Chapter 10: Measuring Innovation and Determining Return On Investment (ROI)

How Project LETS Measures Innovation

By Stefanie Lyn Kaufman

What is the problem?

During my freshman year at Brown University, I chose to manage my own mental health care in fear of being forced on medical leave and losing my place in academia. I wasn't alone. Many peers were afraid to use university mental health resources because they didn't know what the explicit policies were for issues like self-harm, suicidal ideation, psychosis, and eating disorders. Ambiguous policies— and stories about students who experienced forced hospitalization, constant surveillance, and mandated leaves from school -- made students hesitant to disclose their concerns to the administration or university mental health centers. Oftentimes, students who did try to seek help were unable to see a therapist because on-campus centers were booked for months at a time, and off-campus providers were too expensive. Other friends did not find traditional forms of mental health care to be especially culturally relevant to them, and struggled to connect with therapists who did not understand critical parts of their identities.

These policies institute fear and take power and autonomy away from students. On top of these institutional power imbalances and issues, rates of mental illness among college students are at a record high, and 64% of students who drop out of college leave school due to complications with their mental illness. Individuals with mental illness face societal stigma, discrimination, and oppression— which is known as ableism; and many barriers exist within the current model of mental health care that prevent people from attemping to and actually being able to access care.

Why Project LETS?

Project LETS believes that we are the experts of our own narratives and lived experiences, and the solution lies in services delivered by peers, for peers. We are comprised of mentally ill, disabled, and neurodivergent individuals who uplift each other and surrounding communities in the hopes of achieving more accessible and culturally competent mental health care. Our model is built on trust, partnership, mutual decision making, and transparency. We actively work to give power back to the students we work with, and therefore make it a top priority to create a safe place for students to talk about heavily feared and stigmatized topics.

I founded Project LETS in 2009, following the suicide of my friend and peer, Brittany Marie Petrocca. Initially, our work was focused on high school- based awareness— but quickly developed into advocacy-based programming and service delivery. In 2013, after incorporating as a non-profit and launching the Project LETS International Crisis Line, our team realized immediate crisis intervention was only one small piece of the puzzle. We began researching programs and interventions that sought to connect those in crisis to longer-term, follow-up care. In early 2014, Project LETS began offering one-on-one peer counseling services to individuals from all over the world. Following the success of this model, and a conversation held with a student at Brown University, the PMHA program was born.

One day, I was helping to connect a struggling student to university resources. The next week, she asked if I could possibly connect her to someone who was in recovery from an eating disorder. Though she saw a therapist and nutritionist, she said, *"There are so many other hours in the week. And I'd really like to see how someone else is surviving."* After that day, I connected her to another student I knew in recovery, and their relationship became an important model for us. After that, I started building our curricular model so we could make these connections on a much larger scale at Brown.

As an organization, we prioritize the concept and core value of disability justice: looking at and recognizing the intersecting histories of supremacy, colonialism, capitalism, gender oppression, and ableism, and really understanding how people's bodies and minds are labeled unproductive or disposable. In our Peer Mental Health Advocate (PMHA) program, we pair students with lived experiences with students who are struggling. They are doing one-on-one emotional-support work, peer counseling, but also advocacy work. A Peer Mental Health Advocate will show up to a meeting on your behalf, talk to the administrator, make phone calls for you, call your insurance company, and/or do background research. Advocates do a lot of the nitty-gritty advocacy and logistical work that is so hard for people who are struggling. We work with folks to remind them about their appointments or help them figure out the logistics of medical leave.

The core of our training curriculum comes from state-level Certified Peer Recovery Specialist (CPRS) training and Intentional Peer Support (IPS). From here, we derive the job responsibilities, ethics, and main roles of a peer supporter. Additional training components were developed by the Project LETS Team, and work to prioritize a social justice lens and anti-oppression framework; as well as social models of disability, and history of psychiatry.

What are the main responsibilities of PMHAs?

- Creating personalized safety/relapse prevention plans
- Sending reminders about medication and appointments
- Cultivating your peers' ability to make informed, independent choices
- Helping your peers identify and build on their strengths
- Supporting your peer in accessing help/resources, and learning how to interact with the healthcare system
- Answering questions about mental illness to develop confidence and reduce stress
- Providing support in times of struggle and crisis
- Providing information relating to coping mechanisms and how to maintain healing
- Assisting your peers in gaining information and support from the community to make their goals a reality

Impact/Results/Outcomes: How do we measure success?

"I think the bottom line is you have to organize. And I think that's the same path a lot of groups have had to use to get heard, to get seen, to get care, to get something to happen for them."
— **Will Meek**, Brown University, Director of Counseling and Psychological Services (CAPS)

Since officially launching our pilot program at Brown University in 2015, Project LETS has trained 200+ PMHAs across multiple universities, and connected over 140 student peers with PMHAs. We have 105+ direct leaders across 20+ campus chapters throughout the United States who have engaged in various critical advocacy and educational programming outside of our direct peer counseling model.

Peers feel that they have gained skills in critical areas. With regards to the post- evaluation taken at the 6-month mark:

- 90% of peers report an increase in their knowledge of and ability to utilize coping skills
- 60% of students report an increase in their quality of life
- 65% of students report an increase in their ability to manage self-destructive behaviors/suicidal thoughts
- 70% report feeling more confident in their ability to handle crises
- 60% report an increase in their help-seeking behaviors

We measure our success through the effectiveness of individual PMHA-peer relationships, as well as the demand for our program. We track the adhesion of a specific program by evaluating the volume of applications from individuals who want to work as a PMHA (and

their demographic characteristics), and applications from students who want to work with a PMHA.

We monitor the effectiveness of our training and programming by evaluating PMHA training pre/post-test, initial PMHA requests, peer's pre-evaluations, bi-monthly check-in's/ evaluation surveys (peers using the program and PMHAs) and notes/documentation from our PMHA's. We measure key metrics such as changes in quality of life and behavioral health, help-seeking behaviors, crisis response, size of support system, coping skill building, self-destructive behaviors/suicidal ideation or attempts, and self-worth/self-esteem. We also compare how folks rate their feelings of agency, safety, and power in PMHA relationships versus institutional, medicalized, and/or state-sanctioned "support"; in addition to quality of care.
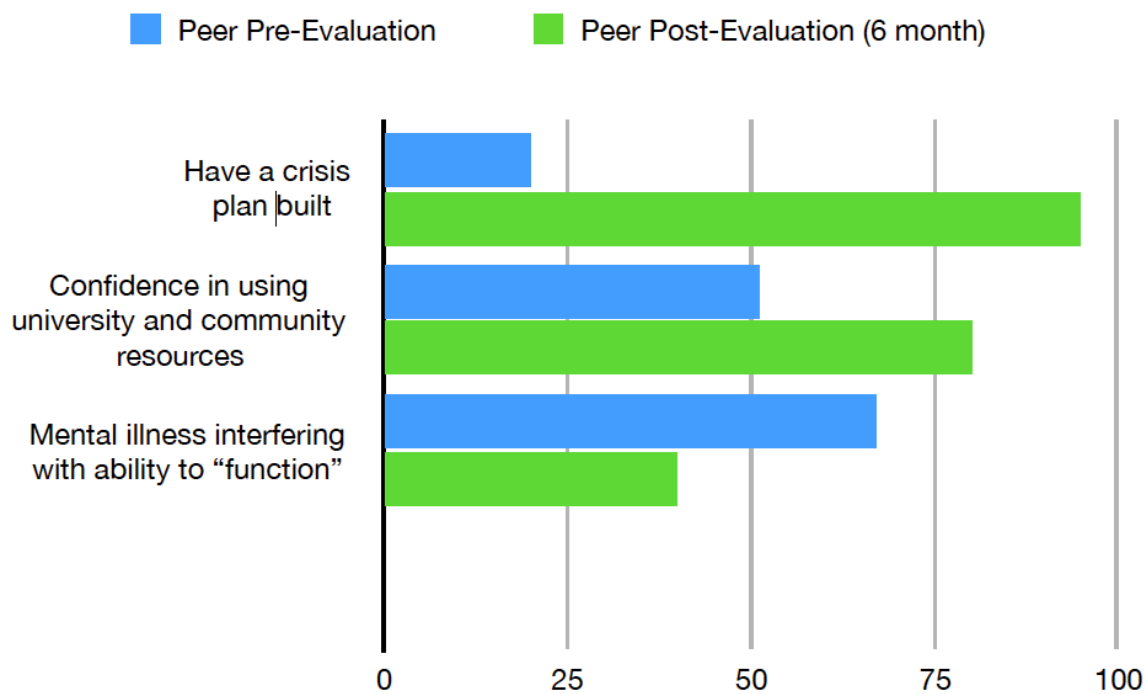
Without PMHAs, students are more likely to drop out of their academic programs. Some students will never seek professional help, but they will talk to a peer. When students connect with trained peers, they are more likely to stay in school. We help students get

connected to professional resources, and navigate a system they would have never gotten to in the first place.

As shown above, our PMHA/peer relationships are having a marked impact in three main areas: **crisis preparation** (20% has a crisis plan before, compared to 95%); **increase in help-seeking behaviors/comfort** using university and community resources (51% to 80%); and a **decrease in how their mental health issues impact** their ability to "function" (67% to 40%). Additionally, in our pre-evaluation measurements 73% of students listed a friend or pet as their primary form of mental health care/support. At the 6-month mark, 65% of individuals listed their PMHA or a professional/community resource as their primary form of support.

Here are some samples of feedback from peers using our program:

- *"I'm no longer scared of entering places on campus that trigger me. Even just creating a safety plan has been really reassuring. I'm better a asking for help when I need it and knowing the language I need to talk about what I'm going through.*

- *"I think I learned a lot about how to be more interdependent, when before I used to be very unwilling to ask for any sort of help. I also created a crisis plan and with the help of my PMHA began to realize a lot more about my thinking patterns and behaviors."*

- *"When I worked with my PMHA, I was able to regulate my studies and manage myself better. I was more conscious of the medical leave re-application deadlines, therefore able to successfully submit to the university before the deadline. This was integral in me returning to Brown. Though I was seeing a therapist, my PMHA was useful in pinpointing academic & emotional issues I had in the past at Brown and how to deal with those in the future (especially as it relates to my first-generation identity). My PMHA also connected me with a student who successfully returned from leave, which was incredibly helpful."*

What we did not expect was how impactful the PMHA training process and curriculum itself would be for our students. Upon training evaluation, we found that:

- 93% feel more confident in their ability to help themselves with their mental health struggles
- 94% feel more confident in their ability to help others with their mental health struggles
- 86% felt more confident in their ability to navigate Brown University's and community resources

Here are some samples of feedback from our 2016 cohort:

- *"Overall, this training has made me realize the lack of an effective support system I had when I was at my lower points of my mental health, and it has prompted me to journal more in order to reflect on the topics discussed in training in relation to my own life. PMHA training helped me reframe and concretize my own recovery narrative and my relationship to self-care, and has reminded me of the power of warmth and non-judgement in all my interactions, with friends, family and strangers."*
- *"I learned that my relapses are part of me... a part of me that I must embrace and take responsibility for. I learned that when recounting my own experience I often tell my story from a second-person perspective, in an attempt to disentangle myself from the pain. This is something I have been able to catch and change, and in doing so I have experienced much less cognitive dissonance. I also learned that I had a substance use disorder, and I still experience cravings, intrusive thoughts, and drastic mood swings. Acknowledging these aspects of my psyche has allowed for more personal growth."*
- *"I learned new ways to consider my own "recovery story", how to interact with myself when dealing with my own symptoms (be more forgiving), and about ways to seek help/maintain a more positive attitude & approach (be less helpless). I*

also feel drastically more prepared to deal with a crisis situation should I find myself one- something that I know from personal experience is of the utmost importance."

What we've found to be most incredible is the impact that PMHA/peer relationships also have on the PMHA. Below is a series of quotes from Dana, a peer — and Lacy, her PMHA (who worked together for 2+ years):

- *"I was skeptical that anything could help, but I finally resorted to applying for a PMHA through Project LETS. From our first meeting, Lacy [my Peer Mental Health Advocate] has cared for me with such kindness and an understanding that I have yet to find in anyone else. She genuinely affirms my feelings because she, too, lives through similar challenges. We fuel each other to carry on despite our struggles, and I now know that I never have to struggle alone."* — Dana, peer

- *"It is difficult to explain exactly how powerful my experience working with Dana has been. There have been times when I've struggled to leave my room, to feed myself, to begin my day, but if Dana needed to meet with me, there was almost a reserve that I could tap into that can only be described as the strength of community care. Dana has cared for me every bit as much as I have cared for her; I don't think I've left a meeting with her without feeling more restored, hopeful, and better prepared to care for myself."* — Lacy, PMHA

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PMHA's like Lacy can provide skills to help their peers more easily navigate the mental health care system and offer consistent social support where they can be honest about their experiences. The partnership and bond developed helps break down internalized stigma for both individuals, highlighting the immense power in that "me, too," moment, especially when you're dealing with a topic that so often makes people feel very vulnerable. It attributes value to the peer counselor's experiences with mental illness, and allows them to use the experiential knowledge they've gained to make a positive change in

somebody else's life. This is unique because so often we're told our mental illnesses are only something to overcome, and aren't anything to be proud of.

We also began measuring the number of peers (individuals using our program) who then apply to become PMHAs. To date, we have trained 16 peers to become PMHAs— which to the Project LETS team, is an incredible sign of impact. A student who was once in a position of feeling scared, isolated, and without resources now feels they can pass along information, be a mentor for, and advocate for another individual. What could be better than that?

- *"I had an incredible PMHA. Her impact made me want to impact someone else the same way by offering my time, expertise, and resources. I hope to gain a few new friends on campus and a sense of impact as both a mentor and an activist."*

- *"Having a PMHA to talk to, who was much closer in age than a psychologist, was really beneficial because they understood firsthand about the difficulties. It felt great to finally be able to talk to someone that I could consider a friend about my mental illness particularly because I had never told anyone outside of my family. I really want to help others and guide them through college as my PMHA did for me."*

- *"I understand the impacts a PMHA can have on a student who is struggling, as mine did when I was struggling with my own mental health. I believe I have a lot to offer and share — and I also believe I have so much to learn from my potential future peers."*

How can other organizations apply our style?

Over the years we have increased our reliance on quantitative measurements, which are absolutely essential to measure impact. We have also continued to utilize qualitative measurements, storytelling, narrative sharing, and open-ended feedback that is then coded, using technologies such as nVivo. It is essential to integrate both quantitative and qualitative measurements into an impact assessment. Without both, you will never truly get the full picture.

It has been important for us to be creative in terms of *where* and *how* we are making impact. For example, it is of critical importance for Project LETS to prioritize working with the most marginalized, targeted, and at-risk members of our communities — most often, LGBTQ+ BIPOC (Black, Indigenous, people of color) with highly-stigmatized illnesses. To this end, we also monitor the percentage of multiple marginalized folks served as an indicator of program accessibility— ensuring we are not primarily serving cisgender, heterosexual, white folks with depression or anxiety. Here is a look at our "illness category" breakdown from Spring 2018 — and our demographic change from Fall 2017 to Spring 2018 at Brown University (looking at indicators of POC, LGBTQ+ folks, and first-gen students applying to be PMHAs):

Illness Category Breakdown: Spring 2018 (Brown University data)
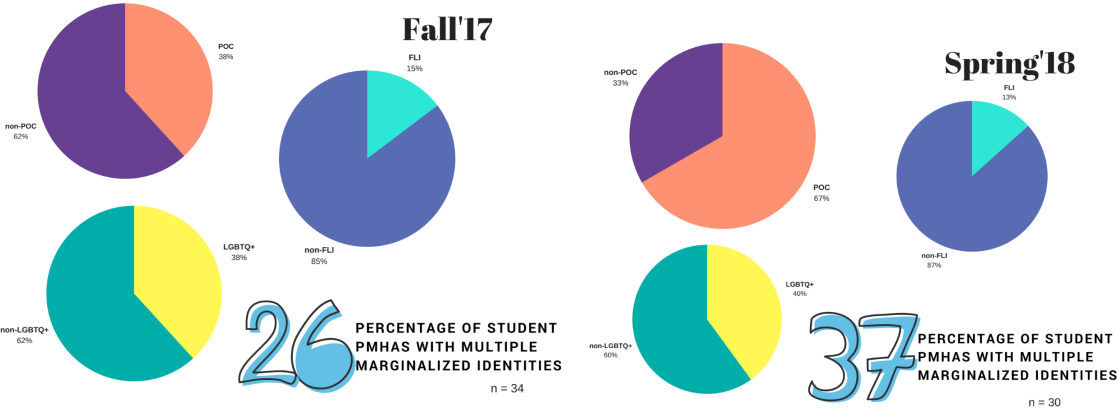
Demographic change amongst students applying to be PMHAs: Fall 2017—Spring 2018

(Brown University data)