Being Present with the Past: Transforming the Future of Community Mental Health
Final Report March 2018

Background

On Monday, January 12th, 2018 a unique two-part event was held for individuals with lived, professional, and research experience in the field of mental health mental health in Vancouver. A private viewing of the multi-media living history exhibit *Mad City: Legacies of the MPA**, Canada's first survivor-led mental health organization, was followed by a post-exhibit guided discussion to envision new possibilities in Vancouver's current community mental health context.

Growing awareness about mental health, increased federal funding, and a new provincial ministry dedicated to addressing mental health and substance use signals prospects for positive change that did not exist in mental health a decade ago. Taking this as a moment of opportunity, the dialogue at *Being Present with the Past: Transforming the Future of Community Mental Health* aimed to generate concrete ideas and best principles for building a more democratic and socially just community mental health system.

Using the lens of the radical and groundbreaking Mental Patients' Association, the *Mad City* exhibit walked visitors back into the 1970s for a look at Vancouver's roots in community mental health. *Mad City* featured the narratives of those who established the MPA, celebrating their vision, spiritedness, and unique contributions to creating and running meaningful services for and by people with lived experience. *Being Present with the Past* challenged participants to consider how the egalitarian values, novel ideas, and path-breaking programs of a project from forty years ago might be applied to present-day Vancouver, where poverty, homelessness, mental health problems and high death rates from substance use create unjust social and health inequities.

Participants

Invitations to participate in *Being Present with the Past* went out to 35 mental health practitioners, people with lived experience, researchers, funders and policy decision makers in Vancouver. There was an effort to ensure representation from a wide range of sectors in mental health including organizations that have a high level of participation or take direction from people with lived experience. 30 people attended.

World Café Dialogue

The event was held from 4:30-7:00 pm and began with a viewing of the exhibit and was then followed by a facilitated World Café style dialogue. After a short introduction and an "ice-breaker" exercise, participants were assigned to dialogue groups that brought individuals from

different sectors (policy, research, practice, lived experience) into conversation. There were five groups in total, each with a notetaker to record the proceedings and a facilitator from the research team to steer discussion through four questions. We then reconvened as a large group to discuss the key issues arising from the discussion. Below, we provide a summary of participant group responses to the exhibit, followed by a detailed account of the discussion relating to the four questions that guided the dialogue.

Responses to the Exhibit

Noting the powerful effect that the photographs in the exhibit had on them, participants acknowledged the strong sense of community and humanity at MPA. Exhibit content also brought forward the conviction that social activism and alternatives in mental health are possible. Participants enjoyed the humour and appreciated the quotations, writing and narratives of MPA members featured in *Mad City*, understanding the group's capacity for fostering expressions of resilience as a powerful force in an era when the voices of people leaving psychiatric institutions were likely not heard. As connections were made between the past and the present, participants commented on the lack of democracy and autonomy in the current mental health system for people with lived experience and noted that stigma was still very much present. The overarching message was that much work has yet to be accomplished and that success hinges on fostering deeper alliances between healthcare workers, politicians and policy decision makers who are committed to a paradigm shift in mental health through policy and practice.

1) If we took a leaf from the MPA book what changes could be made to the current approaches in community mental health?
    - What could be the first steps towards building equity, diversity and justice into the foundations of community mental health?

For many participants the story of the MPA brought out a kind of nostalgia for the social activism of the 70s where there was a space to make radical changes to the system. At the same time, it was recognized that applying specific MPA practices today would not work because so much has changed. A theme running through the discussion generated by this question was the need for mental health services that demonstrate respect for people's rights, provide them with choices and value non-medical approaches, such as is currently found in child-birth, cancer treatment and pain management. Participants called for more citizen engagement, an egalitarian model, and less emphasis on symptom management through medication. The biomedical focus of the existing system (and the fact that most resources go to hospitals) and its disconnect from larger conversations about health promotion and community health was discussed. Underlying this was a questioning of the kinds of evidence that have been used to develop the current mental health care system – that is, evidence from biomedical/clinical approaches has been favored over lived experience, Indigenous healing

perspectives and frameworks arising from non-Western cultures and the experiences of immigrants and refugees. Thus, there was an emphasis on person-centred, community-based approaches that involve representation of the diversity of communities and perspectives, over current approaches that were often experienced as dehumanizing and silencing. Attention was given to the power of language and how it can reflect hierarchies in the mental health system and reinforce stigma and thus make services difficult to access. Systemic changes in mental health were thought to require a paradigm shift, which would in turn foster open dialogue, place social justice at the core, and move toward a bigger focus on social supports.

In this discussion concrete suggestions for how change could occur were offered. Lived experiences and people's stories should be recognized as critical elements of the mental health evidence base and employed in policy formation. Organizations and approaches that have pioneered (and built on the MPA model) were also held up as exemplars (e.g., VANDU, Insite, Gallery Gachet, Housing First, the Warm Line) but it was noted that the good work of these organizations is undermined because they do not receive core funding and are tied to accountability structures that value numbers of people served over quality of engagement. It was suggested that funding structures need to change. Participants also spoke about the need for building peer support into the system in ways that values this work and its impact. Additionally, the provision of services that help people reduce or cease using psychiatric drugs was discussed. Others spoke about the impact of stigma and the challenge of educating the public and better involving families in care and support. Further suggestions included making more transitional housing available and changing housing policies so that they are not tied to medication compliance.

2) When and how do we currently recognize lived experience as a legitimate form of knowledge? How can we integrate these knowledges more purposively and meaningfully and what resources are needed to accomplish this? (15-20)

Participants noted that lived experience is beginning to be recognized as an important component of the mental health system (e.g., peer navigators and support through paid positions) but is still undervalued as expressed in the lower wages of peer workers and the continuing stigma in the mental health system itself. Participants commented on the term 'lived experience' with some arguing that this language is academic and does not reflect the community. A lot of concern was expressed about the way in which peer support is being co-opted (or expressed through tokenism) by mainstream mental health and thus losing its grassroots connection. It was suggested that government and policy support should be put behind autonomous well-funded peer support. Alongside this thread was a discussion about how 'lived experience' should be understood as valuable in and of itself – that it does not just need to be integrated with other forms of knowledge. Additionally, mechanisms and support for involving people with lived experience in policy discussions is required. Celebrating lived experience through arts and culture and positive images of resilience and empowerment were also acknowledged as important.

3) What unique opportunities are presenting themselves right now to influence the future of community mental health? (15-20)

Current initiatives that are promising for the future of mental health are programs such as the three-day knowledge translation training (SPARK), street-degree (community-based learning), peer navigation programs and the adoption of Housing First models. Disability Rights Promotion International (DPRI), a disability rights monitoring project housed at York University, monitors the human rights of people with disabilities and works towards holding organizations and governments accountable. The DTES Second Generation Strategy is creating centralized hubs for a variety of supports. Another positive that was noted is that with the change in government there is more openness for discussion and a new Ministry of Mental Health and Substance Use that will raise the profile of mental health. The government initiated Poverty Reduction Strategy consultations, that are getting underway, were presented as a key opportunity to discuss mental health as it connects with poverty, trauma and homelessness. Some participants also spoke about how diversity and non-western approaches to mental health are an opportunity to think about things differently.

Participants saw opportunity in the growth of mental health literacy and the use of social media to help people have conversations in ways that feel safe. Schools are also increasingly paying more attention to wellness, mental health and the rise in youth anxiety. Initiatives through the arts, such as Gallery Gachet and the Mad Pride festival, are examples of influential movements working towards community mental health. Finally, participants noted the paradox of how tragedy can open doors to opportunity, such the current opioid crisis resulting in new funding streams and initiatives. One participant noted "We're at the forefront of change. There's more of a voice". Overall, the sentiment was that there should be a collective effort towards *humanizing* the system.

4) Whose voices do we need to add to this conversation? How can we continue and/or extend this conversation?

Participants stressed that the voices of those with lived experience as well as front-line service providers must be included in community and government level dialogue about, and planning for, a more democratic and social just community mental health system. This cannot be intermittent or one-time consultation, but needs to be regarded as an essential part of crafting effective and humane policy (with compensation) as is now seen as best practice with Indigenous people. Social movements are transformative and powerful, and while it is encouraging that the academe is attending to the grassroots voice, the state must do the same. Additionally, some participants thought having a provincial mental health advocate (independent from government) would help to ensure that the system respected people's rights.

Moving forward in this conversation toward the goals articulated in *Mad City*, participants noted that it is important to change the biomedical language surrounding "mental health" and

embrace culturally safe practices. Examining treatment through alternative lenses will shift the focus away from the biomedical model to a more inclusive system that addresses the social determinants of mental health. Funding bodies should be encouraged to offer grassroots organizations greater autonomy and reduce funding-directed restrictions on programming delivery and evaluation. The benefits of peer navigation as an integral part of treatment must be acknowledged, and lived experience must be recognized as a voice of authority and given merit in funding and grant programs. Employing mechanisms to ensure accountability for the meaningful participation of people with lived experience could be instrumental in mobilizing a paradigm shift in mental health. One participant noted that the new Ministry of Mental Health and Addictions has acknowledged front-line workers and favoured meetings with these individuals over organizational leads. This approach to connecting with those who are handling crises first hand might be one salient example that positive changes are happening in community mental health. As one participant exclaimed: "It's an exciting time to be in Vancouver."

Next Steps:

At the conclusion of the event no immediate next steps were identified, however, people indicated that they had found it useful to have a space to engage in dialogue that focused on building a more democratic and socially just community mental health system.

**Mad City: Legacies of the MPA* ran at the Gallery Gachet from January 12- February 23, 2018. The activities associated with the exhibit were supported by the Social Sciences and Humanities Research Council (SSHRC), Canadian Institutes of Health Research (CIHR), Robarts Centre for Canadian Studies (York University), Faculty of Liberal Arts and Professional Studies and Faculty of Health York University and Simon Fraser University. The material resulting from the project will be examined with an aim to understanding how socially engaged research projects can support enhanced individual and community capacity for reducing the stigma related to mental illness and maintain mental wellness.