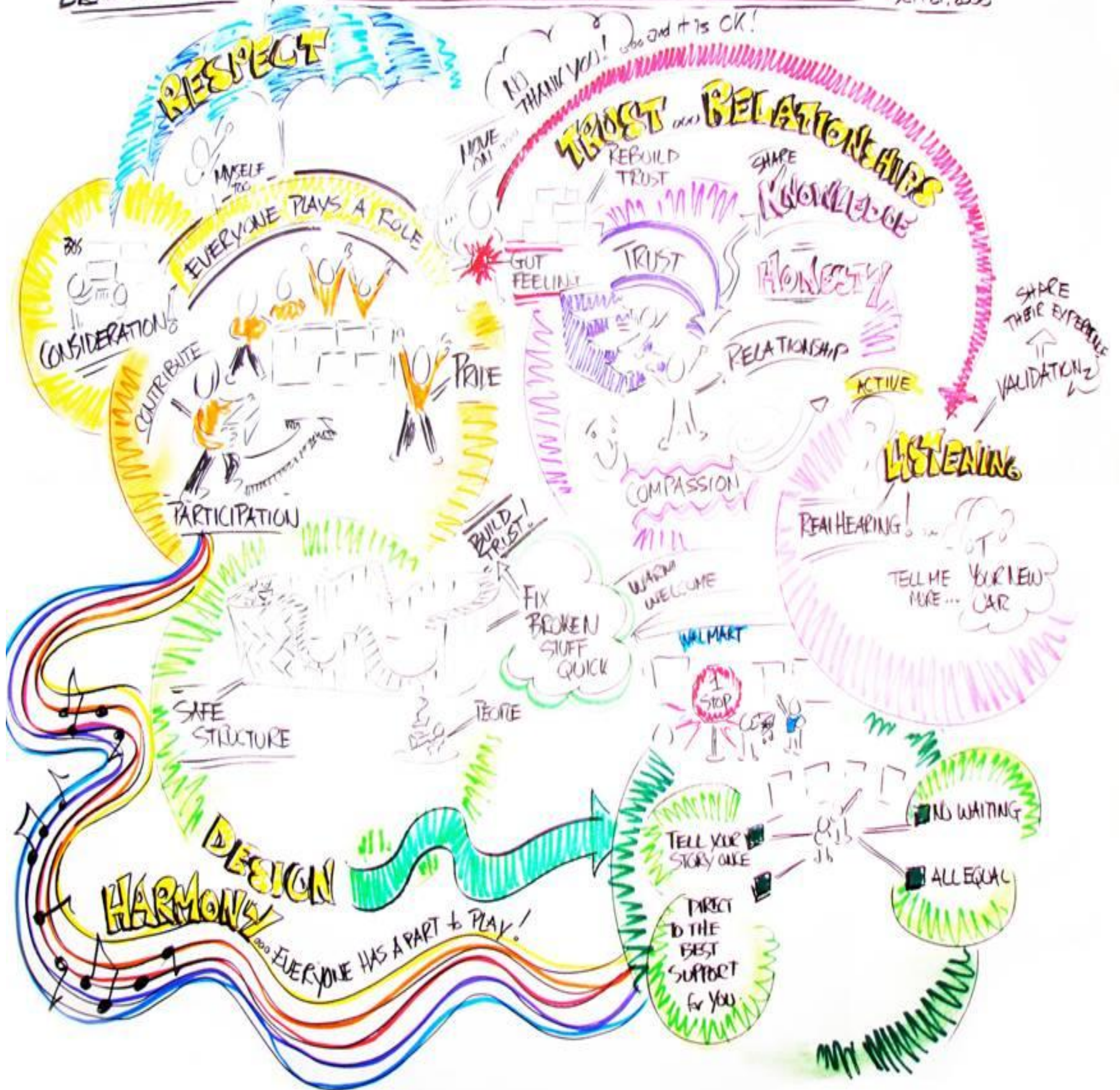

NORTHERN ONTARIO LIVED EXPERIENCE

MOHLTC 10-year Strategy FOCUS GROUP CONSULTATION SESSIONS

January & February 2010

A Collaboration between Consumer Survivor Leads- North East & North West LHIN areas and the Centre for Addiction and Mental Health (CAMH)

Cover Image: A Decade in the Making 10th Annual Consumer & Family Conference (Kenora, Ontario- September 21, 2008)

Creator: **David Hasbury** **www.cocreation.ca**

For a lot of people there are many small "bottoms" along the way to the big crash, before addiction sets in, before the suicide attempts, but instead of offering help at those points, the system says we can't do anything for [you] because you're not bad enough, sad enough, mad enough, in enough pain, you don't qualify for help because you're not destitute, you haven't lost everything. Why must I wait to lose everything, if I can feel myself losing control and can speak out about it? Why does it have to go to the level of psychotic episodes where I'm threatening a life? If a person comes in with a small cut that's bleeding, you bandage it right away. You don't say wait until gangrene sets in. I think there needs to be clearer guidelines about early warning signs, depression, dissatisfaction, fatigue, increased anxiety, losses (job, deaths, friends) and better support at that level. There are already many support groups in place, make more referrals to them, have contact people who can accompany those in need. Sometimes it is the opposite, if someone comes in with way too many activities, they are trying to fill a void and avoid facing something. Something is off; something is not balanced.

Listen to Our Voices…

Hear Our Priorities………

Determinants of Health & Person-Centred Care

Housing, Income, Transportation, Safety
Sense of Belonging; Purpose; Accomplishment, Self-Determination

A safety net with fairly open criteria a place where you don't have to be "raped by a boyfriend" or you "must be drinking and not in early recovery", housing with a focus on getting you in a place of your own and contributing to society, so it's not just about not drinking, it's about finding a job, or applying to school, it's counseling about depression, but also help nutrition, not just an apartment building where there's a hall and people gather sometimes, but a program that helps you figure out how to gather with people and socialize; a place where you have pets and where there is a fair bit of flexibility, but you are still accountable to someone and a system with a code of behaviors

More training on the holistic approach for Service providers - hard to get well and stay well, when I am homeless, hungry, feeling alone, feeling worthless and helpless. Tired of being told to just take meds and all will be ok, when there is no home, food or clean clothes.

Women recommended increasing and implementing a number of services to build community resilience, including: warm lines programs, mental health first aid, including child care in support programs, and improving follow-up care. They also identified a number of policy improvements which would help foster community resilience, including: taking a strengths-based approach, supporting Aboriginal self-determination, and allowing communities to define what "at risk" means to them.

A type of work that allows the individual to feel productive, whether they earn money at it or not

From my experience with the Eating Disorders Clinic – asking too big changes, too quickly and high expectation, I felt like a failure; I felt pressured because we only had a very limited number of counseling sessions and it was extremely difficult to implement the changes alone.

A person-centred system was considered a significant upgrade, and women supported the direction's notions of diversity and focus on harm reduction. In order to meet people on their terms, women suggested developing ways of including families in treatment and engaging agencies in policy development because they are very familiar with client needs. Finally, improving access means more than getting women through the door; creating more women-only services will increase the acceptability of many services, and decrease treatment barriers for women.

Follow up meetings or phone calls after discharge

Despite Canada's reputation as a leader in health promotion and population health, implementation of public policies in support of the social determinants of health has been inadequate. The continuing presence of income, housing and food insecurity reflects the failure to address child and family poverty, discrimination against women and Aboriginal groups, and most recently the crisis of homelessness and housing insecurity.

Empathy and education in the community, better understanding, dealing with prejudice

Community health promotion (fitness, nutrition, community activities etc…)

More personalized control of care

Housing

Too many consumers lack adequate, safe and affordable housing. A home is more than just four walls and a roof. It's a whole life situation that means being welcomed into a safe, secure and dignified place to live; healthy, nurturing relationships; the opportunity for education, meaningful work for reasonable pay; and to worship, dream and play in vibrant community. Housing initiatives need to take these values into account, and aim at creating far more than "affordable" space.

If you are in crisis without children, it will take 1 year or more to be considered for housing…

24 hour emergency housing or shelters; transitional housing

MOHLTC policy establishes that the mh system is person-centered and the person has the right to choose their own treatment plan. An individual becomes homeless in order to exercise their right to choose their own treatment plan. (It's easier to dodge the providers if the individual is homeless).This leads to new set of overwhelming issues, a sense of hopelessness, and crisis. The prescribed treatment for this individual is usually a lengthy hospitalization (1-3 months) and enforced medication. This time a CSI referred the individual to a psychiatric crisis unit for a 4 night stay. The individual stabilized and found housing, as per their personal choice. The financial savings are astounding, 1-3 months of hospitalization versus 4 nights in a crisis unit. The benefits to the individual are inestimable.

Housing must be affordable, up to standard, and, in some cases, supportive in order to meet the needs of tenants with complex issues

Income

Poverty can be a greater contributor to social exclusion than a mental health diagnosis. Poverty prevents individuals and families from bettering their lives. An individual can be symptom free and yet still excluded from educational opportunities, employment and recreational activities that most Canadians enjoy because they lack money to buy healthy foods, new clothes, get a stylish haircut, pay for childcare, or any of the many factors that permit others to live well.

Working with the employer. If someone is trying to make changes and they have a high stress job, it's very difficult. I would have needed an advocate to help me negotiate concessions with my employer and teach me about setting healthy boundaries

Enough money to pay for rent, heat, and eat well (healthy)

Lack of prescriptions and eye glasses that were covered

Housing and income emerged as major foci for participants. They were pleased that the Direction mentioned the need for safe and affordable housing…. However, participants strongly felt that the current housing and income situation is inadequate and wanted more tangible direction regarding how to make significant improvements in these areas. They suggested policy improvements such as increasing social support and housing supplements. They also provided a number of service suggestions, building on programs that are proven to help women and men heal…

Being financially able to get my meds as prescribed; not all prescribed meds are covered on drug cards.

Make dental, prescriptions etc more affordable for people with a low income

Increase list of medications covered on drug cards

Learning to live best on a low income

Transportation

Transportation (there are hardly any bus routes left in Kenora, but some communities have no public transportation)

Transportation provided to appointments etc…

Meeting people on their terms means helping clients overcome geographical and language barriers by providing more local services, better transportation, childcare services, and expand the types of language services are offered in.

Organizations could provide transportation or bring back the town bus

Stigma

Educating doctors, nurses, police people about the nature of these diseases. We don’t hit people, shoot people, try to kill ourselves because we want attention or we’re trying to make their lives difficult or because we’re dumb. They are no better than us, and they also think they are invulnerable; they could just as easily end up in our place.

… sensitivity of health-care and other front-line workers to issues of mental illness is a common issue. There exists mental illness stigma and discrimination amongst front-line workers and primary-care physicians alike that acts as an impediment to early intervention. There is a strong need to enhance the knowledge of health-care workers and gatekeepers (e.g., child welfare workers, police officers, guidance counselors, and frontline staff) about mental illness and its treatment.

more doctors and psychiatrists with sensitivity around mental illness

Stigma is a significant issue for women with mental illness and addictions. Women face greater stigma with regards to these issues than men and this also increases when women are members of other marginalized groups based on sexuality, race, class and dis/ability. Eliminating stigma and self-stigma is a worthwhile effort, although participants were concerned that it be done in a way that would not further stigmatize or label women, particularly women of colour who already experience discrimination based on their race and gender.

Addressing the stigmas and lack of public knowledge about the different areas of mental illness and addictions with more publicity, better outreach, through the arts (TV shows or sitcoms like Seinfeld, theatre productions, meet the celebrity [Margaret Trudeau's work], children's story books, comic strips)

Early Identification & Early Intervention

Enhancing our ability to bring education into the schools

Presenting such programs as the Tami Project

Reduce stigma by funding recovery education and promoting both important philosophies: "Nothing about us without us", and "There is no health without mental health"

School officials are afraid to open the curriculum to education about addictions and, especially, mental health. Addressing this fear starts with targeting school and boards of education administrators, to promote positive messages about mental health

Again, ideas relating to education and stigma reduction centre around community education campaigns, health fairs, conventions, and conferences

System Design

Inclusion in system design involves participation at all levels and all stages of planning and implementation, from inception to evaluation, [better time frames] instead of occurring as an afterthought.

Inclusion requires the opportunity for consumer/survivors to network with experienced mental health decision makers as well as with other consumer advocates and to have access to training and education on services options and administrative processes.

Few, if any, consumers will come to the table already familiar with the professional language of health systems design. Terms and acronyms can be learned, but at least initially, documents and questions need to be in laymen's language so all consumers can understand the questions and respond.

Work to eliminate long waiting lists for programs and services; hire nurse practitioners and other professionals who can take over some of the work physicians do now in order to free up their time for high level physical and mental health treatment and care.

There are ways to better orient mental health systems to help consumers in their journeys through the recovery process. Consumers benefit when mental health system planners understand the vision, philosophy, values, and procedures necessary to ensure the full inclusion of consumer/survivors. A recovery-oriented mental health system acknowledges and encourages consumer involvement and decision-making. Furthermore, a recovery-oriented mental system is structured in ways that support consumers in their journeys of recovery.

Support must come from all political parties, i.e., programs that are implemented by one administration should not be at risk of change or elimination by a new government after an election

Timely/complete medical workup

Knowledgeable Primary Care giver is vital for diagnosis and treatment

So much information is gathered for "reporting" purposes and does not necessarily affect the outcome for the consumer

Consumers and family members are left "in the dark" due to processes that are little understood or agreed to

Family members able to participate by providing their input to broaden the understanding of needs

Unlike shopping, the consumer does not get to choose the service, it chooses them

Peer Support

Nothing about us without us - Support the implementation of Peer Support training and train-the-trainers programs across the province. Consumers can and should train and support their peers, other mental health providers and provide peer support. Act on the many recommendations from Task Force Reports that say lived experience is a valuable and respected resource.

Having peer support available to assist people with addictions and/or mental health problems – stops the people from feeling all alone and offers hope with knowledge

A sort of tourist guide for leisure activities who can help get you connected to people of like interests; someone whose job it is to know the groups in town and help you find what you're looking for and for the various agencies to be connected to that hub. So if you are coming out of treatment, or you went through crisis intervention or you intersected with the system at any point, you have that contact – essentially multidisciplinary people who can help in many areas of life, a life coach

Have a safety plan made and places that can help when in trouble

An easy to understand chart of services available; walking into the system, I can't get a global picture unless I hit many entry points

Have a list of phone numbers (that people in recovery are willing to give) for peer support for people struggling or new to Sudbury

All costs related to equal partnerships and decision-making should be covered by agency and project funders; peer support deserves to be a paid position

Educating family members to work with sick family members

Ontario Peer Development Initiative (OPDI) position is strongly supported by those with Lived Experience re: Peer Support employment (attached to submission)

Service Coordination

Importance of any door being the right door...each door will get you what you need the first time and every subsequent time- every first door is the right door!

Agencies need to be more in sync with each other to provide effectively for consumers

The possibility of inviting the different professionals who have worked my case to meet together with me to discuss future steps. Eliminate going over the same area with different people and eliminate the confusion of having too many areas (spiritual, mental, physical, social, self, etc.) being changed or worked over by different people at the same time

Lack of communication between agencies

….women want more attention to be paid to addictions. Do justice to both mental illness and addictions without assimilating one to the other and, in so doing, leaving addictions on the back burner.

Planning with home community supports (i.e. housing, ODSP, etc…) when approaching hospital discharge

One assessment and then directed to the service that would be able to help, instead of being told that they don't provide that, but not helped to find the one that will provide it.

Service providers that know what all the services are and can direct [people] appropriately. This is not just for mental health, but overall health, like housing, and specialized services.

Everyone involved needs to be aware of what is available and who is involved and what they do and what they provide

Lack of access to primary health care in Northwestern Ontario hampers access to programs, services and, sometimes, life saving treatment. Too many consumers must rely on walk-in clinics and the hospital Emergency Department. Those without a family doctor may have difficulty getting prescriptions renewed. Physicians without knowledge of a patient's history may be understandably reluctant to provide medications they may not realize a person requires. And consumers are not always treated with respect by overwhelmed health professionals. Stigma leads many nurses and doctors to dismiss the genuine health needs of people with mental health issues as hypochonria and/or malingering.

Priority is for one point of entry; common assessment is needed; build on the strengths of the OCAN pilot rollout; need to address inclusion of addictions; CSIs needs and experiences and concerns with the current North East LHIN implementation need to be listened to. NW LHIN CSIs are looking forward to a Common assessment and potential of this being realized through OCAN.

Staff & Staff Development

Dumb down the terminology; I need a guide at the outset of what are the different broad categories of medications, broad categories of treatment available (cognitive and whatsits) and what are some of the most common theories of why mental health issues happen, when I cut myself or get a black eye or a burn, I know what to do. When I feel fear, anxiety, out of control and have suicidal thoughts, or the “what’s wrong with me? I should be able to…” or “this used to be easy and now I cannot start”>

Better informed G.P's - doctors and nurses need to be better educated about mental illness

They were pleased that there is recognition that the workforce needs more training and support to prevent burnout and ensure that high quality care is provided. Volunteers are an important and value added element of the workforce, however women felt that this valuable work ought to be paid. Women also felt that this focus on increasing the capacity of the workforce provides an excellent opportunity to train existing workers and trainees on important but often overlooked areas such as trauma and addictions.

More education around recovery and the holistic approach

Hospital emergency and crisis intervention need to be more helpful and less judgemental towards addicts/alcoholics

Family and Child Services and Weechi - More education on mental illness and resources

Stricter application qualifications for the staff

Board training for consumer/survivors interested in becoming board members or who are currently on Boards; a lot of Board members have many years of tenure...this is a benefit/challenge....sometimes it is difficult to recruit someone to replace them on Board ie. read financial statements; scope of influence and responsibility of board members

Some agencies don't have training budgets...there is interest but no funds to access new/emerging practices; also, lack of staff ie. only 1 staff per organization- if participate in training, need to close office; smaller/remote communities even have an enhanced difficulty ie. travel time to training and accessibility of training- could mean closing agency for several days.

Great upcoming resource: Peer Support Toolkit

Funding

Continued and increased funding across the mental health and addiction sector, including adequate and equitable funding of CSIs and Peer Support

Funding for projects such as Tami [Talking About Mental Illness]

Undo the cuts to social assistance implemented by Premier Harris in the mid-1990s. Provide an immediate, substantial raise in social assistance rates that gives back the money the government took and then increase it, (retroactively and indexed to inflation) based on cost of living increases.

Northern Ontario Lived Experience
MOHLTC 10 year Mental Health and Addictions Strategy Consultations

Gathering the Voices of Lived Experience

- 8 Focus Groups were held January & February 2010
- Individual Responses were gathered January & February 2010
- Inclusion of voices from a Focus Group held in Fort Frances June 2009
- Inclusion of Nipissing Family Program Focus Group held September 2009
- Inclusion of women's voices from Focus Group facilitated by ECHO in Sudbury, Fall 2009 re: MOHLTC: Every Door is the Right Door framework. At least 75% of the women represented those with lived mental health and addictions experience
- Of the consultation sessions, 2 Addictions specific Agencies (3 focus groups & individual responses)
- Virtual focus groups: although there were 4 session time set up via Adobe Connect (evening and weekend time for each LHIN) there were no participants * see learnings

Focus Group Submissions from the following Participating Partners:

Reflects the voices of at least 170 Northern Ontarians with Lived Experience

- Iris Recovery Home for Women— Sudbury
- Changes Recovery Homes: Del-Art Men's Residence— Kenora
- CMHA Fort Frances
- People Advocating for Change through Empowerment- Thunder Bay
- Sunset Country Psychiatric Survivors – Dryden
- Sunset Country Psychiatric Survivors- Kenora
- Sunset Country Psychiatric Survivors- Fort Frances
- ECHO Women's Every Door is the Right Door Consult-Sudbury
- Nipissing Family Program—North Bay

Learnings & Future Recommendations:

- **Mental Health & Addictions Sector partners; Ministries and LHINs need to ensure that all future consultation processes have dedicated opportunities to 'gather the voices of lived experience'**

- **Organizers need to allow for sufficient lead time. Several months would be recommended (even more time if it is during busy time periods). For this consultation process in Northern Ontario, we proactively sought approval to conduct these consultations with the desire to forward the submission by the end of January to the MOHLTC. Planning took place in late December. The consultation sessions took place in January & early February. In reflecting on our lessons learned, this time period wasn't ideal for a number of reasons therefore, the number of consultations was less than what we would have liked. There was very high interest in participating in the focus groups within communities, however, the resources and timing limited these opportunities. We know that future opportunities will significantly build on the success of this initial consultation process. Overall, we are pleased with this foundational level of engagement but are even more encouraged that future consultations will significantly reflect a greater number of voices.**

- **Virtual technology was attempted to expand the timing of participation ie. weekend and evenings as well as in an attempt to reach rural and remote participants. In the future, we will provide more detailed information and enhance our attention to publicizing this emerging venue for gathering the voices of lived experience**

Final Thoughts from Maria, Krista and Christine

We began this collaborative journey with hopes of gathering the voices of lived experience in Northern Ontario to guide the Ministry's 10 year strategy. The three of us developed a relationship; a vision and a plan. Our hopes have been realized beyond expectations and we are extremely happy to provide a platform for the Northern Ontario voices of Lived Experience to be heard. This submission will be used for our individual and collaborative planning efforts. The draft version was circulated for review by some who had participated in sessions as well as those beyond…there was a resounding validation of the voices and there is a great level of anticipation for the final version to be shared and used within the mental health and addictions planning community.

We urge you to 'listen' to these voices as a beginning to all of your discussions related to the 10 year strategy and inter-ministerial planning.