues would be beneficial.

13. FINAL COMMENTS

Ontario was ahead of its time when it funded CSIs in 1991 but since then the growth and development of CSIs has been too slow. There is a risk that Ontario will slip behind the times if it doesn't take effective action to resource and revitalize the consumer/survivor sector. Ontario has at its disposal much more information and evidence than it did in 1991 of the diverse and evolving nature of peer run initiatives, of policy and funding approaches in other countries, of new practice methodologies, and of examples of success. It can now create a better defined and supported CSI sector that becomes a core service in a reformed mental health system, for all consumers/survivors who need them.

In this report we have considered the situation of CSIs in Ontario through many different lenses – values, policy, funding, the research evidence, examples of good practice, new methodologies and the elements of success. Using these lenses, we have examined CSIs at the levels of governance, management, staff and the members. We have also considered the external relationships that CSIs have with marginalized and minority consumers/survivors as well as other stakeholders.

Through this process we have found a rich diversity of CSIs that nevertheless face many barriers to becoming a strong and equitable presence in the Ontario mental health system. Some of these barriers are systemic, others are internal to CSIs, and the rest are attitudinal. Our recommendations call for coordinated planning and action to develop CSIs into a core mental health service that all consumers/survivors in Ontario can access, if and when they need to.

RECOMMENDATIONS

It is absolutely essential that consumers/survivors in Ontario lead the consideration and implementation of these recommendations, including the Patient Councils to which these recommendations also apply. To do this they need to establish a broad-based Ontario-wide network, have access to the necessary financial, technical and human resources, and enlist the support of the MOHLTC and the LHINs at the highest levels.

1. Policy and funding

The provincial consumer/survivor leaders and MOHLTC, with involvement from LHINs, and the backing of the Minister's Advisory Group and the Select Advisory Committee, create new policy and funding frameworks for CSIs, using recovery and social justice principles:

DEFINITIONS 1.1 Define and delineate the different types of CSIs in Ontario and develop statements of values, standards, performance measures and outcome measures specific to CSIs.

PLANNING 1.2 Describe and plan the range of CSIs needed in Ontario, taking into account marginalized and minority groups.

FUNDING 1.3 Quantify the funding needed for CSIs in Ontario, including for provincial development and advocacy.

1.4 Prepare a long term funding plan for a staged increase in the funding that goes to CSIs over the next ten years, and for the implementation of these recommendations.

1.5 Investigate the alleged disappearance of some CSI funds in the transfer between MOHLTC and the LHINs. Fully compensate the CSI sector for any loss of funding, and prevent loss of funding from happening again.

2. Guidelines

The provincial consumer/survivor leaders and MOHLTC, with involvement from LHINs, create guidelines for the LHINS and others, to assist them in developing a strong and equitable CSI presence in Ontario:

GUIDELINES 2.1 Produce guidelines for LHINs and MOHLTC on the planning and equitable funding of CSIs.

2.2 Produce guidelines for LHINs and MOHLTC on the leadership and participation of consumers/survivors in LHINS and MOHTLC.

2.3 Produce guidelines for LHINs and CSIs on ensuring the equitable remuneration for CSI staff, including health benefits.

2.4 Produce guidelines for LHINs and Health Service Providers on their relationships with CSIs, including:

- Protecting and restoring CSI organizational autonomy.
- The development of MOUs for absorbed CSIs.
- Sub-contracting CSI peer workers to work in mainstream services.
- Understanding confidentiality issues within CSIs.

MONITORING 2.5 Monitor and evaluate the implementation of the all the guidelines.

3. Provincial advocacy and support to CSIs

The provincial consumer/survivor leaders, with the involvement of MOHLTC and the LHINs, strengthen the provincial consumer/survivor development and advocacy role for CSIs:

REVIEW 3.1 Analyze past and present difficulties in provincial development and advocacy for CSIs, and consider how the current provincial consumer/survivor networks can be better defined, aligned or integrated, to fulfil the provincial development and advocacy roles.

REDESIGN 3.2 Ensure provincial development and advocacy structure/s has adequate funding and capacity to:

- Advocate for CSIs and promote them to funders, policy agencies and government.
- Establish opportunities and resources for CSI organizational and workforce development.
- Lead evaluation of CSIs as well as mainstream mental health services.
- Provide thoughtful leadership, information and advice to CSIs.
- Connect CSIs to each other, particularly rural ones.

WORKING TOGETHER 3.3 Ensure that CSIs at the provincial and local levels have workable efficient processes for collaboration with each other.

4. Organizational development and evaluation

The strengthened provincial development and advocacy structure/s offer opportunities and resources to CSIs to develop and evaluate their services:

DEVELOPMENT 4.1 Promote CSI values, standards and measures through guidance on CSI strategy, planning, programming, funding applications and empowerment of members.

4.2 Increase CSI capacity to collect and use data for planning, evaluation and accountability purposes.

4.3 Produce advice for CSIs on their responsiveness to marginalized and minority groups.

4.4 Promote the implementation of the guidelines in recommendation 2.

EVALUATION 4.5 Oversee and provide training and mentoring on the development of consumer/survivor evaluation of CSIs and mainstream services in Ontario.

GOOD PRACTICE 4.6 Disseminate information to MOHLTC, LHINs and CSIs on CSI activities and enlist successful CSIs to mentor other CSIs.

5. Workforce Development

The strengthened provincial development and advocacy structure/s offer opportunities and resources for the CSI workforce to be recruited, trained and educated:

HR 5.1 Develop guidance and mentoring for CSIs on defining issues such as:

- peer workforce roles
- ethnic and age diversity in the peer workforce
- boundaries
- ethics
- competencies
- remuneration
- recruitment

- supervision
- performance appraisal

TRAINING 5.2 Define peer workforce roles and competencies

5.3 Develop curricula, standards, advice on educational accommodations and affordable opportunities for the education and possible credentialing for all CSI workforce roles.

5.4 Ensure that training and education takes place.

ADVOCACY 5.5 Advocate for CSI equitable pay and health benefits with equivalent mainstream positions.

6. Urgent action

Over the last decade other reports have made recommendations for CSIs in Ontario:
- Trainor, Shepherd, Boydell, Leff, & Crawford, 1996.
- Health Systems Research Unit, Clarke Institute of Psychiatry, 1997.
- Forchuk, Hartford, Blomqvist, Martin, Chan, & Donner, 2002.
- Centre for Research and Education in Human Services, 2004.
- Canadian Mental Health Association (CMHA), Ontario, Centre for Addiction and Mental Health, Ontario Federation of Community Mental Health and Addiction Programs, & Ontario Peer Development Initiative, 2005.

These reports have stated many of the same things we have in this report. Little action has followed.

Our overriding recommendation is that urgent action must follow this report.

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APPENDIX 1 – LITERATURE REVIEW

Consumer/Survivor Initiatives Builder Project 2008-2009
Literature Review

1. Description of literature review

This is a review of academic, grey literature and policy reports and documents on the roles and capacities of Consumer/Survivor Initiatives - mental health agencies and programs run by consumers and survivors of mental health services. The focus of the review is on research, evaluation, theory and analysis primarily from 2000 and on, but including some key pieces from earlier dates. The literature comes from mental health systems in Ontario and other Canadian provinces, American federal and state systems, Britain, Scotland, Australia and New Zealand.

Academic articles were acquired using several social science and medical databases including MedLine PsycInfo, CINAL, PubMed, Google Scholar, and Health Business Full Text Elite.

Using internet searches and building upon extensive personal collections of the consultancy team, this review included grey literature sources, including material developed directly by Consumer/Survivor Initiatives and organizations.

Literature was evaluated for contribution to key conceptual themes originally developed by the consultancy team and approved by the Consumer/Survivor Initiative Builder project steering committee, including,

- Definitions of consumer/survivor organizations
- History
- Funding
- Values
- Governance and management
- Delivery models
- Human resources
- Involvement of marginalized and minority consumer
- Stakeholder relationships

An additional theme, evaluation and research methods and processes, was identified in the literature and added to the review.

A note about the terms used in the review. ‘Consumer/Survivor Initiatives’ or ‘CSI’ is used in general in this review to refer to consumer run programs and agencies in Ontario. This includes those who received a specific type of health funding (CSDI), both peer support groups, and alternative businesses. It is also used to refer to groups who were in existence prior to this source of funding, those who receive other sources of funding (e.g. Patient Councils, funded by their hospital) or who are unfunded. When the review is referring to a specific type of Ontario CSI, such as alternative businesses, then the specific term is used.

There are a wide range of terms used to describe these groups in other jurisdictions. Occasionally these different terms may reflect different structures or philosophies of service, but in general, these differences appear primarily to be different names for similar concepts. The generic term 'Consumer/Survivor Organization' or 'CSO' is used generally to refer to groups outside of Ontario.

This review uses a variety of terms to refer to individuals who experience mental illness, experiences of madness, and/or the mental health system.

We recognize and respect that different terms may have different meaning for readers. The use of terms are not meant to indicate a preference for some values or approaches over others.

2. Knowledge: Academic, Academic Consumers/survivors and Consumers/survivors

There is a wide range of academic literature and policy documents written and produced about CSIs and CSOs. However, much of this is not written by or even read by the people who are members, and who work, volunteer, govern and manage these organizations of peers. This divide between the worlds of traditional sites of knowledge production and the experiential knowledge of people who live with and recover from mental illness or experiences of madness is a fundamental limitation to this literature review.

Consumers/survivors can and do conduct academic research and evaluation (Brunel University, West London, 2009; Lee, 2002; Turner and Beresford, 2005) and there is growing interest in consumer led and controlled research (Beresford, 2002). Some consumer researchers use traditional conceptions of knowledge, for example the use of levels of evidence to evaluate the effectiveness of CSOs (Doughty & Tse, 2005). But there are also challenges by consumer to the privileging of academic, professional, medical and other traditional types of knowledge as well as traditional processes of knowledge production, including literature reviews (Campbell & Leaver, 2003; Campbell-Orde, Chamberlin, Carpenter, & Leff, 2005; Glasby & Beresford, 2006).

The move towards a health and mental health care system based on the philosophy and practice of 'evidence-based practice' (EBP) has been identified by some as problematic in terms of consumer leadership and involvement because "most EBPs were established in an environment in which the lived experiences of consumers were not part of the process of evaluation" (Campbell-Orde, et al., 2005, p. 18). In response, consumer researchers and advocates have proposed alternative principles be used to evaluate the quality and effectiveness of services. These principles would recognize that "the lived experience of service users/carers and the practice wisdom of practitioners can be just as valid a way of understanding the world as formal research" (Glasby & Beresford, 2006, p. 281).

Increasingly, the lack of cultural appropriateness of EBP for consumer of minority and marginalized racial, cultural, gender, sexual orientation and other diversities of experience and identity is being acknowledged (Maher, 2007; NAMI, 2008). While these critiques appear to have come primarily from minority and racialized service providers, rather than directly from consumers and survivors, this may lead to an openness to questioning the potential limitations of this approach.

For the purpose of this review, we acknowledge the important information provided by traditional academic research, including that produced by consumer researchers and through alternative research and evaluation methods. The review also includes sources of knowledge about outcomes and evaluations developed directly by CSOs and consumer. In the words of Judi Chamberlin, a leading American survivor activist, "as people who have recovered often say: "We are the evidence!" (Campbell-Orde, et al., 2005, p. 19).

3. Definitions and Values

Consumer-run organizations can and do take a wide variety of forms, so that it can be difficult to define them. According to one of the earliest activists in the modern consumer movement "a self-help group can take many different forms; its parameters are limited only by the desires, energy, and possibilities of its members" (Zinman quote from Campbell & Leaver, 2003, p. 13).

To define consumer/survivor organizations, Mowbray, et al., propose a two by two matrix model of two key concepts; who has control of the organizations (consumers or service providers), and what is the aim (mutual support or formal service provision)? (Citing Mowbray et al., 1997 in Mowbray et al., 2005).

Survivor activists proposed a similar definition asking two questions; "Who holds the real power? Clients or not?" and "Is there a spirit of advocacy in the group? To some degree or another is there an expression of the liberation dream? For this is the root of real self-help groups" (Zinman, quoted in Leblanc & St-Amand (2008), p. 187).

Building upon these key concepts, consumer/survivor-run organizations can be defined by some of the unique structural and process features that set them apart from other services in the traditional mental health system. As specific values are a key definition of CSOs, this section incorporates a review of both structural features and values.

As will be discussed later in the model section, CSOs in Ontario, nationally and internationally, can take a wide range of structures:

- unfunded meetings for self-help,
- drop-in peer support and social recreational centres,
- Patient Councils of general hospitals with psychiatric beds; specialty hospitals or former provincial psychiatric hospitals,
- alternative businesses, or social purpose enterprises, offering a range of services and goods,
- survivor operated and delivered mental health services, e.g., community support, harm reduction,
- academic research and evaluation units and groups,
- housing,
- crisis supports and warm lines,

- system navigators,
- recovery training programs,
- political and legal advocacy and lobbying groups,
- historical remembrance and recognition
- peer support training programs and worker associations,
- provincial/state/national/international networks,
- arts and cultural activity groups,
- Mad Pride celebration planning groups,
- peer support with consumers who have experienced the criminal justice system

These don't represent the entire range of types of groups or activities, nor the fact that many consumer work in partnership with service providers, family members/carers and other allied groups in a wide variety of ways. While these structures represent a vibrant array of visions and creativity, they do share the essential feature of being controlled and run by consumers/survivors.

As will be discussed later (stakeholders and CSI section), while some CSOs started off as alternatives to the traditional mental health system, they have increasingly moved to be complements of, or one type, of service within a mental health system that now claims to strive to be recovery based.

A broad distinction can be made between two key activities for CSOs - advocacy and support. One review concluded that, for CSOs who take on both of these roles, consciousness-raising, advocating for changes within the system and other advocacy activities needed to be balanced with the resources and time dedicated to peer support among members (National Empowerment Center, 2007). In other situations, CSOs may choose to focus on one activity or the other (Nelson, Janzen, Trainor, & Ochocka, 2008).

Structure, process, and values interrelate to shape and influence each other. The key process element of peer support can look quite different when it takes place in a self-help group, one to one peer support, or through being an employee of an alternative business or an activist in a political group. Values can shape what structures are chosen and what processes are implemented.

The elements of peer support and a value system of liberation, empowerment and recovery are key processes for CSOs. In Ontario, member CSIs of the Ontario Peer Development Initiative, a provincial consumer-run organization, reaffirmed peer support "as the fundamental value of consumer/survivor organizations" (The Herrington Group, 2005, p. 2). CSOs based on a critical stance towards mental health services define the role of peer support to be an alternative to mainstream services with the goal of promoting critical learning and the "renaming of experiences" (MacNeil & Mead, 2005)

Value systems within CSOs range from complete rejection of psychiatry to the use of self help as a complement to medical treatment, with most representing a complex blending of these opposites. Written in 1994, one group described, and celebrated, this diversity, "we are a complex and diverse community … [with] a broad spectrum of values and beliefs" (Consumer Survivor Business Council of Ontario & National Network for Mental Health, p. 2).

What CSOs have in common is an emphasis on the important role played directly by survivors, users, clients or patients. Regardless of the explicit philosophical approach of the group, simply by the act of self-organizing, CSOs can be defined by the value that there is something unique to the peer experience that cannot be achieved through professional services.

Recovery has increasingly become a key value of CSOs around the world (Clay, 2005; National Empowerment Center, 2007; OPDI, n.d.; Orwin, 2008). Consumer/survivor led activities are key to recovery as “peer support is the only mental health role to emerge that is grounded intrinsically in recovery” (Orwin, 2008, p. 3). As mental health systems increasingly adopt the language and vision of ‘recovery’, the role of CSOs may become even more important, to “ensure that what is being promoted is *real* recovery and empowerment – that is, the opportunity for people to make their own decisions and control their own lives” (National Empowerment Center, 2007, p. 50).

Empowerment is another central value for consumers/survivors. In the context of CSOs, empowerment includes reciprocity between people in the giving and receiving of help, gaining control over one’s life and being able to influence your environment (Campbell & Leaver 2003, p. 14) Other related values that have been found to be the foundation of CSOs include social support, valuing and sharing experiential knowledge, respect for the experiences of others who have gone through similar situations, and a sense of community identity related to shared lived experiences (Solomon, 2004). Empowerment is also one of the key outcomes for people involved in CSOs (Rogers, Teague, Lichenstein, Campbell, Lyass, Chen, & Banks, 2007).

4. Funding

Many CSOs in Ontario, other Canadian provinces and territories and international jurisdictions receive different types of government funding, as well as other sources financial support. The major theme about funding of CSOs is the need for more of it. Government policy, advocacy groups and researchers have all proposed increasing the percentage of government health funding relative to larger mental health and health care budgets. Historically, however, most self help and consumer groups ran on volunteer labour and limited resources and some activists rejected government money. The attitude on this issue in the CSO community today appears to have reversed towards complete acceptance. In addition to more money, some have called for protected and dedicated funding.

The original CSDI source of funding for CSIs in 1991 was part of an anti-recession strategy of the government. It was a project designed to create jobs for consumers/survivors and resulted in 81 full time equivalent positions being created across the province. Of those individuals hired, 75% had been on social assistance prior to the project. Among those, 60% either no longer received social assistance payments or had their benefits reduced as their income earnings increased. (Ontario Peer Development Initiative, 2001).

This framing of government funding of CSIs as an investment into the employment of people who might otherwise be unemployed and receiving social assistance is a common theme in the literature (see also Canadian Mental Health Association, Ontario, Centre for Addiction and Mental Health, Ontario Federation of Community Mental Health and Addiction Programs, & Ontario Peer Development Initiative, 2005).

Funding – the amount, source and administration – is debated extensively in the literature. The original CSDI funds have been viewed in different ways. One view is that the amount of funding, $3.1 million in 1991, “had been [a] set up for failure from the outset” (Reville & Associates, 2007, p. 62). Conversely, key informants who were active in the movement at the time recalled the impact of receiving relatively large sums of funding, with only general guidelines for implementation and few comparable programs to learn from, as being overwhelming (Everett, 2000; Shimrat, 1997).

Activists in some of the early (1970s) consumer groups viewed government funding with suspicion, fearing that it would reduce their ability to critique the psychiatric system, a common theme for groups in other parts of the world (Van Tosh & del Vecchio, 2000). When accepted, funding could also destabilize small, grassroots groups who grew quickly. The original CSDI funds may have actually contributed to the demise of one of the larger consumer groups of the time, the Ontario Psychiatric Survivors Alliance (Shimrat, 1997).

Relative to other programs and institutions in the mental health sector, CSIs represent an extremely small percentage of the overall government health care funding. One report calculated that CSIs received approximately 3 percent of the community mental health funding and less than 0.2 percent of the total mental health budget in 2004 (Centre for Addiction and Mental Health, Canadian Mental Health Association, Ontario, Ontario Mental Health Foundation, & Government of Ontario, 2004, p.37). For 2006-07, CSIs received approximately 2 percent of the community mental health budget (Auditor General of Ontario, 2008, p. 174).

These low funding levels are viewed in the literature as both a strength of CSOs and a fundamental barrier to their fulfilling their potential in a recovery-oriented mental health system. Research on CSOs and peer support workers often describes them as ‘cost-effective’ because of the low salaries that are paid, reliance on unpaid ‘volunteer’ labour and location in low-rent spaces (Brown et al., 2007; Center for Mental Health Services, 2005; Scottish Executive, 2007).

However, others describe the negative impact that lack of resources have on these organizations, including being forced to be located in sub-standard locations, relying upon mainstream agencies for reduced or free rent, losing staff and volunteers to higher paying mainstream agencies, unavailability in a range of regions, and overall stress and lack of growth (Canadian Mental Health Association, Ontario, et al., 2005; Centre for Addiction and Mental Health, et al., 2004; Centre for Research and Education in Human Services, 2004).

In response, numerous policy reports and advocacy documents have called for increased funding to CSIs as part of a reformed, community based mental health system. The recommendation for increased funding is echoed nationally and in other jurisdictions. Specific funding allocations have been recommended, often as a percentage of total mental health funding. These specific figures range from 5 to 10% (Campbell & Leaver, 2003; Centre for Research and Education in Human Services, 2004; Lurie, 2008).

In addition to more funding, advocates and policy makers have also stressed the need to protect CSI funding from being subsumed into general mental health funding by ‘ring-fencing’ the funds (CMHA Ontario, et al., 2005). The recently signed accountability agreements between the Ontario Ministry of Health and Long Term Care and the fourteen Local Health Integration Networks (LHINs) have created ‘dedicated funding envelopes’ for a variety of health care services, including community mental health services. As a result, funding for CSIs will be determined by the Ministry for each LHIN. In turn, each LHIN will “provide funding for Consumer Survivor Initiatives at least at 2006/07 levels, and maintain the viability of such services in the local health system” (see the Accountability Agreement for Champlain LHIN, 2007 for an example of the standard language of the agreement, p. 18).

While this funding appears ‘protected’, it is important to note that the funding levels it sets reflect the investments that took place in the sector between 2005 and 2008. While these investments totalled approximately $200 million dollars of new money into the community mental health sector, a recent report claims that these investments were not distributed evenly over the sector (Auditor General, 2008). None of the enhanced funding was specifically targeted to CSIs for their peer support programs, save for an additional 30,000 dollars for each LHIN to create a network of CSIs in order to support their work with the new regional funders (Reville & Associates, 2007).

Enhanced research is proposed as one way to advocate for increased funding for CSIs. Mowbray, et al. note that funders demand that groups can define the critical elements of their services. The development of fidelity instruments for CSIs could be used to demonstrate the impact of inputs (such as funding) to outcomes. Accordingly, CSIs need to conduct research to do this and be able to prove that they are a “viable model” (2005, p. 287).

However, the ‘catch-22’ of this situation has been articulated by consumer activists, one who describes an evidence-based mental health system as “you have no evidence; you get no funding; you have no funding, so you can’t produce no evidence” (Curtis et al. cited in MacNeil, & Mead, p. 243).

As described in the earlier section on definitions and values, process and structure are interrelated in the shape of CSOs. In turn, these are impacted upon by the external political, economic and social environment in which they are located. The funding structures of each jurisdiction will have an impact on the type of peer support services that are available. The American situation is a prime example of this, as their health care system is fragmented into state and federal sources, and privatized. In this context “peer support services are often funded through time-limited special project grants” (Campbell & Leaver, 2003, p. 26) and must develop services that can fit into the requirements of funders. Other American CSOs have responded to this challenge by seeking to diversify their sources of financial support (National Empowerment Center, 2007).

5. Governance and Management

If consumer/survivor control is a key structure and value of CSOs, then the governance and management of these organizations can be viewed as the day to day practice of this value.

Ontario CSIs have a variety of governance structures, often as a result of different sources and history of funding. The issue of governance has long been a central and contested issue for CSIs. The original CSDI funding source was designed to promote organizationally autonomous groups. Groups were expected to be independent, non-profit organizations. If they were sponsored by another agency, they were expected to develop a plan to become autonomous. This policy existed until 1996 (Nelson, et al., 2008). Since then, many CSIs have lost their autonomous status and have been absorbed into mainstream mental health agencies (Longitudinal Summary Report, 2004).

Until the introduction of the Local Health Integration Networks, mental health and addiction services funded by the Ontario Ministry of Health and Long Term Care took direction from an operating manual. In cases where a program was sponsored by another agency, the sponsored program was required to have an advisory committee who was accountable and reported to the Board of Directors of the sponsoring agency. Committees were to consist of individuals with expertise in mental health and addiction services including those who have the ability to "represent the interests of clients and their families" (Ontario Ministry of Health and Long Term Care, 2003, p. 9).

Despite the existence of written regulations, CSIs (and other sponsored programs) could be vulnerable to having their sponsoring group not respect their autonomy. While some CSIs had excellent relationships with their sponsoring agency, other CSIs complained of a lack of respect by their mainstream funder of their status as consumer-controlled, including failing to acknowledge the governance role of their advisory committee or fulfil their accountability requirements (Auditor General of Ontario 2008; CMHA Ontario et al., 2005; Reville & Associates, 2007).

These different governance structures, and differences between policies and realities, represents one of the reasons there have been repeated recommendations made for support to CSIs in key areas of non-profit governance and management (CMHA Ontario et al., 2005; Nelson, et al., 2008; OCAB, 2004; Reville & Associates, 2007). The provincial network group of CSIs, the Ontario Peer Development Initiative (formerly Consumer/Survivor Development Initiative) was originally funded to provide this expertise. Despite their existence, organizational instability was an ongoing feature of the CSIs and resulted in a shift in policy due the funders' concerns about their governance and management (Nelson, et al., 2008).

Ironically, the organization funded to provide organizational support to the CSIs itself lacked an independent board until a full decade after its' initial funding, 2001 (OPDI, n.d.). Following a recent critical review of their functioning, the government stopped providing funding to OPDI for this role, but did not provide alternative sources of support for the member groups (Reville & Associates, 2007).

The experience of the Ontarian CSIs highlights the tension between values and structures. When faced with challenges with structures, the response of the funder was to remove consumers from direct control of their organizations and subsume CSIs into mainstream mental health agencies. For the government funder, "the other course of action that was available, but not taken, was to strengthen the central team of consumers and enhance its support role" (Nelson, et al., 2008, p.198)

In addition to OPDI, the provincial government also funded the Ontario Council of Alternative Businesses (formerly Consumer/Survivor Business Council) to provide support to established and new alternative businesses, but they too have faced challenges in doing so. Over the years, OCAB took on the role of directly managing several businesses, with the result that staff time and efforts were increasingly focused on day-to-day management, taking away resources to provide technical support and advocacy although this remains a key activity (Ontario Council of Alternative Businesses, 2004).

While the original CSDI funding required that applicants have a democratic governance structure in place and that members be directly involved in the control and organization, they did not dictate the specific governance form that they took. In practice, most CSIs follow a traditional non-profit structure with a board of directors or advisory committee.

There is little in the literature to suggest that CSOs have adopted or developed alternative governance structures, such as collective models, co-operatives or non-hierarchical structures. This contrasts with some of the first CSOs, such as the Mental Patients Association in Vancouver, British Columbia, which was described by one of it's founders as being built on a vision of direct democracy and "a suspicion of leaders and of organizations" (Shimrat, 1997, p. 53).

Alternative businesses (or social purpose enterprises) have developed and promoted a unique governance structure for alternative businesses, with current employees of the businesses being able to serve on the board. This was seen as being key to having consumer control over the businesses/organizations and represents an innovative combination of a traditional non-profit board of directors structure with aspects of a worker's owned co-operative (Canadian CED Network, 2006).

While training in board governance and other issues is often stressed, there may also be structural features that impact upon the ability of consumers/survivors to control their own organizations. One study conducted on mainstream mental health agencies concluded that policy boards, in contrast with management ones, were most conducive to consumer involvement. This was based on the unique experiential knowledge that consumers brought to the board and with which they were more likely to be able to contribute to governance (Newberry, 2004). However, this finding raises the issue of the need for consumers to also have, or to develop, management expertise in order to ensure control of consumer-run organizations where they represent a majority of the voting members.

Interestingly, there is little discussion in the academic and grey leadership of management of consumer-run organizations, although their role would likely be key to the difference between a successful and unsuccessful group. In their review of successful state consumer organizations, the National Empowerment Center stresses the role of low funding levels has upon the ability to attract and retain strong leadership (2007).

Just as for staff, consumer/survivor managers require workplace accommodations. The specialized skills needed to run a CSO, maintaining a balance between the needs of the organization and the members served with those of the staff leaves CSIs and alternative businesses "vulnerable when their managers go on sick leave and they are unable to find (and pay) replacements" (Reville & Associates, 2007, p. 62).

Orwin's report (2008) from New Zealand includes the one of the most detailed discussions of themes related to leadership, both governance and management, based primarily on interviews with key informants in New Zealand and the United States. This report concludes that management training is key to the successful functioning of consumer-run organizations due to their "emerging role" (p. 20). The importance of providing high quality supervision of peer support workers is also stressed.

Orwin also includes a discussion on the role of "charismatic" leaders, claiming that they are a common feature of the consumer movement and noting both the strength and weaknesses of this type of leadership. The weakness is that a popular leader without skills can reduce the effectiveness of an organization. However, as CSO arise from a social movement, "they are on a mission, and charismatic leadership can prove essential…however, it can leave the organization reliant on one individual and therefore vulnerable" (p.29).

As stressed repeatedly elsewhere, (Campbell & Leaver, 2003; National Empowerment Center, 2007; Nelson et al., 2008; Van Tosh & del Vecchio, 2000), Orwin's report emphasizes the importance of good governance and management in consumer-run organizations. However, despite these repeated recommendations for technical support for organizational development, none of the research appears to address the issue of why CSOs apparently continually require this support.

Although different CSOs may be at different levels of development, and the literature does reflect changes in structure and process over time, there appears to be an unstated acceptance of a certain degree of limited competence for consumer/survivor run organizations. This acceptance may not exist or may not exist uniformly, but, as Orwin quotes one leader on this issue, "it is time to lose the assumption that to be mad is to be incompetent" (p.29).

The importance of overcoming negative attitudes towards the leadership skills of consumers is mentioned by an evaluation of the Kansas, United States consumer-run organizations (Brown, et al., 2007). Using a 'goal-attainment' measurement tool, this study concluded that these groups demonstrated "general organizational competence" that "runs counter to a common scepticism about CSOs – that people with mental illnesses are not competent enough to operate a non-profit." (p. 80)

Although it will be discussed in more detail in a later section, it is noteworthy that few of the peer support worker training programs appear to include training in management and governance roles (Center for Mental Health Services, 2005; Woodhouse & Vincent, 2006). As well, one American funding body requires peer support workers to be supervised by a "competent mental health professional (as defined by the State)", which, while not explicitly excluding people with psychiatric disabilities, many of whom have professional jobs, does not necessarily support the growth of peer management capabilities (Centers for Medicare and Medicaid, 2007). This stands in stark contrast to much work in the consumer movement over the decades on the important role of leadership training (Church with Capponi, 1991; OCAB, 2004).

6. Delivery (models / trends / advocacy / support / employment / education / recreation)

CSIs in Ontario and internationally have developed a wide range of models of delivery and organization, a heterogeneity of goals and structure that is viewed as both a strength of the consumer movement and a challenge to research and the development of policy guidelines.

Many different models of consumer/survivor run groups existed in Ontario prior to 1991. Self help and peer support groups have a long history in Ontario and elsewhere. There was also a strong grassroots, self-organizing anti-psychiatry movement (Nelson, et al., 2008; Shimrat, 1997). A few groups started as programs or projects of traditional mental health agencies and eventually became independently run groups (e.g., A-Way Courier Express in Toronto).

The CSDI funds directed CSIs to a wide range of models, with a clear intent of not funding traditional services. The argument for this was that "one of the primary reasons for developing C.S.D.I. was the limitations of the service system" (Consumer/Survivor Development Initiative, 1992, p. 2). Traditional services were based on a model of expert professionals and help-receiving clients, while the CSIs were "designed to create new kinds of opportunities" (Consumer/Survivor Development Initiative, 1992, p. 2).

Originally then, the specific content of the activities was therefore less relevant to the model than the way in which activities took place, that is, through consumer control and peer support. Program activities that CSDI would fund included;

- self-help groups,
- one to one support,
- community-economic development,
- education and training for the public and mental health professionals,
- advocacy to create systems-level change,
- opportunities for consumers/survivors to develop their skills, the creation and distribution of resources based on consumer/survivor knowledge, and
- artistic and cultural activities (Longitudinal Study, Summary Bulletin, 2004).

Alternative businesses developed a unique and vibrant model in Ontario which emphasized the importance of building community, respecting and accommodating people's genuine fears of working (due to loss of disability income benefits and other factors), working hard to overcome the tremendous barriers people living in poverty faced, and "overcoming disbelief" in their ability to succeed (Church, 1995; Consumer Survivor Business Council & National Network for Mental Health, 1994, p. 10).

The degree to which the funded CSIs adhered to a non-service model, or how, in practice, service alternatives would be defined has been an issue debated in the grey and academic literatures since the first CSOs developed. Even after the first year of funding, CSDI noted the challenge where alternative models began to adopt service approaches, which "do not give people the chance to use their own skills and capacities. Instead, they become clients again" (CSDI, 1992, p.3).

However, even at the outset of funding for 'non-service' alternatives, the interest in and the need for a diversity of consumer-run organizations was acknowledged. CSDI policy did not take a position on consumer-services in principle, only that these "be seen as different from C.S.D.I. and funded from another source" (CSDI, 1992, p. 4).

Due to the impact of the CSDI original funding framework and ongoing self-definition by many CSIs, Ontario may be somewhere unique in that the growth of CSIs developed in a grassroots fashion but with some shared organizing principles. In contrast, research in some other jurisdictions has noted the wide range of types of models described as 'consumer-run'. Mowbray et al., argue that while this heterogeneity makes it particularly challenging to evaluate CSIs as an evidence-based practice (because they lack the formal set of standards found in other programs, like ACT), it also makes it all the more necessary for CSIs to develop fidelity standards, to ensure adherence to key values within a wide range of models (2005).

Growth and innovation in CSI models is encouraged in the research and grey literature. One of the key findings/recommendations to emerge from the Ontario Longitudinal study was proposals for the development of new models such as peer supported employment and education, and consumer-owned housing (Centre for Research and Education in Human Services, 2004). Preliminary research for a CSI housing co-op was developed in one community (Hamilton Addiction and Mental Health Network, 2006). Development of a core set of standards for CSIs might support the growth of new models in that it would clarify some shared values but also allow for response to local need and innovation in the specific type of service.

Interestingly, some ‘new’ models of service delivery have actually been practiced by consumer for many decades and are being rediscovered again. Some CSIs are developing formal training for peer support workers to support individuals making the transition from inpatient hospital stay to returning home, or building a home in the community, building upon the success of the Connections program run by several CSIs in south-western Ontario (CMHA Ontario, et al., 2005; Psychiatric Survivors of Ottawa , 2009).

This models work done by consumer activists in the 1970s and ‘80s who organized personal care packages to deliver to inpatients, both as practical support, but also to let people know they had peers in the community (Shimrat, 1997). One of the key differences between older and newer versions of this type of peer support is that professionals have appeared to shift their attitudes from hostility to support; in part it would appear because they now play a role in organizing.

While these formalized peer support programs are a variation of peer support, for which CSIs receive core funding, these programs have often relied upon additional funding, often project based, for costs associated with coordinating, training and offering honoraria to volunteers.

7. Human Resources

Research findings on human resources issues for CSIs are often derived from studies on both consumer run organizations and on peer support workers in mainstream agencies. Much of this focuses on paid staff, rather than volunteer or member led activities. Evidence on effective human resources practices specific to CSIs includes the supportive work environment and workplace accommodations that empower consumer employees to work productively.

One of the key strengths of CSOs is that, by definition, everyone involved, from staff to member and manager and board, shares a common experience of mental illness or having been in the mental health system. This shared social support acts as a form of workplace accommodation without any bureaucratic formality. The experience of working in an alternative business, for example, is described as “comfort, ownership, pride, teamwork, safety, responsibility and respect” (Brown as cited in Canadian CED Network, 2006, p.4).

Training and support for staff is, in many CSOs, built into the job. The alternative businesses have developed an explicit vision of this support, as employment is key to their model, which is based on peer learning and confidence building (Canadian CED Network, 2006; Church, 1995). However, all CSOs who have staff or volunteers must take their needs into consideration and many have adopted supportive workplace practices, such as flexible work hours, acceptance of so-called ‘unusual’ behaviour, recognition of the need for time off for therapist and medical appointments (Woodhouse & Vincent, 2006).

However, the success of this model has, inadvertently, worked to the disadvantage of some CSOs. Staff and management of CSOs are generally paid less than comparable agencies and, as the mainstream begins to value peer work, they are recruited for similar jobs at higher pay in mainstream services. Thus, one of the key demands of CSOs has been increased funding in order to pay competitive wages and provide health care benefits for CSI staff relative to other community mental health agencies (CMHA Ontario, et al., 2005)

Orwin's report represents one of the most specific reviews of human resources, although even this relies on research about peer support workers in mainstream agencies (2008). He offers a contrasting view of the 'peer helper principle' often used by research to explain the benefits of peer support work. While the importance is noted, CSO leaders also stress the importance of staff being able to do their jobs, and most definitely not view peer work as a type of 'vocational rehabilitation'. Another finding is the importance of having a minimum number of peer support workers in order to ensure a full staff complement by anticipating a certain degree of sick leave and turnover. While not based on research within CSIs, the findings may be transferable to this setting.

Solomon's review of the research with the goal of defining some critical standards for CSOs includes the role of peer providers. Three very general claims are made, noting that in the hierarchy of evidence standards used by the review, only anecdotal-level evidence exists for this area. Peer providers are expected to have experience with the mental health system, to be stable and in recovery and not to be current substance abusers or dependent (2004).

As these characteristics are clearly described as not very robust findings, it is not difficult to note their limitations. While these characteristics would appear to be, at first glance, both obvious and essential, they raise many questions. For example, debates over the specific features that define 'experience with the mental health system' have a long and difficult history within the consumer movement (Everett, 2000; Shimrat, 1997). As well, there is growing specialization with the peer support movement, recognizing differences among consumers and being able to train people from different communities and experiences of the mental health system and mental illness.

Expecting peer providers to be 'stable' and in 'recovery' as well as refraining from harmful uses of substance abuse again raise the issue of measurement and management. By what definition would a CSO employee be evaluated as 'stable'? As well, they seem to ignore a wealth of qualitative and personal literature that describes the ways in which CSIs have thrived as much as because of the unique personalities and qualities of consumer than despite them, although these qualities may also contribute to failed groups as well (Schnell, 2005; Shimrat, 1997). This does not even begin to address the potential human rights violations where an employer would presume to evaluate an employee's mental health status.

As the literature on essential qualities for peer providers remains preliminary, there is little to associate specific qualities with specific types of peer support. This would seem to be key for future, more refined research. Clear definitions between the types or continuum that exists of 'peer support' remain elusive and contested. Many researchers and advocates are clear that there are differences between friendship, peer support, peer support services, and general mental health services provided by consumer employees, but there is no consensus yet on specifics (and terminology) (Davidson, et al., 2006; Forchuk, 2005; MacNeil & Mead, 2005; Pocklington, 2006).

One of the most significant developments that has taken place in peer support has been the growth of the concept of the ‘peer support worker’. Often identified with a dedicated position on assertive community treatment teams, much of the current enthusiasm for this role appears to stem from the Georgia (U.S.) peer support certification process, which has led to the creation of over 200 new employment opportunities for consumers/survivors in that state and increasingly across the US as other states adopt the model (Center for Mental Health Services, 2005). Certified peer specialists work in both mainstream mental health and other services and independent consumer/survivor run organizations.

Many advocates feel strongly that the development of formalized training and certification of peer support workers is essential if CSOs are ever to take their place as equals within the mental health system. Advocates stress the challenge of making recovery oriented changes in the mainstream mental health system, “mental health system providers often resist transformation initiatives that focus on consumer-directed services and may not want to hire consumers as professionals” (Center for Mental Health Services, 2005, p. 15). Georgia peer specialists argue that training and certification has been key to supporting that transformation.

For those advocates who support certification, it represents improved relationships with the mainstream mental health system, for example, through access to funding but “respect from within the mental health service community could also be a de facto result of certification” (Campbell & Leaver, 2003, p. 29). Ontarian CSIs have also recognized the importance of gaining recognition from mainstream services for the value of peer support work (The Herrington Group, 2005).

The peer support worker training and certification processes also provide a foundation for increased recognition of peer support as an evidence-based practice. Training can be built upon standardized manuals, either one of the many currently in existence or locally developed (for a review of some see Woodhouse & Vincent, 2006) which can allow for the replication of practices, a component of the type of research evidence needed to define a ‘best practice’ (Addis & Krasnow cited in Campbell & Leaver, 2003, p. 26).

As CSOs and peer support worker continues to expand and grow, both in the number, types and complexities of service, increasingly there is recognition for the need to ensure the quality of peer support work. Again, certification is one way to support this objective.

There are pragmatic reasons as well. Particularly in the American health care model of privatized services, without some type of formal training and certification, peer workers will not be eligible for funding (Campbell & Leaver, 2003; Center for Mental Health Services, 2005)

The expansion of peer support training programs may be of benefit beyond training for employment. Many consumers take a variety of peer support and recovery education training programs for the intrinsic value of sharing and learning with peers, regardless of whether it leads to employment (Story, Shute, & Thompson, 2008).

However, there is debate within the consumer movement about the role of peer support workers both within CSOs and mainstream services (Campbell & Leaver, 2003; The Herrington Group, 2005, Pocklington, 2006). As has often been the case with the consumer movement, there can be debate over language, such as the use of the term peer support ‘specialist’ versus worker (McIntyre, 2008).

But the broader issue is the "danger of professionalizing recovery", self help and the CSIs themselves (The Herrington Group, 2005, p.6). Advocates express concern about becoming too much like the system that CSIs are supposed to be an alternative to, and adopting the language and culture of professionals. The notion that certification would earn professionals' respect seems questionable in light of persistent stigma and discrimination against people with labels of mental illness. How would participation in a two-week training course overcome personal and structural discrimination? Other concerns raised include whether certification would become mandatory and what would become of the relationship between 'specialist' and regular 'peer'.

Issues that are not often raised in the literature about the role of formalized recognition of peer support workers include recognition that, in many countries and regions including Ontario, CSOs have been engaged in facilitating peer support for many decades. While training and certification in some jurisdictions may have been the key to creating a peer workforce, in Ontario an extensive workforce already exists. If peer support training is introduced now to CSIs who have not previously employed a 'specialist' or provided peer support, then what role did they perform previously (The Herrington Group, 2005, p. 5)?

Ontario, in particular, has developed a variety of forms of consumer-run organizations including those such as alternative businesses that, while fundamentally built upon peer support relationships, would not easily fit the image of 'peer support' as presented in some of these training programs.

The issue of resource allocation for peer support workers is also not often addressed. Should government funding be directed to existing, underfunded CSIs, or to mainstream mental health agencies to hire individual peer support 'specialists' or workers? OPDI has proposed an arrangement, currently being model in one city, whereby peer support workers would be employed by CSIs but work at mainstream agencies.

8. Marginalized and minority consumers/survivors

Among people who experience mental health challenges and the mental health system is a wide range of experiences and identities, which are in turn reflected in the diversity of the consumer movement. While there are a variety of perspectives within the consumer community, some view CSOs as a social justice movement, like that of the anti-racism, women's and gay, lesbian, bisexual, and transgender movements (Consumer Survivor Business Council & National Network for Mental Health, 1994). The concept of 'anti-oppression is often used to describe the process of putting "structures of oppression and discrimination at the centre of analysis, attending to the diversity of oppressions and their interlocking nature, in an attempt to eradicate oppression, in all its forms" (Supportive Housing and Diversity Group, 2008, p. 4). CSOs, like other groups, are working to recognize the diversities of experience and oppressions that exist within the consumer community, although the range of these issues have not yet received much research attention.

In Ontario, funding policy explicitly recognized differences and multiple identities within the consumer/survivor community and the need to recognize diversity within the organizational make up of CSIs. The 1991 CSDI funding included specific focus on two groups of consumers, ethno-racial and Francophone.

The experiences of racialized consumers in CSOs, both general ones and those created specifically by racialized survivors, has received some research attention. British ‘Black and Minority Ethnic’ users have, in particular, have created a number of user-run organizations and developed a relatively significant amount of literature on their experiences. Over the past few years, British social and health care services have been reorganized to include within the meaning of ‘user’ anyone using a variety of services, including mental health, learning disability (developmental disability in Canada), elder, youth and disability services. Based on the experiences of these users, one review concludes that black and minority ethnic users do want to participate in shaping the services that affect their lives but face increasing barriers to doing so (Begum, 2006).

Users from black and minority ethnic communities experience both the strengths and challenges of the interconnection of different identities. As such, they may often have their unique experiences devalued or unrecognized by both mental health peers from dominant racial and cultural groups, and by non-psychiatrized members of their racial and ethnic communities. Begum notes that while funders and policy makers may connect with community leaders, they often fail to directly connect with minority users. As well, “the mainstream service user movement cannot represent black and minority ethnic service users until race equality and anti-discriminatory practice becomes integral to everyone’s work” (2006, p. viii).

Support for this comes from other countries as well. In one of the few studies specifically on differences among consumers within CSOs, significant differences were found in the sense of community and social support depending on the racial composition of the membership (Woodward, Mowbray, Holter, & Bybee, 2007). Based on clubhouses (a non-CSO model) and CSOs located in Michigan, US, the study found that as the number of African-American consumers participating in these agencies increased, so too did their individual sense of community. However, at the same time, white consumers perceived a decrease in community with growing racial diversity.

The authors note that there is no reason to assume that the racism against African-Americans and other communities by whites that exists in the broader mental illness system and society will not also exist in CSOs. However, such findings speak to the ways in which the identity of ‘consumer’ and the experience of madness are not necessarily enough to overcome other oppressive social structures.

Ontarian consumers/survivors report some similar experiences. In a series of qualitative interviews with racialized consumers in Toronto, many spoke of the need to have their experiences and identities reflected in the staff of the mental health services they came into contact with (Shahsiah, & Yee, 2006).

CSOs have recognized the need to move beyond a singular focus on the shared experience of madness and develop cultural competency understandings and practices (National Empowerment Center, 2007; Van Tosh & del Vecchio, 2000). As the understanding of the how to do this remains an ongoing process within mainstream mental health organizations, as in society at large, an area for future research may be to develop a unique process for CSOs (see Supportive Housing and Diversity Group, 2008 for an overview of different models developed by service providers).

The impact and interrelationship among diverse identities is particularly evident in the growing number of people with mental health problems who are coming into contact with the criminal justice system. In Ontario, funding investments over the past years have been directed to mental health and justice services, with the goal of diverting consumers/survivors from the criminal system and instead connecting them with mental health services.

The experiences of consumer who come into contact with police, jails, the court system and mental health and justice services also demonstrates the potential for divisions within CSOs and the community they serve. One American CSO says of the experiences of criminalized consumers, “it’s just a different door – race, ethnicity and class, not criminality, often dictates whether a person enters the mental health system and treatment or the criminal justice system” (Mayes, 2008, slide 2).

Despite this reality, again, a divide may exist between members of the consumer community, this time through the experience of incarceration or even contact with police and diversion. According to the Howie the Harp Advocacy Center, an American CSO, most consumers who have been in jail haven’t been connected with the consumer movement and most CSOs have not made much effort to connect with this group (Mayes, 2008, slide 4). The Center has been active in addressing this divide by developing peer support training for people with forensic histories, who in turn connect with peers.

Ontario CSIs have also begun comparable work, particularly the few CSIs who received additional dedicated mental health and justice funding and now offer a variety of survivor-driven services, such as release from custody planning and prevention (Sound Times, 2008).

Consumers/survivors who are gay, lesbian, bisexual, transgender and other sexual and gender minorities have been active both within the broader mainstream CSO movement and, in some places, have created their own spaces. For some consumer, their experience of madness and queer identity are strongly interconnected. Some make the connection between their experiences of homophobia within the mental health system to their roles as activists in the consumer community (Suhanic, 2001).

While traditional mental health services are increasingly providing culturally competent services that recognize the experiences of lesbian, gay, bisexual and transgender (LGBT) consumers/survivors, the need for consumer-run support has led to the creation of a few groups and organizations (Rainbow Heights Club in New York, US, ‘Pink and Blue’ peer support groups, Davis, 2006).

One diversity that has historically been highly debated within the mental health system has been the needs and experiences of people with so-called serious or severe mental illness, including those who the system often considers ‘hard to serve’. Some researchers have concluded that CSOs are particularly accessible to individuals who would not otherwise use traditional mental health services, either through choice, ineligibility, or denial of service (Beresford & Branfield 2006; Campbell & Leaver, 2003; Hardiman, 2005; Mowbray et al., 2005).

In Ontario, CSIs have been challenged by some critics on the basis that self help is not useful for people with the most severe experiences of mental illness. The Longitudinal study specifically asked ‘who uses self –help organizations’? They found that, while different from people receiving assertive community treatment team services, members of CSIs experienced both severe illness, along with some degree of ‘functioning’ but also significant instability in their lives (Goering, Durbin, Sheldon, Ochocka, Nelson, & Krupa, 2006).

9. Stakeholder Relations

The academic literature primarily addresses stakeholder relations between CSIs and mainstream mental health agencies, with some attention paid to relationship building between CSIs and individual consumer. One theme that runs throughout the literature in general, and in terms of stakeholder relations in particular, is the relationship between CSIs and peer support workers in mainstream organizations (Hardiman, 2007).

Less formal attention has been directed towards relationships with funders, politicians, legal services, other social service sectors (e.g., criminal justice, income support) or other equity seeking groups (e.g., newcomer serving services, LGBT activists and services, associations of and for people with other disabilities). In practice, these are often key relationships for many consumers and activists but do not appear to be addressed in the research.

Building collaborative relationships and partnerships with CSOs and mainstream mental health agencies is considered to be a positive goal for all parties (Campbell & Leaver, 2003; Centre for Research and Education in Human Services, 2004; Forchuk, 2005; Gordon, 2005; Hardiman, 2007; Ontario Peer Development Initiative, n.d.; Orwin, 2008; Wituk, 2008;). Wituk, et al., (2008), for example, states that there is growing recognition of the need for more “formal collaboration” between CSOs and MHAs as the numbers of CSOs increase.

Some authors consider this move towards more collaboration to be a change from an original vision of CSOs as alternatives to the formal mental health system (Campbell & Leaver, 2003; Forchuk, 2005; Van Tosh & del Vecchio; 2000). However, other research shows that the consumer movement has long included groups with a variety of approaches to relationship to the formal system, from collaboration to rejection (Nelson, Janzen, Trainor, & Ochocka, 2008).

Barriers and challenges raised in the literature to strengthening these relationships include the lack of understanding in mainstream services of referral pathways to CSIs. Orwin (2008) writing about the New Zealand context, argues that the service system should not “refer in the normal sense” due to the value held by CSIs on voluntariness and consumer choice in participating in peer-run agencies. Others, in contrast, says that in a competitive system, such as in the United States, CSIs need to insist upon formalized referrals and that referrals are one of the key ways that the mainstream system can support CSIs. (Brown, et al., 2007; Hardiman, et al., 2007).

The need for a more formalized approach can be seen to be supported by the evidence produced by Hardiman et al., of “relatively low” (p. 205) referral rate by mainstream services to CSIs, with the strongest predictor of referral being “organizational collaboration” (p. 364). This study also found evidence that professionals placed a higher value on peer support provider by peer support workers within agencies. The authors interpret this finding to recommend increased hiring of peer support workers in mainstream services in part as a way to connect with CSIs. However, this finding also raises the issue of the tensions between autonomous CSIs and non-labelled professionals’ control of peer support.

None of the literature included in this review touched upon the issue of CSIs referrals to mainstream mental health services, although this may becomes an issue in integrated and network systems where there are often preferred or exclusive referral patterns.

One author claims that discriminatory attitudes by service providers (Gordon, 2005) is one of the biggest barriers to consumer participation in the mental health system in general and advocates for strengthening consumer leadership through a variety of means including the development of CSOs.

10. Outcomes and Evaluation

Developing outcome and evaluation systems that can measure the unique process and structural features of CSOs is a consistent theme in both the academic and consumer/survivor literature (Brown et al., 2007; Campbell & Leaver, 2003; Davidson et al., 2006; Hardiman, et al., 2005; Holter, et. al., 2004; MacNeil & Mead, 2005; Mowbray et al., 2005; Nelson, Ochocka, Janzen, Trainor, & Lauzon, 2004). There is currently a growing body of research demonstrating the effectiveness of CSOs (Campbell & Leaver, 2003; Centre for Research and Education in Human Services, 2004; Doughty & Tse, 2005; Forchuk, 2005; Rogers, Teague, Lichenstein, Campbell, Lyass, Chen, & Banks, 2007). Some have concluded that CSIs can be considered to be an evidence-based practice (Centre for Research and Education in Human Services, 2004).

In order to measure the results of CSIs a shared understanding is needed of what outcomes they seek to achieve and how these will be measured and evaluated. For CSIs, having in many cases developed as an alternative or non-traditional type of support, there is a challenge in using traditional measurement criteria to define success or failure. Many authors have addressed these potential conflicts between CSI values and mainstream accountability processes. Most argue for a balanced approach between the grassroots values of CSIs and larger system goals of formalized accountability through various data collection and reporting methods (Brown, 2007; Hardiman, 2005; Nelson, et al., 2004; Orwin, 2008).

International research, both empirical studies of local CSOs and theory developed out of practice, reflects many of these themes of balancing different values and approaches. A variety of unique and creative ways to move forward have been proposed.

Brown et al., (2007) describe this as the tension between non-profit organizations staying true to their mission while meeting their funders' needs for accountability. For CSOs this tension is particularly problematic as they have "have historically struggled with cooptation". Independence is even more than a value for CSOs "because consumer control is an essential organizational characteristic". Autonomy is also key for individual participants as consumer control was found in one study to be "the best predictor of personal empowerment and social functioning" (citing Segal and Silverman, p. 75).

Program evaluation for CSOs would require the creation of data collection and management systems that were consistent with CSO values. In one survey, conducted with American peer support programs, 40% of programs said that collecting data from members would discourage people from using their services. Data collection also requires resources and 43% of the surveyed programs felt that it would financially burden them (Campbell, quoted in Campbell & Leaver, 2003, p.32).

Hardiman et al., (2005) directly connect the tension to the broader movement in the health and mental health care systems to the evidence-based practice (EBP) movement. They encourage consumer/survivor groups to talk with each other and with other stakeholders and ask the questions,

> What is evidence? What is knowledge? What does EBP mean for us? How will it impact our services? What assumptions are we making? What assumptions underlie the evidence? (p. 116)

Orwin (2008) makes one of the more assertive claims for CSI's uniqueness in mental health systems, stating that they should in no way be expected to or evaluated for meeting "clinical outcomes", such as reduction in inpatient stays (p. 20). However, this review of New Zealand's CSO community does acknowledge the importance of achieving a balance.

Many authors stress that CSOs need to be centrally involved in developing and implementing any alternative evaluation framework (Beresford & Branfield, 2006; Centre for Research and Education in Human Services, 2004; Hardiman, 2005; MacNeil & Mead, 2005; OCAB, 2004; Orwin, 2008). For MacNeil & Mead, "this is one of our standards for developing standards" (2005, p. 241).

Despite the strong emphasis in much of the literature of the tension and the need to centrally involve consumers and survivors in developing outcome measures, there are some authors who, while supporting the value of CSOs, propose evaluation strategies and measures without explicit consumer leadership in the process (Davidson, et al., 2006; Mowbray, et al., 2005). However, they often come to similar conclusions on outcomes and measurements.

With many studies in different contexts reaching the same conclusion – that CSOs must control their own evaluation processes, building capacity for research and evaluation within the consumer community becomes even more important. Most evaluation research studies come to the conclusion that more research is needed to understand the unique practice of peer support and how it takes place within CSOs. While some stress the importance of particular types of research, such as participatory or action research (Centre for Community Based Research, 2004), or qualitative (Orwin, 2008), others focus on the need for consumers to be directly controlling the process and call for increased representation of consumer in academia (Beresford & Bransfield, 2006; Hardiman, 2005).

Limited resources applies not only to human resources but also basic organizational infrastructure. One of the benefits noted for the four CSIs who participated in the Longitudinal study in Ontario was access to a software program that allowed them to keep an inventory of activities "as CSIs typically have no way of mapping this information" (Centre for Addiction and Mental Health, et al., 2004, p. 41). The potentially problematic circular logic of an 'evidenced-based' system appears here.

Capacity building of consumer skills would need to be individualized and flexible to respond to the diversity of the consumer community. Beresford & Bransfield (2006) in their description of research with British consumer, offer one of the few examples a study that included a focus on specific groups of consumers, in this case, black and minority ethnic individuals. While they concluded that groups run by black and minority ethnic consumer shared similar issues with the wider community, they recommend supporting black and minority ethnic consumers' participation in research and evaluation activities to ensure recognition of diversity.

As noted earlier, another issue that does not seem to receive much attention is the specific legislative and policy context under which studies take place. While authors routinely acknowledge as a limitation that their findings and conclusions may be limited to the specific communities being studied, they rarely elaborate on what those contexts are and what specific impacts they might have (Brown et al., 2007, Mowbray, et al., 2005). In light of the recent changes in the policy and funding structures for health care in Ontario, understanding the role of context seems to be particularly important.

MacNeil's & Mead finding regarding the process standards they developed in one CSO (2005) provides an interesting example of the potential importance of context. They describe how consumer working in a variety of organizational contexts and structures responded differently to their standards when they presented at an event on peer support. Many peer support workers and consumer-run programs located within mainstream agencies felt that the standards could be applied to their work. In contrast, autonomous groups were more likely to sense that, while some standards were shared, their situations required the development of localized structural and process standards. MacNeil & Mead suggest that one response to this may be to "identify a range of standards that characterize each element of a program initiative" (p. 242).

As the complexity of the CSO movement and the mental health system overall increases, so too has demands from the public and government funders for increasingly formalized methods of accountability. Accreditation, a formal process of external review of the services offered by an agency or program based on defined standards designed to measure processes and outcomes, is increasingly being applied to community mental health organizations. CSOs have also begun to consider the potential for accreditation of their programs.

Some advocates consider accreditation for CSOs to be an essential next step for the movement, claiming that "lack of an appropriate accrediting body has worked to the disadvantage of peer services that choose to participate in quality improvement and funding opportunities" (Campbell & Leaver, 2003, p. 30). Similar to the process of certification of peer support work, some concern is also expressed that this would lead to the dilution of the unique model of peer support organizations and represents the professionalization of formerly alternative services (The Herrington Group, 2005; Nelson, et al., 2008).

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APPENDIX 2 – CONSULTATION

1. Initial consultation

Most of the initial consultation was completed in November/December 2008.

Focus Groups
We held 11 focus groups with CSIs in most of the LHIN areas:

LHIN 1	Chatham
LHIN 2	London
LHIN 4	Hamilton
LHIN 6	Mississauga
LHIN 7	Toronto
LHIN 9	Oshawa
LHIN 10	Belleville
LHIN 11	Ottawa
LHIN 13	North Bay
LHIN 14	Thunder Bay/Kenora
PCSLL	Toronto

We also met with the Ontario Federation of Community Mental Health and Addiction Programs Mental Health Council and gave each member a copy of the questionnaire.

Individual interviews
We interviewed a diverse group of individuals in Ontario and other countries in person or by phone.

Written submissions
We received 15 written responses

We also emailed project information and the questionnaire to all the LHINs and invited them to make contact if they would like to be part of the process. Five made contact and two LHINs participated in a phone interview

2. The people consulted

Most of the people below took part in focus groups; some took part in individual interviews.

LHIN 1 Erie St Clair

NAME	TITLE	ORGANIZATION
Jean Laforge	Executive Director	Mental Health Connections Windsor
Mary Hopkins	Executive Director	Consumer Survivor Association of Lambton
Kelly Wilken Gottschling	Executive Director	Chatham Kent Consumer and Family Network
Tom Glazier	Peer Facilitator	Chatham Kent Consumer and Family Network
Jeff Dube	Youth Peer Worker	Chatham Kent Consumer and Family Network
Mary Bigham	Member	Mental Health Connections Windsor
Terry Warwick	Board President	Consumer Survivor Association of Lambton
Bill Warwick	Previous Chair	Lambton Family Initiatives

LHIN 2 South West

NAME	TITLE	ORGANIZATION
Barbara Frampton	Regional Director	South Western Alliance Network
Walter Osaka	Staff member	Can-Voice Community Support Services
Betty Edwards	Staff member	Can-Voice Community Support Services
Sheila Fisher	Volunteer Coordinator	Consumer Survivor Initiative of Huron
Kathy Mitchell	Assistant	Consumer Survivor Initiative of Huron
Ann Riley	Assistant	Consumer Survivor Initiative of Huron
Jutta Seibel	Executive Director	Phoenix Survivors Perth County
Don Vulders	Board President	Phoenix Survivors Perth County
Jim Lonie	Project Coordinator	Consumer/Survivor Development Project
Victoria MacAleese	Staff	Consumer/Survivor Development Project
Jack Edwards	Executive Director	Oxford Self Help Network
Elizabeth Crawford	Board member	Oxford Self Help Network
Kathy Garrett	Board member	Oxford Self Help Network
Chris Boyd	Board member	Patient Council, Regional Mental Health Care
Barb Peters	Board member	Patient Council, Regional Mental Health Care
Patricia Dwyer	Planning and Integration Lead	South West LHIN

LHIN 3 Waterloo Wellington

NAME	TITLE	ORGANIZATION
Allan Strong	Coordinator	Recovery Education, Self Help Alliance

LHIN 4 Hamilton Niagara Haldimand Brant

NAME	TITLE	ORGANIZATION
Frances Jewell	Executive Director	Mental Health Rights Coalition
Martha Rybiak	Director Program Development	Brantford Vocational Training Association
Judy Hoover	Executive Director	Consumer/Survivor of Niagara
Susan Roach	Program Manager	Haldimand Norfolk Resource Centre
Fiona Wilson	Coordinator, Peer Support	MH and Addiction Program, St Joseph’s Healthcare

LHIN 5 Central West

NAME	TITLE	ORGANIZATION
Michelle Kelly	C/S Network Coordinator	Friends and Advocates Peel
Scott Brooker	Executive Director	Friends and Advocates Peel

LHIN 6 Mississauga Halton

NAME	TITLE	ORGANIZATION
Valerie Despins	Manager	Consumer/Survivor Support Network (CSSN)
Susanne Robinson	Director	MH Promotion, CMHA (flow through agency)
Debbie Jones	Supervisor Peer Programs	Teach
John	Member	Eden Place
Craig	Member	Eden Place
Tracey	Member	Eden Place
Sylvia	Member	Eden Place
Peter Mielke	Outreach and Support Worker	Eden Place
Gregory	Member	Eden Place
Rose	Member	Eden Place
Cathy Turner	Support Worker	Eden Place
Katie	Member	Par South Clubhouse/CSSN
Maria	Member	Par South Clubhouse
Brian	Member	CSSN
Steve Farstad	Manager	Par Clubhouses
Kathleen	Staff	Destination Cafe Business

LHIN 7 Toronto Central

NAME	TITLE	ORGANIZATION
Laurie Hall	Executive Director	AWAY Couriers
Michelle MacAulay	Employee Resource Asst	AWAY Couriers
Lana Frado	Executive Director	Sound Times
Steve Carroll	Program Manager	Sound Times
Crystal Smith	Harm Reduction Worker	Sound Times
Nadine Reid	Harm Reduction Worker	Sound Times
Jeremiah Bach	Community Support Worker	Sound Times
Aaron Winacott	Program Administrator	Sound Times
Mohammed Abdi	Community Support Worker	Sound Times
Jeff Hartry	Community Support Worker	Sound Times
Richard Worr	Executive Director	Fresh Start
Karen Swartz		Fresh Start
Lynette Powell-Flowers	Executive Director	Friends and Advocates
Helen Hook	Executive Director	Consumer Survivor Information Centre
Pat Fowler	Office Manager	Ontario Council Alternative Businesses
Jennifer Chambers	Coordinator	Empowerment Centre
Steve Lurie	Executive Director	CMHA Toronto
Greg Kim	C/S Participation Initiative Mgr	CMHA Toronto
Lori Lucier	Senior Integration Consultant	LHIN

LHIN 8 Central

NAME	TITLE	ORGANIZATION
Theresa Claxton	Chair	Ontario Association of Patient Councils

LHIN 9 Central East

NAME	TITLE	ORGANIZATION
Candy Williams	Executive Director	United Survivors
Paul Orchard	Executive Director	SPAN
John Empey	Volunteer	Minden
Marie Wok	Chairperson	Hong Fook
Member	Member	Hong Fook

LHIN 10 South East

NAME	TITLE	ORGANIZATION
Elisabeth Ziegler	Area Site Coordinator	Mental Health Support Network
Laurie Albertini	Area Site Coordinator	Mental Health Support Network
Ross Wagner	Acting Executive Director	Mental Health Support Network
Selma Bocknek	Board Chair	Mental Health Support Network
Mabel McLellan	Board Secretary	Mental Health Support Network
Carol Wannamaker	Board Treasurer	Mental Health Support Network
Jessica Hughson	Executive Assistant	Mental Health Support Network
Barbara Loner	Peer Supporter - Belleville	Mental Health Support Network
Tanya Souci	Team Leader - Belleville	Mental Health Support Network
Christine Peets	Team Leader - Kingston	Mental Health Support Network
Cindy Ward	Team Leader - Trentham	Mental Health Support Network
Robbie Turner	Peer Supporter - Picton	Mental Health Support Network
Salina Mcgregor	Peer Supporter - Napanee	Mental Health Support Network
Melissa Yaxley - Stillman	Team Leader - Madoc	Mental Health Support Network

LHIN 11 Champlain

NAME	TITLE	ORGANIZATION
Denise Linnay	Peer Support & Advocacy Coordinator	Psychiatric Survivors Ottawa/Champlain Peer Network
Sonja Cronkhite	Program Coordinator	Psychiatric Survivors Ottawa/Champlain Peer Network
Peggy Chivers-Wilson	Treasurer	APPLE
Deborah Moss	Coordinator	SHARE
France Perreault	Supervisor - Peer Support	CHMA
Alfred Cormier	Community Liaison	CMHA

LHIN 12 North Simcoe Muskoka

NAME	TITLE	ORGANIZATION
Len Wood	Coordinator	Voices United Consumer/Survivor and Family Network North Simcoe/Muskoka

LHIN 13 North East

NAME	TITLE	ORGANIZATION
Ellen Cohen	Regional Coordinator	NEON
Krista Tovey	Executive Director	Northern Initiative for Social Action
Gerrard Souckey	NEON & TCN Board member	Timmins Consumer Network
Catherine Helson	Executive Director	Built Network North Bay
Carla Harmer	Programme Coordinator	Council of Initiatives
John Bowcott	Executive Director	PEP
Janis Hare	NEON Board Director	Muskoka
Mina Thiebeault	Executive Director	Peer Support Sudbury
Christine Toppi	Program Coordinator	North Star - Kirkland Lake
April Maksymchuck	NEON Director -co-chair	Parry Sound
Trina Breault	Program Coordinator	Northern Star - New Liskard
Bill Davies	Executive Director	Muskoka-Parry Sound Community MH Service
Jean Beckett	C/S Volunteer	Steering Committee CSI Builder
6 consumer survivors	Members	PEP
2 consumer survivors	Members	North Star
Shirley-Anne Bedard	Support Programs Supervisor	Nipissing MH Housing & Support Services
8 staff members	Varied roles	Nipissing MH Housing & Support Services
Rick Doris	Aboriginal Healing and Wellness	North Bay Indian Friendship Centre
Robert Cunningham	President and CEO	North East Mental Health Centre

LHIN 14 North West

NAME	TITLE	ORGANIZATION
Susan Marshall	Team Leader	CAN Help
Maria Coleman	Community Liaison Worker	CAN Help
Kathleen Morrison	Peer Support /Justice Liaison	CAN Help
Mary Deciantis	Coordination Team	Sunset County Psychiatric Survivors
Lisa Vigfusson	Peer Support Worker	Sunset County Psychiatric Survivors
Leslie Scriblo	Peer Support Worker	Sunset County Psychiatric Survivors
3 consumer/survivors	Members	Sunset County Psychiatric Survivors
Michelle Martin	Executive Director	PACE
Evelyne LeBlanc	Education Worker	PACE
Annie Jollymore	Advocacy Worker	PACE
Jaylene Ledoux	Membership Worker	PACE
Lori Oliverie	Community Outreach Worker	MISN - Manitouwadge
Cindy Clarke	Community Outreach Worker	MISN - Schreiber
Shelley Cormier	Community Outreach Worker	MISN - Geraldton

Candace Raciborsky	Community Outreach Worker	MISN - Marathon
James Heino	Vice Chair Board of Directors	PACE
Dave Stewart	Board of Governance	PACE
Calvin Jewitt	Board of Directors	PACE
Joe Japps	Chair Board of Directors	PACE
Richard Lefebvre	Board of Directors	PACE
Agi Farkas	Board of Directors	PACE
6 consumer/survivors	Members	PACE
Nancy Black	Manager, Addiction Services	St Joseph's Care Group

Other Ontario Informants

NAME	TITLE	ORGANIZATION
Jim Buchanan	Consumer/Survivor	CSI Builder Steering Committee
Deb Sherman	Executive Director	Ontario Peer Development Initiative
Constance McKnight	Executive Director	National Network Mental Health
David Reville	Instructor & Research Associate	School of Disability, Ryerson University
Kathryn Church	Associate Professor	School of Disability, Ryerson University
Neasa Martin	Consultant	MHCC
Pedro	Coordinator	Dream Team
Phillip	Member	Dream Team
Hugh	Member	Dream Team
Dennis	Member	Dream Team
Esther	Member	Dream Team
Neil	Member	Dream Team
Mark	Member	Dream Team
Peter	Member	Dream Team
Jacqueline Rankine	Program Manager	Houselink – (flow through)
Linda Briggs	Program Manager	The Ontario Trillium Foundation
Diana Capponi	Employment Works Coord	CAMH
Robin Daly	Senior Program Consultant, LHIN Liaison Branch	Health System and Accountability Performance Division, MOHLTC

International Informants

NAME	TITLE	ORGANIZATION
UNITED STATES		
Shery Mead	Consultant	Shery Mead Consulting
Chris Hansen	Consultant	Shery Mead Consulting
Larry Fricks	Consultant	
Jayme Lynch	Director	Peer Support and Wellness Center - Georgia
Charlene Webber	Contract manager	Dept of Health & Human Services, New Hampshire
Kelly Staples	Consumer Affairs Specialist	Office of Consumer Affairs - Maine
Paolo del Vecchio	Assoc Dir Consumer Affairs	SAMHSA
AUSTRALIA		
Geoff Cheverton	Executive Director	Queensland Alliance
Cath Roper	Consumer Academic	Melbourne University

Desley Casey	Development Manager	CAN Mental Health Inc
Janet Magher	Director of Development	Psychiatric Rehabilitation Association
Gaynor Ellis	Senior Program Officer	Mental Health Directorate, Disability Services Queensland
Jill Read	Manager	Personal Helpers and Mentors Program, Karingal
NEW ZEALAND		
Jos Vander Pol	Coordinator	Compass
Jim Burdett	Director	Mind and Body Consulting
ENGLAND		
Anne Beales – England	Director	Service User Involvement Directorate, Together
SCOTLAND		
Simon Bradstreet	Director	Scottish Recovery Network
Shaun McNeil	Board Secretary	VOX – (National Service User Network)

3. Consultation questionnaire

Definitions

Q1. How do you define a consumer survivor initiative in terms of:

- Values and culture
- Degree of independence from the mainstream mental health system
- Proportion of consumer survivors in governance, management and staffing

Q2. What would a strong and equitable CSI presence in the mental health system look like to you?

History of CSIs

Q3. What is the situation of CSIs like in Ontario now, compared to 10 or 15 years ago?

Political Context

Q5. What barriers and/or opportunities for the growth and development of CSIs have been created by:

- Federal government
- Ontario government
- Ontario health system – new legislation & structures, old attitudes...
- Ontario consumer /survivor movement

Legislation and Policy

Q6. What barriers and/or opportunities for the growth and development of CSIs have been created by:

- Ontario legislation
- Ontario policy

Funding for CSIs

Q7. How sustainable is the level of funding for individual CSIs compared to other providers?

Q8. What proportion of the mental health budget should go to CSIs?

Values

Q9. What are the values shared by CSIs?

Q10. How do these values differ from the mental health system values?

Q11.What are the opportunities and barriers to putting these values into practice?

Governance

Q12. What barriers and/or opportunities for the growth and development of CSIs are created by:

- Maintaining an independent structure and board
- Integrating into a larger provider organization

Q13. What are the powers of an independent CSI board versus an advisory in a larger organization?

Q14. How effective is CSI governance at strategy, financial control, risk management and employment of the CEO?

Q15. Is there any difference between the effectiveness of a board and of an advisory?

Q16. What could improve CSI governance performance?

Management

Q17. How effective are CSI managers at:

- leading the vision
- planning
- relationships with funder/s
- budget control
- management of staff
- relationship with membership
- quality management?

Q18. What could help improve the performance of CSI managers?

Delivery

Q19. What kinds of supports, services and opportunities do CSIs offer?

Q20. What other supports, services and opportunities could they offer?

Human Resources

Q21. What are the barriers and/or opportunities for CSI staff in the areas of:

- Recruitment
- Retention
- Pay
- Performance problems
- Job satisfaction
- Career paths

Q22. What could improve these staffing issues in CSIs?

Education& Training

Q23. What are the barriers and opportunities for the education and training of CSI people in the areas of:

- Governance
- Management
- Practice

Marginalized and Minority Consumer/Survivor Groups

Q24. What are the barriers and opportunities faced by the following groups when it comes to participating in and benefiting from CSIs?

- Aboriginal / indigenous
- Francophone
- Ethnic minorities
- Consumer/survivors involved with criminal justice system
- GLBT
- Young people
- Rural people

Stakeholders

Q25. What are the barriers and opportunities within the relationships CSIs have with

- MOHLTC
- LHINS
- Provincial consumer/survivor groups e.g. OPDI, OCAB, provincial LHIN leads network
- Consumer survivors (not involved in CSIs)
- Families
- MHCC
- Mainstream providers

Innovation & Development

Q26. What are the most innovative and creative CSIs you know of?

Q27. What enables them to do such a good job?

Q28. How could the opportunities for CSIs to be creative and innovative be maximised?

Recommendations to the MOHLTC and LHINs

Q29. How can the MOHLTC and LHINs best support the development of strong and equitable CSIs in Ontario?

4. Focus group evaluations

The consulting team have a strong commitment to quality and sent out an evaluation form to focus group members after all the focus groups had been completed. This was to allow for any adjustments to be made to the consultation on the draft report, if necessary.

We received only six completed evaluations. People were asked to score on a five point scale – excellent- above average-average-below average-poor. Responses were all in excellent to average range:

Organization of the meeting:
- Two - excellent
- Three - above average
- One - average

Clarity about the purpose of the consultation:
- Two - excellent
- Three - above average
- One - average

The facilitation style:
- Three - excellent
- Three - above average

The relevance of the questions:
- Three - excellent
- Three - above average

The audience participation:
- Two – excellent
- Two – above average
- Two – average

Comments:
- More time for the meeting would have been of benefit
- The written questions daunting but the live session was good
- As a new staff member it was a great learning experience

Verbal responses to the focus groups were all positive.

5. Consultation on draft report

We distributed the draft report to all our contacts on 1 February.

Focus groups

We held the following focus groups over the next two weeks in:

LHIN 1, 2 & 3	London
LHIN 7,8 & 9	Toronto
LHIN 11	Ottawa
LHIN 13	Sudbury
LHIN 14	Kenora/Thunder bay
CSI Builder Steering Group	Toronto

Written Feedback

We received written feedback from several people.

APPENDIX 3 – PROVINCIAL CSI DATABASE

The people in the focus groups talked about the need for a provincial CSI database with information about services provided, budgets, HR issues and so on.

In response to this we developed a trial questionnaire and sent to three CSIs to complete and provide us with feedback. They were Sound Times, A Way Couriers and CAN Help, chosen for their diversity of activities, locations and perspectives. The database questionnaire was finalized and sent to all CSI LHIN leads who were asked to distribute it to their local CSIs.

To date there have been only two or three responses.

The questionnaire and results will be forwarded to the CSI Steering Group.

The questionnaire

1. CSI Name

2. Main Office
Main Office Address:
Address 2:
City/Town:
Province:
Postal Code:
Website:
Email Address:
Phone Number:

2.2. Geographic area covered

2.3. Satellite offices (if any)

2.4. Satellite office (if you have more than two, please add the additional sites at the end of the survey).

3. Structure
3.1 Is your CSI an independent agency (i.e., with a board of directors and a direct payment relationship with the LHIN)

4. Structure for independent CSIs
4.1 What is the legal structure of your CSI?

4.2 What percentage of the voting members of your board of directors are consumer/survivors?

4.3 What percentage of your board consists of consumer/survivor members of your CSI?

4.4 Was your CSI ever sponsored by another agency (i.e., it did not have its own board of directors or direct payment, but ‘flowed through’ or was sponsored)

Yes
No
Don’t Know

5. Structure for CSIs whose funding comes through another agency

5.1 What is the nature of the agreement you have with the agency that flows through/sponsors your CSI?

5.2 Does your CSI have a memorandum (MOU) with this agency?

Yes
No
Don’t Know

5.3 Is this agency another CSI or a mainstream agency?

5.4 What percentage of your funding does the agency charge for administrative or other costs related to the sponsorship?

5.5 Does your CSI have a Consumer/Survivor advisory committee?

Yes
No
Don’t Know

5.6 If your CSI has a Consumer/Survivor advisory committee, what roles and authority does it have?

5.7 If your CSI has a Consumer/Survivor advisory committee, what percentage of the committee are members of your CSI?

5.8 Has your CSI ever been an independent agency (i.e., with it’s board of directors and direct payment from funders)?

Yes
No
Don’t Know

6. Membership

6.1 How many members (or employees for alternative businesses) does your CSI have?

6.2 Who is eligible to be a member?

6.3 How do members participate in decisions about your CSI?

7. Funding in last financial year

7.1 What was the total budget/income for the last fiscal year for your CSI?

7.2 What was the total budget your CSI received from the LHINs/ Ministry of Health and Long Term Care for Peer Support/Self Help or Alternative Business services?

7.3 What types of services or supports did your CSI provide with this funding?

7.4 What was the total funding your CSI received from the LHINs/ Ministry of Health and Long Term Care for other types of community mental health services (e.g., family initiatives, case management, housing, social recreation)?

7.5 What types of services or supports did your CSI provide with this funding?

7.6 What was the total amount your CSI received from any other funding source?

7.7 What types of services or supports did your CSI provide with this funding?

8. Management and Staff

8.1 How many full time equivalent management positions does your CSI have funding for?

8.2 What percentage of management positions are held by consumer/survivors?

8.3 What is the pay scale of management positions at your CSI? (Please provide the range for each management position)

8.4 How many full time equivalent staff positions does your CSI have funding for?

8.5 What percentage of staff positions are held by consumer/survivors?

8.6 For each individual employee, how many hours per week do they work?

8.7 What is the pay scale for staff positions at your CSI? (Please include the scale for each type of position, including part time and hourly waged)

8.8 How many volunteers does your CSI have?

8.9 Does your CSI have a staff education budget?

Yes
No
Don’t Know

8.10 If your CSI has a staff education budget, what was the amount in the last fiscal year?

9. Other information

9.1 Is there any other information about your CSI that you want to share?

10. Confidentiality

10.1 Is there any information about your CSI that you have provided that you don’t want to make public? Please describe.