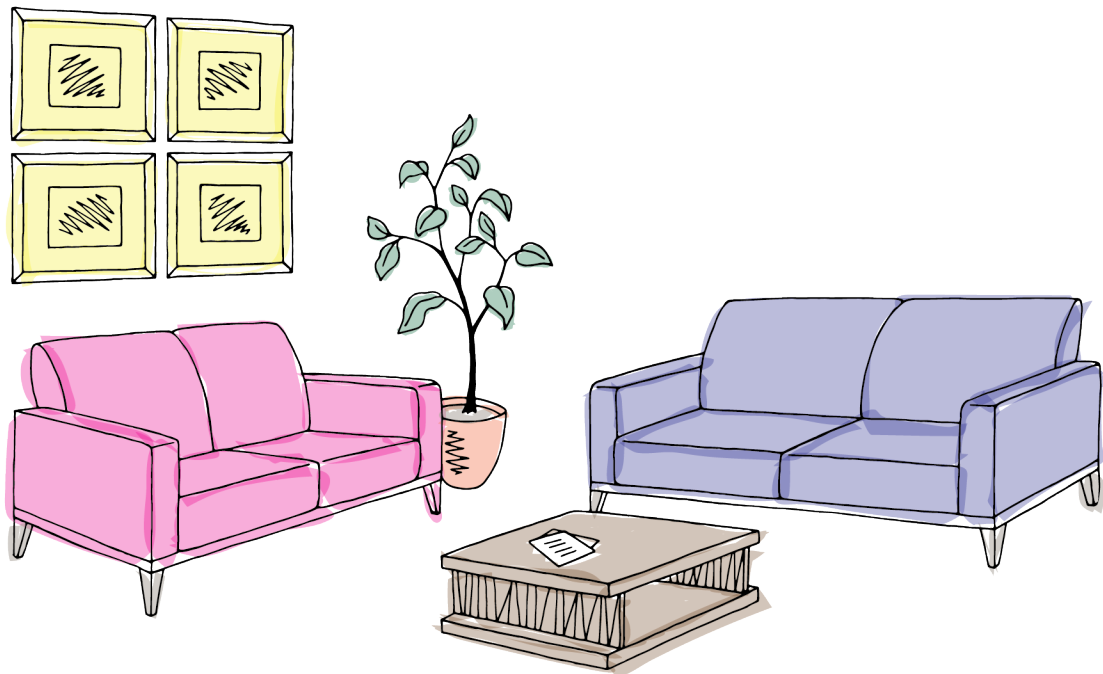# More than Paint Colours

Dialogue about Power and Process in Patient Engagement

for InSight, Advisory to Pillar 4
Julie Devaney, Lucy Costa, Priya Raju

TABLE OF CONTENTS

ACKNOWLEDGMENTS

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CONTEXT

Engaging patients in health care decision making can mean anything from collaborating on treatment plans, to designing waiting areas, to service users[1] creating core policies for hospitals and medical schools. In the past five years, the Department of Psychiatry at the University of Toronto has begun the early stages of collaborating with service users in the production of curriculum, the training of staff[2] and residents, policy development, and admissions. Much of this work has happened under the umbrella of "Pillar Four," part of a series of goals set out by the department as part of their Strategic Plan in 2012.[3] Pillar Four objectives include: addressing stigma, developing advocacy work for social responsibility, and increasing community and consumer input in departmental education.

InSight, a committee comprised of critical community stakeholder organizations[4] and a representative of the department, was formed to provide advice and feedback to Pillar Four activities. Co-chairs Lucy Costa of the Empowerment Council at CAMH and Dr. Priya Raju, along with other members of InSight, have collaborated with the Department of Psychiatry combining critical reflection with an extensive history of consultation on psychiatric education and practices. InSight's collective values are informed by history:

> Psychiatric service users have been working with hospitals, universities, community organizations and government administrations to improve practices and public policies for almost four decades both locally and internationally. Mental health consumer/survivors have also been an influential force in promoting the current evolution in mental health recovery work, drawing from personal experiences, social justice, and human rights. For example, the first recovery conference in Toronto was organized by a consumer/survivor group in 2002.[5]

In this report, we reflect on our own process in the development and work of InSight and in the creation of a collaboratively designed curriculum in the course, "Centering Madness." The course launched with its first group of residents in July 2017 during a pilot for competency-based education in psychiatry. In discussions with five psychiatrists and one psychologist who are currently working with service users on various initiatives in the department, we explore the strengths and challenges of Pillar Four's "Dialogue" mandate and draw from recent experiences of patient engagement. We focused on speaking with

> "While we respect and endorse any level of participation and decision-making that service users choose to undertake, we want to highlight the potential for service users to positively colour institutional practices beyond aesthetics."

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[1]   We are using the term 'patient engagement' for clarity and to address this current trend in health care research and delivery, but will be referring to consumers of psychiatric care as 'service users' throughout the report.

[2]   Kidd S, McKenzie K, Collins A, Clark C, Costa L, Mihalakakos G, et al. "Advancing the recovery orientation of hospital care through staff engagement with former clients of inpatient units." Psychiatric services. 65 no. 2 (2014): 221–5.

[3]   Pillar Four: Dialogue Committee, Department of Psychiatry at the University of Toronto. http://www.psychiatry.utoronto.ca/about/strategic-plan/pillar-4/

[4]   While not all of these stakeholder organizations represent service user communities (some represent anti-racism and family interests), all are aligned with the principles of service user leadership in psychiatry.

[5]   InSight "Values Statement." See: Appendix I (2014).

staff members about their experiences and impressions with an eye to identifying gaps in knowledge and areas in which resources could be better directed to support service user inclusion in departmental mandates. In one of these conversations, a staff member commented on the ways patients engage in health care institutions outside of psychiatry, referring specifically to cancer patients who have physically transformed clinical spaces through choosing paint colours. While we respect and endorse any level of participation and decision-making that service users choose to undertake, we want to highlight the potential for service users to positively colour institutional practices beyond aesthetics. At the same time, we discuss how this potential can be limited by challenging dynamics that emerge when staff and service users work collaboratively as equals. In particular, when service users take leadership in collaborative initiatives, this dynamic can intensify. As such, in the final sections, we offer insights regarding staff learning needs with recommendations for future directions.
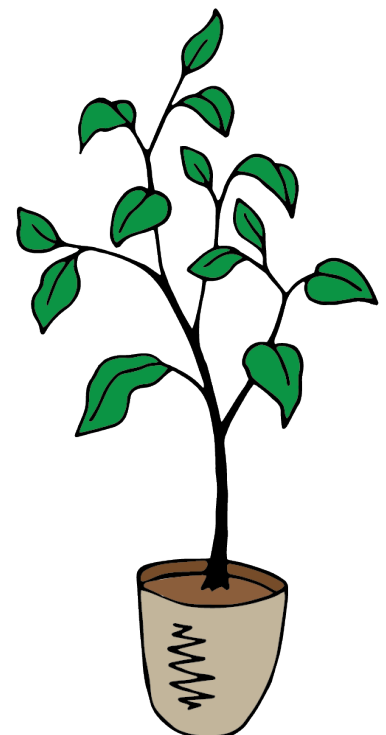
FIVE QUESTIONS TO ASSESS QUALITY OF PATIENT ENGAGEMENT

In grappling with the challenges of acknowledging the power imbalance in the relationship between service users and health care professionals, we reflected on the rewards and difficulties of working on common projects with shared goals while holding different institutional interests. Over many decades, Community Based Research (CBR) practices have systematically addressed these issues. In particular, Indigenous community members and scholars have provided leadership on how to engage in such work responsibly. In the 2009 document, *Ethics in First Nations Research*, the Assembly for First Nations (AFN) highlights the following principles: sharing power from the inception of the project, respecting Indigenous knowledge throughout, honouring the intellectual property and labour of participants in the knowledge exchange process and by providing compensation for participation.[6]

Similar ethics are identified using CBR for mental health research in a report launched in Toronto in March of 2017, *Key Practices for Community Engagement in Research on Mental Health or Substance Use.* Researchers forefront the history of such collaborations:

> As a consequence of the past abuses of the power held by academic researchers many communities approach research and researchers with distrust. In CBR, researchers attempt to address this by working with communities to share power over the research process and results; that is, in ensuring that communities have an equal role in all decision making about the research process and outcomes. As a result of the attention to power in the research process, CBR approaches may be particularly valuable to work with communities which have experienced oppression or marginalization.[7]

Rather than reinventing existing practices, our intention is to apply the principles of power-sharing established by equity-driven collaborative research generally and service user involvement in mental health decision-making specifically[8] to the work currently being undertaken in the department. We acknowledge that service users as a group do not share the same history of colonialism that Indigenous communities are addressing. We are grateful for the leadership offered by AFN's ethical research principles as they have been an important guidepost in our analysis.

InSight offers the questions we developed through synthesizing these literatures with our own observations about collaborations between professionals and service users:

> *Were service users included at planning stage?*
>
> *Who does preliminary research to set up ground rules and context?*
>
> *Who manages the budget and decides how funds are allotted?*
>
> *When service users are engaged do they shape day-to-day decisions and outcomes?*
>
> *Are measures in place to assess and ensure accountability?*

6   Assembly of First Nations Environmental Stewardship Unit *Ethics in First Nations Research*. http://www.afn.ca/uploads/files/rp-research_ethics_final.pdf (March 2009).

7   Ross, L. et al. *Key Practices for Community Engagement in Research on Mental Health or Substance Use*. http://lgbtqhealth.ca/projects/docs/practicesforresearchonmhandsu.pdf (2017).

8   Rose, D., Fleischmann, P., Tonkiss, F., Campbell, P. and Wykes, T. *User and Carer Involvement in Change Management in a Mental Health Context: Review of The Literature*. (London: Natural Co-ordinating Centre for NHS Service Delivery and Organization Research and Development, 2002).

PROCESS AND POWER

These five questions provide a basic starting point to address the ethics and efficacy of collaborations between professionals and service users. More than that, they offer an opportunity to create the kind of dialogue about power and process that is necessary to build strong relationships. When those who have traditionally held power in health care are seeking the insight and labour of those who have been marginalized, whether through peer-support initiatives[9] or collaborative projects, self-interrogation and negotiation are required. Asking these questions has shaped our analysis of the strengths and challenges of efforts to engage service users under Pillar Four's Dialogue mandate.

In the first two questions, we address process. When service users are engaged at the very beginning, the potential for effective collaboration increases. There is a qualitative difference between inviting participation on existing projects where the ground rules and context are predetermined, and beginning an open discussion of what type of project would be useful in meeting the goals and needs of both service users and professionals *before* any decisions are made. When initial discussions are authentically collaborative, everyone's needs are taken into account, and process and goals can be mutually agreed upon.

The next two questions speak to power. Whether the project's inception involved service users sufficiently or not, transparency and collaboration in finances and decision-making are essential to appropriately share power. When a project is funded, through grants or departmental budgets, service users need to be involved in determining financial priorities and determining how money is allocated. The day-to-day management of projects requires detailed planning to ensure that service users' ideas and opinions are not negated. Often, this negation happens unconsciously and without intention, simply for administrative convenience and to ensure the smooth running of operations. Nonetheless, small decisions are sites of power that can be as significant in determining outcomes and the quality of relationships as big budget issues.

We end with the question of accountability, which fundamentally informs necessary dialogue at every level. Collaborations are difficult. Things will go wrong. Having an accountability mechanism in place builds trust and creates a context where genuine reflection can happen at regular intervals and adjustments can be made to redress missteps. Without accountability, cracks in the process can too readily be papered over in ways that lead to the deterioration of trust and the breakdown of collaborative relationships.

> "Small decisions are sites of power that can be as significant in determining outcomes and the quality of relationships as big budget issues."

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9   Voronka, J. "Turning Mad Knowledge into Affective Labor: The Case of the Peer Support Worker." *American Quarterly* 69 no. 2 (2017): 333-338.

INSIGHT AND DIALOGUE

Our dialogue about the production of this report began in April 2017. Lucy is the Deputy Executive Director and systemic advocate for the Empowerment Council at the Centre for Addictions and Mental Health (CAMH), where she has worked with and for people with psychosocial disabilities to ensure representation in psychiatry for over a decade. Priya is a psychiatrist and Assistant Professor in the Department of Psychiatry at the University of Toronto whose clinical work focuses on marginalized populations, particularly Indigenous and recent newcomer groups. In 2012, they founded InSight, Advisory to Pillar Four, and as co-chairs, invited representatives of critical stakeholder organizations to participate. In InSight's initial meetings the need for accountability was identified as central to the group's mandate. The approach was two-pronged: InSight needed to be accountable to their member organizations' constituents, and, in addition, InSight had a responsibility to enable greater accountability between the department and the broader community. Paramount to achieving such accountability was reporting observations and analysis once the five year mandate of Pillar Four was reached. To facilitate the writing of this report, Lucy and Priya invited Julie to the table. Julie is a health care advocate who has designed curriculum, and consulted on patient engagement across the country and in the US and UK. We determined that Julie would begin by sitting down with key staff members at the University of Toronto who have engaged in collaborative work with service users and asking about their experiences as well as participating in relevant meetings. We recognize that InSight itself is a collaboration, and as such, have taken some time to critically reflect on our own histories, process, and engagement with power dynamics.

> " Lucy identifies her first indication of trustworthiness in their collaboration: 'We talked about power on the first day.' "

FOUNDING OF INSIGHT: LEADERSHIP AND RELATIONSHIP-BUILDING

InSight was founded shortly after the early meetings of Pillar Four of the Department of Psychiatry's strategic plan in 2012. Priya was in attendance to observe how priorities were chosen and where her efforts would be best placed. Reflecting on her experiences as a medical resident in 2007, working on a collaborative initiative with service users called the Resident and Consumer Initiative (RACI),[10] Priya recalled service users talking about needing to be in on the ground floor. Looking around the Pillar Four meeting room and noting that everyone in attendance was from the university, she recognized the opportunity to bring organizations representing service user interests to the table.

Peer-support work is widespread both in Canada and internationally[11] and many initiatives have been happening at CAMH as well as more broadly throughout Toronto.

> Currently, principles including patient-centered care, cultural competency and diversity models, community engagement and consultation, and service user involvement are reorganizing the ways in which health and social service care are

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[10]   Reville, D. and Church, K. "Mad Activism Enters Its Fifth Decade." *Organize! Building from the Local to Global Justice* eds. Choudry, A., Hanley, J. and Schrage, E. (Toronto: Between the Lines, 2012).

[11]   Costa L. and McKee H. *Consults, Feedback, and the Future of Service User Inclusion in System Planning* (Access Point Consumer Reference Group, 2016).

delivered. In mental health service deliveries, incorporating 'people with lived experience' as workers within systems that affect us has become accepted as a 'best practice.'[12]

But while there are no shortage of service users participating in the delivery of mental health care, a critical analysis of *how* such participation happens, and organizational leadership, was necessary to create an effective advisory to Pillar Four. Priya approached Lucy with these factors in mind. It is important to note that strong collaborations are not just the meeting of two titles. They work best when people who work well together share an analysis of what they are trying to achieve. A mutual understanding of subtle and overt power dynamics and relationships is essential. Priya had seen Lucy negotiate the minefield of professional and service user committees before, so she trusted her as an effective partner in the work.

Lucy identifies her first indication of trustworthiness in their collaboration: *"We talked about power on the first day."* The person with institutional power—in this case, Priya, as a physician and faculty member in the department—was able to own her power in this context and discuss it openly. Priya's skill and willingness to negotiate this dynamic is rooted in her own history: *"Although I bear all kinds of privilege, I am also a woman who is racialized, and I have felt marginalized in certain contexts… so I am increasingly aware of the dynamics of power in my life."* In keeping with the centrality of their relationship, they wanted InSight to be distinct from accepted patient advisory group recruitment methods, where patients and family members are typically sought out for opinion based on personal experience.

Representation is a complicated and frequently contested subject across many communities internationally, and the mental health field is no exception. Often, the less power a marginalized community has, the more pressure the mainstream puts on individuals to represent their entire community; and when they cannot meet this impossible standard, their credibility is questioned.

> It appears to be a particular problem that users and carers are asked to be more 'representative' than any other group of stakeholders in the change management process. Articulate users may be criticized as unrepresentative because 'ordinary' users are often not seen as articulate. Other stakeholder groups, in contrast, will not be subject to such challenges – articulate and assertive professional and managers for instance, are not likely to be questioned as 'unrepresentative.'[13]

In this way, the demand for broad representation in service user alliances can be a barrier to collaborations, or in more extreme cases, a way that providers can silence critical voices by questioning the authenticity of service user organizations. At the same time, it is essential to note that service users are not a monolithic group. In 2008, the National Survivor User Network in the UK released the report Dancing to our Own Tunes, addressing the particular barriers that racialized service users experience in meaningfully participating in user involvement initiatives.[14] In Canada, racialized people accessing psychiatric services also experience marginalization[15] which undoubtedly creates barriers to full and equal inclusion in collaborations between service users and providers.

When we continue to factor in all forms of

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[12]   Voronka, "Turning Mad Knowledge" p 334.

[13]   Rose, D. et al., *User and Carer Involvement*.

[14]   Kalathil, J. *Dancing to our own tunes: Reassessing black and minority ethnic mental health service user involvement*. (London: National Survivor User Network, 2008).

[15]   Cotneau, S. and Stergiopolous, V. "More than being against it: Anti-racism and anti-oppression in mental health services." *Transcultural Psychiatry* 49 no. 2 (2012): 261-282.

marginalization, whether related to discrimination against LGBTQ populations,[16] Indigenous identity, or as a result of both psychiatric and other disabilities, it is clear that additional analyses and supports are required in order to create ethical collaborations. With careful attention paid to intersectional experiences as related to mental health generally, and service user collaborations specifically, InSight was devised to create a dialogue with organizations who have a history of working for and with service users, offering leadership to improve and centre the self-determination of people with psychiatric disabilities. InSight wanted to ensure that our collaborative work would be effective in addressing a broad range of service user experiences and create accountability so that potentially difficult experiences in these collaborations do not deter service users from engaging in future collaborative work. A group of community members who were accountable to organizations were assembled; including, Karyn Baker and later Gillian Gray from Family Outreach and Response, Jijian Voronka from Ryerson University and the Mental Health Commission of Canada, Lana Frado from Soundtimes; and Aseefa Sarang from Across Boundaries.[17] An initial meeting was held to collectively create ground rules. Sensitive to the fact that very busy people were being asked for their expertise and insight, respect for their efforts and time-commitment was a priority. The original pitch to Pillar 4 included funds to compensate InSight members for their time. This funding was approved but as the committee is comprised of organizations, not individuals, they collectively determined that the money would be better used to facilitate events. Over the next five years,

InSight attended Pillar 4 retreats and Advocacy Day,[18] sat as members on community organizing committees, and worked toward creating joint statements to strengthen community perspectives within the Department of Psychiatry.

ACCOUNTABILITY AND VALUES

Primary to InSight's mandate was self-governance, accountability and collective establishment of values and priorities that both meet the needs and are relevant to the members' organizations, and the communities they represent.[19]

InSight Values:

- *People with psycho-social disabilities have the right to life, self-determination, and inclusion in all society*

- *Persons with psycho-social disabilities should determine their own priorities*

- *Critical thinking promotes analysis about the structural barriers to inclusion such as the role of the state in controlling access to resources and assets;*

- *Empowering our community is facilitated from an anti-oppression, anti-racist/anti-colonialist, disability-positive framework; this requires an attention to social conditions affecting mental health.*

These values are based on a shared understanding of the stakes for service users of psychiatric facilities, who face higher risks of being socially and economically marginalized and subject to violence than the general population.[20] As a consequence of

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[16]   Robinson, M. for Rainbow Health Ontario. *LGBTQ Mental Health*. https://www.rainbowhealthontario.ca/wp-content/uploads/woocommerce_uploads/2011/06/RHO_FactSheet_LGBTQMENTALHEALTH_E.pdf 2012.

[17]   For full bios see Appendix I.

[18]   See: http://www.psychiatry.utoronto.ca/event/advocacy-day/

[19]   For full InSight Terms of Reference see Appendix I.

[20]   Psychiatric Survivor Anti-Violence Coalition, *Clearing a Path: A Psychiatric Survivor Anti-Violence Framework*. https://torontoantiviolencecoalition.files.wordpress.com/2016/02/clearing-a-path-dec-2015.pdf (2015)

this marginalization, service users are not only excluded from participating in decisions that have direct effects on their lives, but often do not have access to research and knowledge that has profound implications for their health.

ADVOCACY WORK FOR SOCIAL RESPONSIBILITY

Pillar Four Co-Chairs Dr. Lisa Andermann and Dr. Kenneth Fung were strong allies of InSight's mandate. They describe the origin of Pillar Four as the recognition of a need for dialogue outside of the "ivory tower". Addressing stigma, improving communication and advocacy with broader community, and advancing the context of global mental health were core issues. Lisa and Kenneth both recognized the need for service user and other critical community-based input at the outset and supported the InSight initiative as a way to move beyond dialogue into advocacy. This dialogue was also intended to bridge the gap between large departments and divisions of large hospitals who otherwise might not be working together.

Some of the ways Pillar Four addressed this learning need was through workshops on writing press releases and public statements, organizing diversity training, and creating MindFest,[21] a mental health and wellness fair that is open to the general public, offering interactive components that go beyond didactic lecture formats normally found in conferences. InSight members contributed time and gave input to multiple initiatives within Pillar Four, including MindFest and in the review of stigma survey results, as well as participating in advocacy initiatives. All of these issues require a great deal of work, discussion, and attention, so despite widespread enthusiasm and genuine intentions, it was a challenge from the outset to group them all together under one "dialogue" umbrella.

ADVOCACY DAY AND BRAIN FORUM

InSight addressed this challenge in collaboration with Pillar Four by creating spaces to welcome broader communities of service users into the process. In 2014, InSight coordinated an event at Pillar Four's Advocacy Day which included discussion on service user's perspectives on advocacy in mental health, featuring Jennifer Chambers from the Empowerment Council and mental health lawyer Anita Szgeti. InSight also organized a forum in 2015 to make advances in neuroscience accessible to service users. Two guest speakers, Dr. Albert Wong and Dr. Jeff Daskalakis presented emergent research and took questions about their work and its relevance. InSight members and Pillar Four co-chairs attended with other interested community members. Albert and Jeff discussed the importance of brain research and audience participants raised concerns regarding social implications, and how and why service users should be engaging their community and constituents in neuro/brain dialogues. The group explored positive ways of moving forward to better work together to align both mutual and times divergent interests. Many possibilities were raised about developing further ethical engagement with research participants and stronger accountability to the community about scientific advances.

"CENTERING MADNESS" COURSE FOR RESIDENTS

In addition to keeping community apprised of departmental research, we also recognized the need to teach trainees and staff about the history and body of knowledge created by service users and mental health advocates over the last four decades.[22] Lucy led the initiative to design a course for first year psychiatry residents at the University of Toronto that launched in July of 2017. "Centering Madness"

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21   MindFest has some funding and administrative support from the Department of Psychiatry at U of T, but is primarily driven by a diverse and inclusive planning committee comprised of various community groups and service users, including representatives from Grad Minds, Workman Arts, Healthy Minds Canada, Family Navigation Project at Sunnybrook and others.

22   For a list of readings that exemplify this body of knowledge see Appendix II.

was driven by service user perspectives, values and principles, and was accountable to community through the Empowerment Council and its board from the outset and through the entire process. The Department of Psychiatry provided funding to pay for a mutually agreed upon instructor, Lauren Munro, a member of the mad community and a community psychology researcher from Wilfred Laurier University.

Regular meetings were held between members of InSight, departmental faculty and scholars with expertise on community research and service-user driven knowledge.[23] With input and discussion from these meetings, Lucy and Lauren designed curricula, created a reading list, and developed evaluation forms. Mutual accountability was systematized through daily evaluations from students about each class and daily marking of the students by Lauren and Lucy. Course content reflects this communication between service user and professional knowledge, while upholding the principles of service user leadership. Beyond discussing "mental health" or "customer service" issues in the way standard psychiatric curriculum does, "Centering Madness" also addresses the limitations and harm within the system that occurs despite good intentions. As Lucy says of her experience, *"Working with psychiatrists to create curricula takes into account what they know about their discipline and at the same time revisits the power within their discipline. This shouldn't be a topic we evade, but be seen instead as an opportunity for deeper discussion about the ethics of care."* The intention of developing this service user driven course for the department was to make research and education richer, more relevant, and more accountable. Service users have accumulated a great deal of documented knowledge about psychiatry as well as decades of theoretical discussion. "Centering Madness" creates a context where psychiatry residents

learn this history and are challenged to interact with the theories and perspectives of the communities they have elected to treat in their future practices. This curriculum worked to incorporate intersecting frameworks such as critical race, disability, queer theory and Indigenous knowledge. Guest speakers in alignment with these theoretical frameworks and the foundational work of service users' experiential knowledge and scholarship—such as InSight member Lana Frado—were a critical part of the teaching of both theory and practice. It is important to also note that similar courses are offered in other university departments.[24]

To further our review of InSight's work, our next steps included conversations with staff to situate ourselves in the context of other collaborative work ongoing at the University of Toronto.

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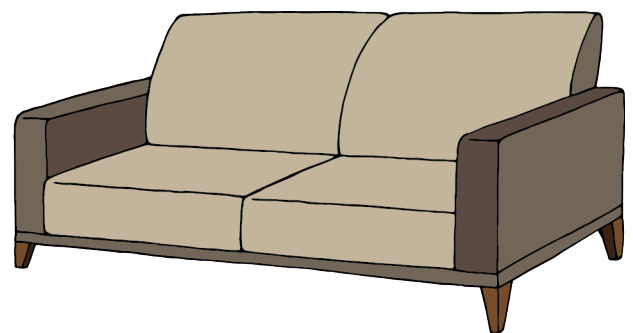
[23]   Lori Ross and Kathryn Church both offered significant contributions and expertise.

[24]   See, for example: *Privilege 101: Power, Privilege and Oppression in the Context of Health Equity* at http://www. physicaltherapy.utoronto.ca/continuing-education/courses/privilege-101-fall-2017/

EXPLORING STAFF LEARNING NEEDS

In order to explore staff learning needs and enhance the relevance of InSight's advisory role, Julie sat down with five psychiatrists and one psychologist, including the Pillar Four co-chairs, to get their impressions and identify areas for future work. Between April and July 2017, she attended a grand rounds lecture on coproduction, and participated in curriculum development meetings for "Centering Madness." Through discussion about her observations with Lucy and Priya, key themes and staff learning needs were identified.

All conversations with staff were guided by the following questions:

Questions to Staff about Service User Collaborations:

* *Which projects have you been involved in?*

* *What has worked, what hasn't?*

* *What is your experience of sitting in the room with service-users?*

* *What future initiatives, projects, and/or conferences, are you working on to promote service user engagement or inclusion?*

Staff responded thoughtfully and spoke candidly about their experiences. All expressed strong motivation to continue collaborative work with service users as a core component of their research and practice. The themes that emerged in these conversations reflect themes in the broader literature about the education and preparation required to maximize efficacy when staff endeavour to engage service users as equal collaborators. These themes include: staff anxiety when faced with vulnerability—their own and that of service user collaborators; examination of stigma and prejudice directed

at psychiatry generally and service users in particular; lack of confidence stemming from limited exposure to service users as leaders, both in literature and in practice; and the institutional constraints of time, resources, focus and energy when staff are not being adequately supported in these collaborations.

The dominant biomedical paradigm prioritizes neuroscience over questions of diversity and social determinants of health. Anthropologist T.M. Luhrmann discusses these themes in her ethnographic study of psychiatric hospitals in the United States more than two decades ago.[25] Rather than be disheartened by the seemingly unchanging nature of underlying conflicts and concerns in psychiatric care, it is useful to situate the above issues in their historical context.

Multiple staff members spoke about the tension between neuroscience and more integrative forms of care in their interviews and identified a need for support in advocating publicly for improved social conditions that affect the quality of medical care they are able to offer. Through understanding the challenges that have arisen at the University of Toronto in the context of broader systemic issues, our intention is to identify potential solutions. Our goal is to strengthen capacity for ethical collaborations in which staff have the tools and resources to demonstrate authentic solidarity with service users in a way that openly addresses power imbalances and is responsive to ongoing interpersonal dynamics that are shaped by historical tensions.

> " On several occasions, the notion that *there's no script* for patient engagement work was raised by staff. "

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25   Luhrmann, T.M., *Of Two Minds: An Anthropologist Looks at American Psychiatry*. (New York: First Vintage Books, 2001).

VULNERABILITY, STIGMA, AND INCREASING CONSUMER AND COMMUNITY INPUT IN DEPARTMENTAL EDUCATION

Pillar Four has a central focus on combatting stigma. Psychiatry is stigmatized as a discipline both inside and outside of the medical profession. Residents are often already defensive about their choice of discipline and this defensiveness can influence both their treatment of patients clinically, and openness to collaborate with service users on projects and in teaching. Given that Pillar Four also mandates increased consumer and community input in departmental education, these dynamics require exploration. Collaborations are difficult work that run counter to the tone of medical training where physician expertise is dominant. While the difficulty is more structural than personal, because it plays out in a relational context, it can be misattributed to tone or personality conflicts. Power dynamics saturate and shape the work from the outset, so self-reflection, motivation, and effort on the part of physicians are required to do it effectively.

On several occasions, the notion that "there's no script" for patient engagement work was raised by staff. While this is as true for this work as it is for any relational context where presence and in-the-moment negotiations are required, there is a whole body of service user driven research and writing that could support physicians in undertaking this work (see Appendix II). Pillar Four's focus on stigma as related to psychiatry, could be informed by a deeper understanding of discrimination as experienced by service users. Broadly, the stigma focus sees the discrimination faced by people with mental health diagnoses, but at times falls short in understanding the more subtle power dynamics that emerge when physicians face service users as equals in collaborative teaching and research. It is clear through staff concerns about not having a "script" that they feel challenged and require more educational and structural support to do this work well.

There are a range of reactions from staff to such collaborative efforts. Some are open and curious, others are highly defensive and dismissive, most are somewhere in the middle. In discussing his first experience working with a service-user as an equal, psychiatrist Dr. Sacha Agrawal identifies the root of these reactions: *"It was so powerful for me. I thought myself a fairly progressive and informed person, but working with my advisor I realized there were huge gaps in my understanding of people's experiences and of myself. For instance, I had somehow thought I was immune to bias but I soon realized I was having a lot of automatic thoughts about her that suggested otherwise. I also became more aware of the subtle discrimination against people that pervades the systems where we work. And the question is – is it just me? I doubt it. And if not, what do we do about it? Because it is possible that professional training strengthens rather than reduces bias. When we work with people at their most vulnerable and in situations where they are utterly powerless we may internalize things that are not helpful in the long run when it comes to approaching people with respect and hope."* There is no question that everyone experiences vulnerability here. As psychiatrist Dr. Michaela Beder describes: *"My first experience with this kind of work was with RACI. I remember the very first meeting I went to as resident. I was really intimidated. One of the people in the group with experiences in Psych Emerg was saying, 'I'm worried about*

> " I'm picturing two anxious people. Especially at the beginning of training, both people put up barriers and act in ways that may appear 'strange' or unusual. "

what the psychiatrist is going to think about me if I smell, am disheveled, and acting strangely.' On the flip side, I'm imagining being the resident and thinking that I'm too junior. I'm picturing two anxious people. Especially at the beginning of training, both people put up barriers and act in ways that may appear 'strange' or unusual. Over time I've become more used to inhabiting certain roles. So some of that goes away from the psychiatrist side. But then co-teaching and working together is breaking out of that again in different ways. I have to be able to acknowledge that I mess up and be willing to stay with it."

Here, Michaela is identifying a shared anxiety between service users and residents about how they're being read. When such fears are discussed openly, they have the potential to vastly improve relations between staff and service users. When they colour the terrain without reflection or acknowledgment, they can further entrench tensions between medical professionals and service users.

Medical training and practice promotes clear lines of authority and favours quantitative data. Physicians typically relate to service users in the context of clinical treatment. Depending on the context of this encounter, the service user's role can range from being a fully collaborating self-advocate, to a patient diagnosed, admitted, and restrained against their will. As psychologist BH[26] puts it, *"Psychiatric residents and inpatient staff are entrenched in medical culture and focused on risk."* It is not surprising to us then, that when service users play more powerful roles, as teachers and

collaborators with residents and staff, physicians often feel unsettled and unsure of how to engage. Questions of power and ownership as discussed in earlier sections are central. Even when intentions are honourable and the quality of this collaborative work is excellent, the bigger issue for us is process. It is our position that unless these issues are addressed, patient-provider collaborations will have difficulty creating productive and concrete changes.

In a similar vein, when staff and residents are trained predominantly using biochemical approaches that do not adequately support a more humanistic psychotherapeutic approach, it becomes difficult to accept service users as teachers or leaders. This challenge intensifies when service user leadership involves the sharing of traumatic histories and discussion of the harm caused in psychiatric contexts. BH continues, *"If I'm overwhelmed with work and I have to listen to lived experience… it doesn't matter who's talking. Is there a culture of reflective learning in general? Is it about lived experience or is it about the problem about teaching people generally? A thread that can happen through their whole experience? You learn the most when you're mortified and embarrassed. Is there a holding space for that? Where you don't get into defensive mode and disown it?"*

It is therefore simpler, when approaching collaborations, for staff to favour patients who are compliant and speak of good experiences. The problem is that nothing changes when we only hear what we already know, and moreover,

> " **Even when intentions are honourable and the quality of this collaborative work is excellent, the bigger issue for us is *process*. It is our position that unless these issues are addressed, patient-provider collaborations will have difficulty creating productive and concrete changes.** "

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[26]   Anonymous at interviewee's request.

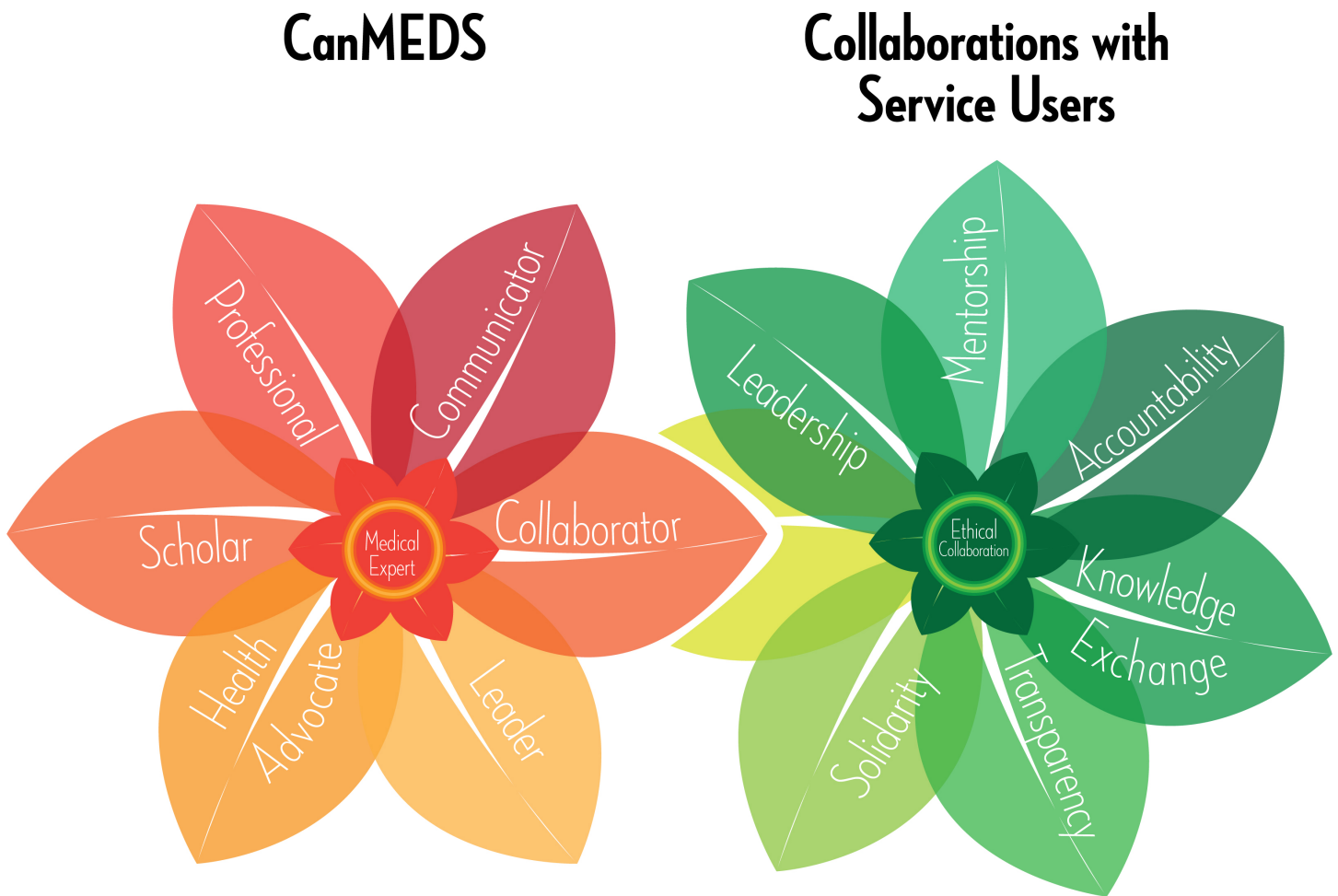want to hear. Ethical collaborations will inevitably challenge hierarchy in both form and content through the sharing of power and critical perspectives from service users. In this way, we once again see process and power as central. As much as "what" consumers teach, the respect they are afforded in teaching and research contexts offers a significant model for residents on "how" to approach collaborative efforts.
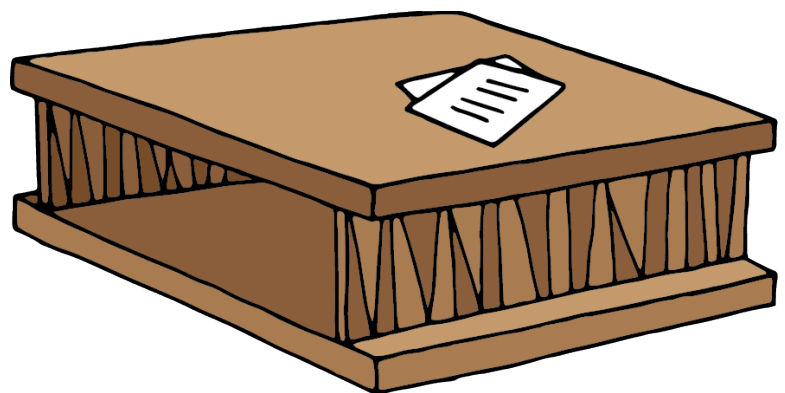
AFTER PILLAR FOUR: RECOMMENDATIONS FOR ONGOING WORK

Figure 1
CanMEDS[27] diagram (left) developed by the Royal College of Physicians and Surgeons of Canada to illustrate seven core competencies for doctors. InSight has created our own diagram, (right) stemming from the "collaborator" role identified by CanMEDS, to illustrate the skills and framework required to ethically collaborate with service users.

CanMEDS

Professional
Communicator
Scholar
Collaborator
Medical Expert
Health Advocate
Leader

Collaborations with Service Users

Mentorship
Leadership
Accountability
Ethical Collaboration
Knowledge Exchange
Solidarity
Transparency

27   Frank, JR. Snell, L, and Sherbino, J. eds. CanMEDS 2015 Physician Competency Framework. (Ottawa: Royal College of Physicians and Surgeons of Canada; 2015.)

1. **ETHICAL COLLABORATION** is our integrating concept. In order for staff to ethically collaborate with service users they need to centre service user expertise as outlined below.

2. **LEADERSHIP**
   It is essential for staff to go beyond acknowledging service user expertise, and "centre" it in a way that accepts and promotes *service user leadership*. Our recommendation is that ethical collaboration begins with staff immersing themselves in theoretical frameworks and literature that has theorized these dynamics over several decades (Appendix II). Ethically collaborative pedagogy flows from prioritising service user expertise and knowledge exchange goals and not dismissing experiential knowledge as "unscientific". Given the history of hierarchical power dynamics in psychiatric care that situate staff as experts and service users as passive recipients of care, doing this well requires a willingness from staff to accept service user *leadership* in collaborations. This means both openly discussing power at the outset, and service users being at the forefront of decision-making.

3. **MENTORSHIP**
   Staff and residents working on these initiatives require mentorship from other staff who are experienced in these collaborations. When anxieties and insecurities inevitably arise, they are best addressed by colleagues who can support both the emotional growth of the staff *and* the knowledge of the service user community—challenging the status quo, promoting critical thinking and encouraging social and political reflection as necessary components of mentorship. Just as supervision in clinical practice gives staff space to examine their own reactions to their patients, so too would experienced supervision supportively address residents' strong reactions to being taught and evaluated by service users.

4. **ACCOUNTABILITY**
   Accountability works on multiple levels. Service users who work in collaborations with staff, particularly around training, have accountability to the broader movement of service user engagement. Accountability measures between staff and service users need to be mutually determined at the outset of projects and revisited regularly to ensure they are being appropriately implemented. Finally, accountability goes beyond the individual psychiatric staff, right up to the level of the institution they represent. The institution has to provide the staff and the project with proper support, or these endeavours cannot succeed. Such support would also ensure mutual accountability because staff who are better supported are more likely to be able to report back and produce outcomes relevant to the institution.

5. **KNOWLEDGE EXCHANGE**
   Like accountability, a knowledge exchange strategy needs to be discussed at the outset and revisited regularly. Discussions of compensation and intellectual property need to be at the forefront of this strategy. If the community is leveraged for knowledge through focus groups or research, there must be some communication strategy as to how this will be incorporated and implemented into quality improvement projects. This framework will create a context where the department will be better situated to offer accessible research to the community and receive feedback about whether this research meets community needs.

6. TRANSPARENCY

Transparency is multi-faceted. As a basic practice, when service users are being brought into an initiative that is predominantly staff-based, staff need to be vigilant about not engaging in side conversations when they encounter one another outside of meetings. It is too easy when people all work together to exclude service users from small decisions. More complicated are issues of conflict of interest and being upfront about what is and is not negotiable and possible in the context of the particular collaboration. Even where no conflict of interest officially exists, in order to effectively build trust, staff should be transparent about benefits they receive from this work through remuneration, research, and career progress.

7. SOLIDARITY

Our final point is the culmination of all of these concerns and recommendations. Authentic solidarity requires respectful relationships with respect to shared goals as well as honest discussion of differences. There are many broad issues which can be addressed in alliances between service users and staff. One common theme that arose in staff discussions was the ongoing devaluation of humanistic approaches to psychiatry with too much emphasis being placed on biochemical approaches to the brain. The Empowerment Council at CAMH has found similar concerns in discussion with their constituents: "Counselling/psychotherapy is a constant client identified need" of service users "who are civil and forensic, inpatient and outpatient, waiting to become clients and discharged clients."[28] Finding common ground to address this issue among others while working in respectful solidarity holds the potential for collaborations to foster concrete changes in the practice of psychiatry. Finally, in solidarity with service users, staff can use this framework to address misuses of power within their own and each other's work.

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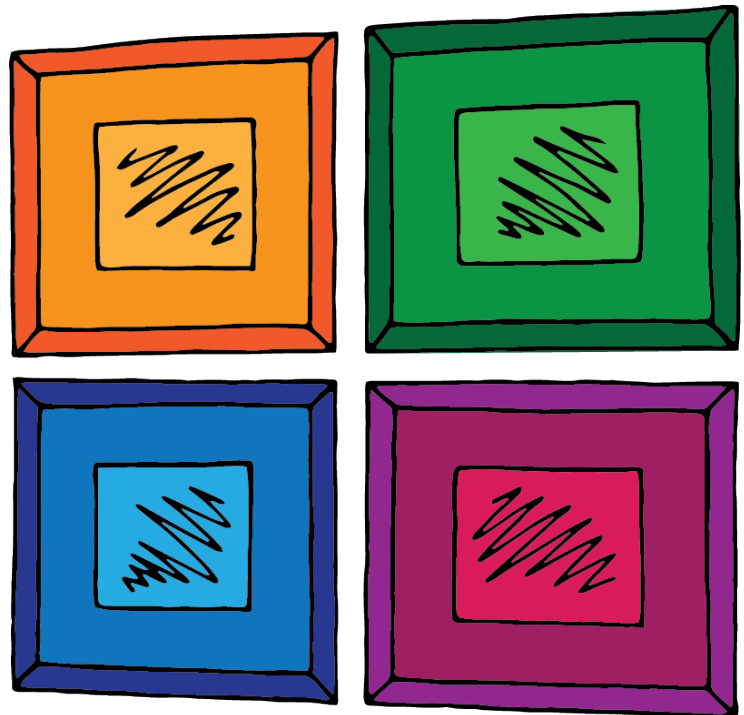
[28]   The Empowerment Council: A Voice for the Clients of the Centre for Addiction and Mental Health *Empowerment Council Activities* 2016/2017 p 3.

FINAL REFLECTIONS

We offer our diagram as a framework for collaborations where service users can take the lead to create meaningful change. For service users, having their presence valued and their insight understood as leadership is a first step to redressing harm caused by histories of psychiatric care *and* past experience of collaborations with staff. The question of harm is dealt with in the 2017 paper, "Exploring the Case for Truth and Reconciliation in Psychiatry."[29] Spandler and McKeown examine the possibility of a grassroots reparative initiative in which service users and staff can engage in "new forms of dialogic communication and horizontal democracy."[30] Without openly addressing the effects of disenfranchisement, it is impossible to forge effective working relationships. As Dr. Mark Fefergrad[31] says of his work at the University of Toronto, this process is necessary and ongoing: *"Mostly people are curious about what we do, so it's like we are pulling back the curtain from the Wizard of Oz. In my experience, people want to contribute in thoughtful ways. There is a contingent who are justifiably angry. Initially I thought this was an impediment, but I've tried to look at as part of the process. Trust to be built and wounds to be healed."* In this vein, it can't be up to the person with *less* power—in this case, the service user—to be responsible for the interpersonal dynamic. How can psychiatrists support each other and their residents in a way that disarms defensiveness about the lived experiences of patients—and rather opens them up to deeper self-reflection about their own role and use of power? Mark is optimistic: *"I want to remove the barriers to people doing this work. I want to be a helpful consultant but mostly I just want to get out of the way and eliminate*

the historical obstacles. I really think we're at a turning point. The things that are developing and the discussions that are happening have never occurred with the institutions in this kind of way. Educating future psychiatrists can affect entire future generations. The fact that this is happening in our resident training program sends a message that has a trickle down effect. It's going to become the norm." While we are also hopeful that service user leadership could someday become "the norm," we want to emphasize that staff self-reflection and mentorship that addresses predictable staff reactions is key.

This process requires rethinking stigma as more than an issue that affects both staff and service users in psychiatry. It must be understood explicitly as an issue with very different impacts on each group. For service users, stigma and discrimination mean risks to their material well-being and physical safety.[32] It is essential to the care and lives of service users that residents' training includes explicit destigmatizing and understanding of service users as *experts*. As Lucy describes, *"The experience of having to constantly push through conscious and unconscious resistance in work with psychiatrists and other professionals in meetings, or supposed 'collaborations' is more than exhausting. You take bullets. Silent bullets. It hurts the body in different ways. I have spoken to other consumer|survivors about their experiences in meetings etc. – everyone reacts in their own "bodily" way. While a lot people may experience discomfort in meetings at times, I am pretty sure there is an unspoken, collective experience consumers|survivors are having that is very specific to having our knowledge disrespected, aborted and then betrayed by a complete feeling of erasure."*

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29   Spandler, H. and Mckeown, M. "Exploring the Case for Truth and Reconciliation in Psychiatry." *Mental Health Review Journal* 22 no. 2, (2017): 83-84.

30   Spandler and Mckeown, p 94.

31   Dr. Mark Fefergrad is the Director of Postgraduate Education in the Department of Psychiatry at the University of Toronto.

32   Psychiatric Survivor Anti-Violence Coalition, *Clearing a Path*.

Julie's experiences with mainstream patient engagement in the broader health care system outside of psychiatry reinforce Lucy's perspective. While some advocacy work and curriculum design does address issues of power, most restricts itself to superficial changes that prioritize cheerful narratives from patients who are unchallenging to medical authority. As such, it is far more ethical and practical to engage challenging dynamics from a deeper understanding of power.

In contrast, service user movements in psychiatry have a long and rich history of social advocacy, both in addressing institutional issues in medicine, and in advocating for better social conditions and against discrimination in solidarity with other marginalized communities. For service users interested in furthering their collective voices in the context of Mad Studies, engaging these questions is central.[33] There is great potential for service users to collaboratively support and offer leadership to promote advocacy work for social responsibility in the department. As a physician and long-time collaborator with service-users, Priya offers this reflection:

"The biggest piece for me in these collaborations is my anxiety that I will eventually betray my values on this, compared to the seductions of something else – career advancement, money, or even simple choices that are 'easier' or 'don't bother my colleagues as much'. I think anyone who's holding the relative power in this arrangement is always going to have to have that anxiety… at least, we should, or else it's worse. We just have to sit with it, worry, scrutinize ourselves, feel awkward, and try to handle it maturely when things do go wrong. It's not like you follow these recommendations and it's all sunshine and roses. I'm not great at this. It doesn't come naturally. I'm always tempted to say and do things that I'll get called out on because of my allegiance with the institution. There are so many micro-moments in this, which reflect broader dangers too. Essentially, I am always aware of the precarity of my own integrity. I suppose the more constructive way to look at it is to realize that some form of betrayal is inevitable. So when that happens, what it's going to look like? How am I going to work it through with my service user colleagues, my psychiatric colleagues, and with myself?."

InSight's work has led to reflections on the nature of power and process and culminated in the creation of this report. This is one addition to the vast literature on similar power-fraught relationships. The schema for ethical collaborations we presented here offers the possibility of approaching these collaborations in such a way that promotes service user leadership and forefronts solidarity. In the past five years of collaborations in the Department of Psychiatry at University of Toronto, Pillar 4 has done important work. One key precedent has been set in the form of InSight as an advisory. As this work continues, we hope that it will be coloured by the principles of mentorship, accountability and transparency. The future health of relations between service users and psychiatric professionals, whether in clinical, research, or educational contexts, depends on us continuing to ask these questions and have these conversations.

> " **Essentially, I am always aware of the precarity of my own integrity.** "

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33 See Russo, J and Beresford, P. "Supporting the sustainability of Mad Studies and preventing its co-option." *Disability & Society* 31 no. 2 (2016): 1-5.

APPENDIX I:
InSight: Service User & Allies *with* Critical Perspectives Advisory to the Pillar 4 Values Statement—2014

InSight includes service users, family and allies committed to the empowerment and self-determination of persons with psycho-social disabilities. We work to promote equity of our constituents through the encouragement of rights, abilities and strengths. Psychiatric service users have been working with hospitals, universities, community organizations and government administrations to improve practices and public policies for almost four decades both locally and internationally. Mental health consumer/survivors have also been an influential force in promoting the current evolution in mental health recovery work, drawing from personal experiences, social justice, and human rights. For example, the first recovery conference in Toronto was organized by a consumer / survivor group in 2002.

In the spirit of equity, we maintain that involvement of service users must extend beyond advising on decisions and directions that have already been set. We believe there should be service user involvement in every aspect of service planning and design improvement.

Groups representing families and other allied interests can have a range of perspectives with respect to this agenda. InSight offers Pillar 4 the chance to access such stakeholders that share the values described herein.

Values

- *People with psycho-social disabilities have the right to life, self-determination, and inclusion in all society;*

- *Persons with psycho-social disabilities should determine their own priorities;*

- *Critical thinking promotes analysis about the structural barriers to inclusion such as the role of the state in controlling access to resources and assets;*

- *Empowering our community is facilitated from an anti-oppression, anti-racist | anti-colonialist, disability-positive framework; this requires an attention to social conditions affecting mental health;*

- *Our collaboration with the Department of Psychiatry combines critical reflection on the system with an extensive history of consultation with the system*

Members

ASEEFA SARANG - ACROSS BOUNDARIES

Ethnoracial mental health centre * individual and community support (case management) * support groups for consumers/survivors * anti-racism education and training in mental health * consumer/survivor initiatives to address economic and social barriers * community outreach * alternative models of support and services, holistic focus * art and music therapy * drop-in * life skills * community kitchen for breakfast and lunch.

LUCY COSTA - EMPOWERMENT COUNCIL

Advocate with and for people with psychosocial disabilities for over a decade. Systemic advocate with the Empowerment Council in CAMH. The Empowerment Council conducts systemic advocacy, ensures representation of the client perspective within the Centre for Addiction and Mental Health (CAMH). The Empowerment Council provides education on choices, self advocacy, critical thinking and political awareness. The Empowerment Council also provides outreach, community development and education for mental health professionals, addiction workers and community members. Experience with the "peer worker" paradigm, disability theory, debates around CTO

legislation, criminality language and mental health (e.g. NCR debates, legal / employment implications of Form 1 or EDP stuff, immigration/ deportation implications of those things, etc).

GILLIAN GRAY - FAMILY OUTREACH AND RESPONSE

The Family Outreach and Response Program (FOR) provides counselling and education to families who have relatives recovering from serious mental health distress. FOR has taken a lead in providing family support to youth and their families who are experiencing an early episode of psychosis. FOR has a Tamil Early Psychosis program in Scarborough. While FOR is primarily funded through the TCLHIN, we also have a youth engagement program funded through the Canada Post Mental Health Foundation. FOR is also working with international partners to deliver on-line family recovery programs. FOR is staff by professionals who have either the lived personal or family experience.

JIJIAN VORONKA RYERSON / UNIVERSITY of TORONTO

PhD student at the Ontario Institute for Studies in Education, University of Toronto. Drawing on anticolonial and critical disability studies, her research explores the possibilities, limits, and conditions of peer involvement in mental health research and service delivery. She teaches at Ryerson University's School of Disability Studies, which has developed a strong curriculum emphasizing consumer/ survivor driven activism and scholarship. She worked as consumer research consultant for the At Home/Chez Soi research demonstration project (2009-2013), and is a current consultant for the Mental Health Commission of Canada's Housing and Homelessness initiative.

LANA FRADO - SOUNDTIMES

Consumer/survivor operated community mental health service * case management and individual support * Mental Health and Justice services * education and information workshops * support groups * opportunities

to learn and use computer skills * social and recreational activities * peer support * advocacy.

REPRESENTATION

While singular narratives are important and have a role to play in understanding the diversity of experience within the mental health and substance use sector, representation as a whole should encompass an expansive perspective about the role of service users and allies. For instance, this would include attention to macro-level dynamics and trends at work within psychiatric service delivery, research and education. Matters of "identity representation" have historically been, and will continue to be, discussed within our heterogeneous group of service users. In that regard, the literature indicates ongoing challenges in this area related to the expectations of professionals:

> "It appears to be a particular problem that users and carers are asked to be more 'representative' than any other group of stakeholders in the change management process. Articulate users may be criticized as unrepresentative because 'ordinary' users are often not seen as articulate. Other stakeholder groups, in contrast, will not be subject to such challenges – articulate and assertive professional and managers for instance, are not likely to be questioned as 'unrepresentative.'"

> - Rose, D., Fleischmann, P., Tonkiss, F., Campbell, P. and Wykes, T. *User and Carer Involvement in Change Management in a Mental Health Context: Review of The Literature*. (London: Natural Co-ordinating Centre for NHS Service Delivery and Organization Research and Development, 2002).

InSight values coalition building that supports the goals of the group, and as such, includes people who do not identify as consumers/ survivors. The common thread is that group members are leaders in non-academic mental health settings and stakeholder organizations, and are in agreement with group values.

APPENDIX II:
Sample Reading List of Service User Scholarship and History

1. Beresford, P. "Developing the theoretical basis for service user/survivor-led research." *Epidemiologia e Psichiatria Sociale* 14 no.1 (2005): 4-9.

2. Capponi, D. "Working for Change in The Psychiatric Patient Advocate Office." In *Mental Health and Patient Rights Ontario: Yesterday, Today and Tomorrow* (Toronto: Queen's Printer, May 2003): 14.

3. Church, K. and Reville, D. "User Involvement in Mental Health Services in Canada: A Work in Progress." In *Common Concerns: International Conference on User Involvement in Mental Health Services*. http://www.ryerson.ca/ds/pdf/userinvolvement.pdf (1988).

4. Demerson, V. *Incorrigible*. (Waterloo: Wilfred Laurier Press, 2004).

5. Faulkner, A. *The Ethics of Survivor Research: Guidelines for the ethical conduct of research carried out by mental health service users and survivors*. (Bristol: The Policy Press, 2004).

6. Kalathil, J. *Dancing to our own tunes: Reassessing black and minority ethnic mental health service user involvement*. (London: National Survivor User Network, 2008).

7. LeFrançois, B., Menzies, R. and Reaume, G. eds. *Mad Matters: A Critical Reader in Canadian Mad Studies*. (Toronto: Canadian Scholars' Press, 2013).

8. Morrison, L. T*alking Back to Psychiatry*. (Chicago: Routledge, 2005).

9. Poole, J. "Sanism" *TedxRyersonU Talks*. (Video: Toronto, 2014). https://www.youtube.com/watch?v=hZvEUbtTBes

10. Reaume, G. *Remembrance of Patients Past: Patient Life at The Toronto Hospital for the Insane, 1870-1940*. (Toronto: University of Toronto Press, 2000).

11. Reaume G. "Lunatic to patient to person: nomenclature in psychiatric history and the influence of patients' activism in North America." *International Journal of Law and Psychiatry* 4 (2002): 405-26.

12. Reville, D. "Mental health reform: Still saying the same thing after all these years." *Canadian Public Policy* 31 (2005): 65-68.

13. Rose, D. "Collaborative research between users and professionals: peaks and pitfalls." *Psychiatric Bulletin* 27 no.1 (2003): 404-406.

14. Usar, O. "Psychiatric System Survivor/Consumer Advocacy A Critical Literature Review" Prepared for the *Black Creek Community Health Centre Advocacy for Change: Community Mental Health Project*. (Toronto: 2014).

15. Sweeney, A., Beresford, P., Faulkner, A., Nettle, M. and Rose, D. eds. T*his Is Survivor Research*. (Monmouth, UK: PCCS Books, 2009).

16. Trivedi, P. "Black Service User Involvement: Rhetoric or Reality?" In S. Fernando and F. Keating, eds. *Mental Health in a Multi-Ethnic Society*. (London: Routledge, 2008).

17. Wallcraft, J., Schrank, B. and Amering, M. eds. *Handbook of Service User Involvement in Mental Health Research* (New York: Wiley, 2009).

18. Yellow Bird, P. "Wild Indians: Native perspectives on the Hiawatha Asylum for the Insane." (n.d.): 1-10. http://www.power2u.org/downloads/NativePerspectivesPeminaYellowBird.pdf

19. Voronka, J., Wise Harris, D., Grant, J., Komaroff, J., Boyle, D., and Kennedy, A. "Un/helpful help and its discontents: peer researchers paying attention to street life narratives to inform social work policy and practice." *Social Work in Mental Health* 12 no. 3 (2014): 249-279.